Ricky 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.

Ricky's gran, Harbaksh, developed Alzheimer's disease in her 80s. Although Ricky and his family had difficulty getting help for her, they were still able to experience moments of joy together. Harbaksh died in early 2024, just a few months before this recording. And that was Ricky's first time experiencing intense grief.

Ricky: I’m forty-two years old, I've been married just over seven years and have a three year old son. It keeps me very busy and very tired. My main passions are raising awareness about dementia and cricket [00:01:00] and India, because that's my background and my parents were born there. You know, being from an Indian background, cricket's sort of a number one sport.

It's been instilled in me from an early age from just watching my dad and my uncles watching it on TV. I played for my local club from about seven or eight years old. I also played with my uncles on their team. So I still love it and I started playing again recently and going to watch games whenever I can.

Jim: Perhaps Ricky's son will take up the mantle one day.

Ricky: I've already bought him a little cricket bat and stumps. He's not that keen yet, but, you know, I think I've got to find the balance of not forcing it on him, but just let him find it his own way like I did. I grew up in Slough. My gran actually lived one door away, so we were, sort of, she's been there since the start of when I was born.

Eventually sort of moved to Leicester for University and stayed up there for a few years and came back to Slough when I needed all my washing done.

Jim: [00:02:00] Ricky grew up with his mum and dad, enough cousins to entirely cancel out his being an only child. And of course, there was Harbaksh.

Ricky: I call her Gran, but she was like a third parent for me from day one.

She was a really brave and courageous woman, you know, fearless I'd say.

She moved here to the UK and with limited resources she managed to build a life for the family. Her sacrifices enabled my generation and the previous generation to have a good life and have a lot of opportunities. She was very strong-willed. I guess she had to be because she was obviously, in a new place, and she didn't speak the language very well.

When I was born, she lived one door away, so she was always there. My parents didn't need to worry about childcare, for instance, because, you know, she was always looking after me, and at that time, they were working har. Sometimes they had two jobs to do, so my grandmother would take on the brunt of raising me.[00:03:00]

She taught me Punjabi, which has enabled me to be able to communicate with a lot of relatives in India. I owe everything to my gran in terms of who I am today.

She was a feeder. She would love to cook food and love to just make sure everyone's eating. You know, it doesn't matter if you're happy, you're sad, you're angry. The answer is always food. You must be hungry. That's the problem. Sometimes I'd, you know, I'd come back from University, very clearly I've been on the beers, I've put on some weight, and she'd still say, you're looking too thin, you need to eat. She loved to have family gatherings at her house, so she would cook for everyone, but she loved to be the centre of attention, and you know, just encouraging everyone to sing and dance, and she had a habit of trying to just pile food into your plate, and so sometimes I would sit a little bit further away from her on purpose, but she would still like pick up a roti and just throw it like a frisbee, and just watch it land perfectly in my plate. I think it was just her way of showing her love [00:04:00] for us.

She wasn't one to sort of give you a big hug and say I love you a lot, because I think she just took that as, you know, you know that anyway, but let me help you, you know, let me help, let me feed you, let me take you here, let me take you there, so that was sort of her way of showing her love, I guess.

She had four children and that turned into nine grandchildren, three great grandchildren. So, you know, she had a nice big family, which is what she always wanted. Anytime any one of us did anything, she was the first one to tell all her friends, my son's done this, my daughter's doing this. I think it was her generation, just wanted to show, you know, that we are making our mark in, in the world.

Jim: Growing up with his gran right next door, and being one of the only family members who could speak Punjabi with her, Ricky and his gran had a particularly close bond.

Ricky: It's just very strange to not have that now. I mean, I [00:05:00] have it in a different way. I guess it's probably a better way of saying it because she's not here, but I like to think she's still watching over and I'm sure she is knowing her personality to just to see what everyone's doing.

And checking that everyone's still talking about her and making sure we haven't forgotten anything.

Jim: Ricky and his family started to notice symptoms of his gran's Alzheimer's disease when she was in her early eighties.

Ricky: She just started sort of mixing up names of the family and forgetting things that she wouldn't normally forget. It was a gradual thing. We thought maybe it's just a case of old age and something that, you know, is bound to happen.

Over time her personality started to change a little bit as well, and she became quite resistant to any sort of change, or resistant to any sort of advice that we would give about something which wasn't really like her. Little changes sort of kept adding up to thinking that something's not quire right. [00:06:00] She started neglecting her personal appearance a little bit and, you know, she'd always been proud of her house and keeping it immaculate and then suddenly she didn't seem to mind if there was a little bit of mess.

Before she'd be like, yeah, you need to hoover, you need to do this. And that motivation wasn't there, I guess is the word. All those things were starting to add up. And then I think when it really started hitting home for me was when we were watching sort of TV together. Like we used to watch game shows and she stopped sort of understanding the rules of the games.

So she didn't know what was actually happening. And then she started sort of almost, well she was talking to the people on the screen. You know, like if they were waving she'd wave back and things like that. And then like, there's like family photographs on the wall. She started talking to them. I'm like, Gran, I'm here, speak to me. Like, why are you looking at the picture?

It became pretty clear that, you know, this isn't the whole day, just, it's just You know, something else is going on. We need to find out what it is so we can come up with, you know, her plan. I was going online and just sort of [00:07:00] researching the symptoms. That's when, you know, sort of first time I saw the word dementia, the more I found out about it, the more convinced I was that, you know, this is what is happening. This explains it. I was mentioning it to my parents and I think initially they, they weren't sure, but obviously we knew something was wrong. So we wanted to go to the GP and just start the ball rolling really in terms of trying to find out what the problem was.

Jim: But Ricky and his family got a lacklustre response from the doctor.

Ricky: The GP wasn't really much use at all. Like, every time we went, the GP would just say the same thing. Oh, it's just old age. Like, they just weren't interested. Once they saw Gran, saw her age, they were like, oh, it's fine. Like, it's just old age. And we had to be really, really persistent and say, look, this is happening.

That this is not just old age, you know. This is not normal. Instead of the GP maybe giving us an idea, look, I don't know, but this could be a sign of dementia or it could be this, you know, [00:08:00] it was more like I or my parents, you know, whoever was at the point was trying to convince the doctor, this is what she's got, you know, and it shouldn't be that way around.

But that's, that's how it felt, unfortunately. My mum was really persistent and eventually my grandma was referred to the memory clinic and that's when it, sort of, the next stage of it started. When they were testing her, they were asking her stuff that was a little bit not relevant to her in terms of, like, some of the questions were about, sort of, previous Prime ministers, or what year did the world war finish and stuff which, even when my gran was was fit and healthy, she probably wouldn't know those things. So it was like if you're judging things based on that then is it going to give an accurate reflection of where my gran is at? It needs to change a little bit maybe for different cultures and have different sort of set of questions

Jim: Ricky's gran did eventually get a diagnosis.

Based on her symptoms, coupled with a brain scan, Harbaksh was diagnosed [00:09:00] with Alzheimer's disease.

Ricky: In a weird way, it was a bit of a relief, because it explained why things had sort of taken that turn. Now we know what it is, you know, we can try and deal with it, come up with a plan, come up with how we're going to move things forward and navigate our way around it.

Jim: It was Ricky's mum who took her back to her next appointment at the memory clinic.

Ricky: She told me that, basically, he was trying to offer her grandson tablets that would potentially help to slow down the symptoms. But he wasn't going into any real detail in terms of, you know, why these tablets could be good, like what are the side effects, just to get a whole picture of, you know, what is possible and then, you know, my mum gave me the name of the tablet.

When I googled it, the side effects included potential issues with the heart or vomiting and at the time, because my grandson You know, she had dementia, but we had a routine with her that was working, and it was a fairly stable environment at that, at that stage. So we just said, okay, well, let's, let's not take it then, let's leave it, because, you [00:10:00] know, she's got a good routine, we know what we're dealing with.

And as soon as, like, we said that we don't want to take the tablets, he just discharged us back to the GP, and basically that whole cycle starts again. So if you wanted to go anywhere, you've got to go back to the GP, probably get referred back to the memory clinic again. Just had no empathy, no support, just didn't really want to be involved to be honest.

It just felt like it was a box-ticking exercise, like I’ve offered them the tablets. They said no, done. Next appointment.

It was really, really frustrating not to have any sort of empathy or help or support. All my information that I was getting was coming from places like Dementia UK website. Reading the stories really helped me because obviously you get comfort in sort of shared experiences. Obviously, every case is different, but there's certain things that are similar.

All our, sort of, knowledge, if you want [00:11:00] to call it that, was coming from, from those sources, rather than, you know, the memory clinic or the doctors telling us what to do. I found that really frustrating. Up until the symptoms of dementia started, you know, Gran was living a very active life. She was very sociable, she was going out, she never really liked to sit at home.

She had a bus pass, she goes, I'm going to use it, I'm getting out and about. You know, for her to go from that to all these changes, and then to be told that, well, you know, it's just old age, it's not right. I understand the NHS is underfunded. I know that social care has just been neglected for years.

I can kind of understand why it is the way it is, because there just isn't enough time and there isn't money, but it just, it doesn't make it any easier when it, when it's affecting you and people you know, and it's just not right, really, the way, the way it all happened. Because it was obviously something new to us, it was just a case of, you know, we need an [00:12:00] understanding of, What helps available, what help we might need in the future, you know, things like, okay, she's at a stage now, but you know, when things get worse, what's it going to be like? What are we going to need? You know, and this is all stuff that we basically learned on the fly. It wasn't a case of someone, you know, sitting down and saying, mapping out the next few years this could happen. You know, that's where our help with the Admiral Nurses came in for me.

Jim: Ricky called Dementia UK's Admiral Nurse Helpline. These are specialist dementia nurses who provide free advice and support to help families care for their loved one.

Ricky: I had quite a few conversations on the phone just to ask questions about what's going on, what is available, you know, what to expect, and when Gran was changing, like, just to talk it through with someone.

I mean, like, to give an example, with the Admiral Nurses, like, I rang them. One of the best bits of advice they gave was, don't always correct your gran. Like, if she [00:13:00] says something that's not factually correct. If you keep doing that consistently, you're just going to agitate the person or make them feel sad. Maybe she's still trying to understand herself what's going on.

So that was a really good bit of advice in terms of just sort of pick your battles, you know, like if it's obviously if it's a health and safety issue and she's trying to reach for a hot drink or something, then you need to explain that. But if she's just talking to me about my three daughters that I don't have, you know, have the conversation, it's fine, you know, you don't need to correct everything and make her feel bad almost.

Towards the evening she would feel a lot more confused and sometimes she would ask for her dinner at like 3 o'clock in the afternoon or, or it's 11 o'clock at night and she's sort of ringing up my mum saying, oh I'm coming round now because she thinks it's the morning time and stuff like that.

I spoke to how my nurse is about and they said it could be like an aspect of sundowning which is something I'd never heard of before.

Jim: Sometimes in the evening, around dusk, [00:14:00] a person with dementia might experience heightened feelings of confusion or agitation. That's called sundowning. They might become more anxious, or feel that they're in the wrong place.

Maybe they want to go home, even though they already are home.

Ricky: Some of these things, there is, there's no solution to it, there's nothing you can do, but it's just nice to talk to someone and get a, “Ok, this is normal, this is something that will happen.” And just, just to talk it through. She never knew that she had dementia, and it wasn't something that was easy to explain to her. Maybe if we could have tried right at the start, but even then I think it would have been very tough for her to get her head around what it actually means, because it's a very difficult thing to explain.

There's not even a word for dementia in Punjabi, you know, so like, it's just not something that's, that's that well known. It's not like a physical injury or your leg's broken. Trying to explain to her that you're going to [00:15:00] start to lose memories and maybe not, you know, understand who we are anymore or your personality is going to change and all these things.

Yeah, it would have been very hard. Sometimes I'm sitting with her and I can see that she's upset. And to me, that was probably her, because she's not understanding why these changes are happening or maybe she, you know, she'd been speaking to me and then I, after a while, she realized that I'm not who she thought she was speaking to.

You could just tell from her eyes that that's what she was thinking. Like I said, she's a very strong, powerful woman, and then to go from that to not knowing why you can't understand certain things or why something that you used to do, you can't do that anymore. It must be very hard to adjust.

We used to play a lot of DVDs for her of old family weddings. Because she loved dancing, you know, any of the old family birthdays and stuff, you can just see if she's there dancing or trying to get everyone else to dance. So she would enjoy watching it and she'd start [00:16:00] clapping and start singing the songs along.

It's amazing because sometimes when she wasn't able to construct a sentence clearly, if she saw a song, suddenly she could remember the words of the song. People say that music's a really powerful tool with dementia, and, it's just hard to explain, but it's just something that connects her, and she really loved the music.

She's watching the TV, I'm watching her, because she's just laughing, enjoying it, and having fun. It was mainly about just trying to inject sort of colour and vibrancy, you know, that she would have in her life and find ways to do that. The best way was just to have the family around her really, because that's when she was happiest and whether she understood everything completely or not.

She understood that everyone's here to see me, which she would love.

Jim: One thing that's precious to Ricky is the time his son and his gran got to spend together.

Ricky: When he was born, it was all [00:17:00] sort of lockdowns and Covid, so the first time she met him was actually on a Zoom call. And it was really sweet because she hadn't sort of made much sense for a little while, but then when I showed her my baby on the, on the screen, her eyes sparkled a little bit and she had this bright, beaming smile and Just for those 20 seconds, it just felt like I had my ground back, I could just see, you know, like the happiness there.

And then for that first 12 to 18 months, she knew enough to know who he was. So when we would go visit, she was able to hold him and she was able to play a little bit with him and sing a few songs to him. After that, you know, her understanding sort of lessened and she didn't really know. Who he was and, you know, what was going on, but I'm really treasure those first 12 to 18 months.

Jim: Ricky's grandmother, Harbaksh, died in April 2024 with her family [00:18:00] around her. She was 87 years old.

Ricky: On the grief side of things, You know, it was obviously a very tough experience and something still, still happening at the moment. But you know, I did like an online course in dementia. I did a lot of research, tried to arm myself with a lot of knowledge, specifically when Graham was in the later stages. I knew what was coming.

She was going to pass, but even when it happened, Just nothing can prepare you for sort of losing a loved one and like, like I said, like a third parent. I felt like I'd already grieved her once while she was living because it wasn't the Gran that I knew, because you're losing someone piece by piece as time goes on.

That kind of gave me a false sense of like, when it does happen, it won't feel that bad because I've kind of already sort of, [00:19:00] but it, in many ways, it kind of went the other way because I finally felt like I lost my original Gran and then I've lost this new Gran that I'd learnt to love. I was, you know, with her on that day, it's something that, yeah, it just fills you with sadness and you also have that relief that she's not suffering anymore.

I'm quite lucky to live to 40 odd years and not have, you know, that much heartache. So when it happened, it's, it's been a learning experience of how to deal with, with grief as well for me. Like I'm usually quite a laid back and. Sort of easygoing person, but I found myself just like really short on patience and quite short tempered and snappy at times and just a bit angry and frustrated at the world.

I think a lot of things suddenly just, that wouldn't normally annoy you, they [00:20:00] suddenly start annoying you and it's just, it's, it's quite strange but it's just my way of, of, I guess, processing what's happened. Kind of almost sort of scheduled my grief in a way because I, because I'm so busy with family and stuff and work in the day, it's usually in the evenings I sit down when everyone's gone to sleep and I just kind of sit and reflect and reminisce and, and sort of grieve to be honest.

It's maybe a strange way of doing it, but that's kind of what's working for me.

Even now, since, since the day she's passed, like every evening before I sleep, I look at my phone, I look at photos of her and a few videos, just like a few favorite ones of her smiling and her singing. And just say a couple of words to her before bed. I don't know how long I'm going to keep on doing that, but at the moment it's just helping me sort of, I guess, heal and just process and just find a way to move forward.[00:21:00]

I'm very lucky, you know, I've got a really supportive wife and, you know, I've got a strong family network. And I think that's one of the things that's come out of it is that, you know, when we do get together we sort of swap stories about Gran, you know, it's a mixture of all the things she used to do.

I've heard lots of stories that I, that I didn't know. I think that's, like, the best legacy to her is, like, all the family getting together and just talking about her and sharing stories. That's what she would have wanted. You know, and obviously, she loved to be the center of attention, so if we were all talking about her, she'd be very happy, I know.

I saw this quote that said, sort of, be the things you love most about the people who are gone, and that's what I'm gonna sort of remember, and for me, when I think about Gran, I just think of someone who's fearless and never backed down from a challenge, so that's what I'm gonna try and carry on.

Jim: An enormous thanks to Ricky for telling us about his gran, [00:22:00] and especially for being so open about his experience with grief. You, or someone you know might well be able to relate to what Ricky shared. So now, two of Dementia UK's Admiral Nurses, Hilda and Vic, are here to discuss some of their reflections on Ricky's story.

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

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

Vic: We've just listened to Ricky talking really openly and generously about his experience of grief in relation to his gran who lived with Alzheimer's.

It's entirely normal to grieve somebody that if you love somebody, you know, that's the price we pay for loving them Is that when they die, we're going to grieve their loss and we're going to feel sadness at their loss I think it's important to perhaps talk about some of the terms we often associate.

So we talk about anticipatory grief or role in [00:23:00] grief. Anticipatory grief is grief in anticipation of losing somebody. So that could be because they're terminally ill and they're dying and you know that the end is coming for somebody. Or it could be because they're living with something like dementia and the changes that you're seeing, you're mourning the loss of that person whilst they're still alive.

And then rolling grief is a term that we also hear talked about. And this is when it's that kind of accumulation of grief and it rolls and it sways. And it's like, if you think about waves that crash over somebody as, as a, as a beach may, may roll. And, and as someone's condition declines, as someone lives longer with dementia, the grief doesn't happen all at once.

It happens in, in stages and unfolds over time. That's really difficult because then you end up, of course, when they die, you end up grieving again. When someone has had dementia, you, you may feel anger as well, you may feel, um, why did they have to live their life this way? Why did their life end that way?

And I [00:24:00] think Ricky’s reaction, um, you know, feeling angry at times could stem from that. There's kind of normal emotions about actually what changed and the fact that Gran didn't get to have the relationships and things that she would have wanted to, to see and do. Her dementia robbed her of those interactions.

Hilda: Yes, and I think Ricky sums up really within his recording about the anger and the frustration that he was actually feeling. And that, those, as you said, Vic, are normal emotions in this situation. And they're so fluctuating, they can fluctuate on an hourly basis, let alone a daily or a weekly basis.

Sometimes as well, I've certainly been with families that have said when the person has died, it has been a relief. And then they feel guilty about that. And those sort of feelings, they think, is this normal? Am I abnormal? Am I being awful? Am I disrespectful to the person's memory? And I think that is very difficult.

difficult for an [00:25:00] individual to cope with or when they're not acting in the way that other people or other family members are expecting that person to act once the person has died. Those are sorts of complex emotions that people actually experience.

Vic: There's a lot you've got to come to terms with, there's a lot of acceptance that's got to happen, and, and actually as humans, we're not very good at accepting we're going to die anyway, it's a bit of the final taboo, isn't it, you know, having these conversations, but if you can have these conversations, And acknowledge your feelings and your emotions and talk about the fact that, you know, we're all going to die.

It's, it's inevitable. So what does a good death look like? What, um, what plans do we want in place? Where do we want to be? Um, you know, who do we want around us? You can help to kind of accept some of what's happening and deal with it in a kind of really practical way, which it's not easy to do that.

Hilda: Ricky mentions that he [00:26:00] was so busy and he was trying to cope with these complex emotions, as well as having a young family, as well as working.

In those sorts of situations, give a call to the Admiral Nurse Dementia Helpline or book a virtual appointment within our clinics. We'll be able to access specialist dementia nurses who will be able to help people to kind of voice some of those feelings and work through that process.

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.

You'll also find links to the website and other resources in the show notes for this episode. Thank you so much for [00:27:00] listening.