

## **Aqib and Shahbanu 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. Akib and Shabanu's mum, Sharma, was diagnosed with Alzheimer's disease when she was 70 years old. Like most siblings, these two know how to push each other's buttons, but they are completely aligned on one thing.

They both want what's best for their mum.

**Shahbanu:** My name is Shahbanu. I'm here with my brother.

**Aqib:** By the way, I might interchange between Shahbanu and Shani. I call her Shani.

**Shahbanu:** We're close siblings. We do look after each other and we're in this together. That's how we feel with Mum.

**Aqib:** She is the archetypal older sister. She's always looked after me. You [00:01:00] know, even, Mum would always previously talk about how she would absolutely do everything to help, even when I was a baby.

**Shahbanu:** I was actually quite a boring and dull child. I wish I'd got up to more hijinks, but I don't think I really did. Sadly.

**Aqib:** Yeah, I'd have to agree. She's extremely responsible, and she's always thinking of other people. That's her default setting. I'm completely the opposite. I'm extremely selfish, the typical younger child.

**Shahbanu:** Mum's name is Sharma and before she was married she was a primary school Headmistress. When she was married she moved to the UK and I came along pretty soon after and she was just amazing. Loving, caring, patient, strong, completely uncomplaining about anything. She absorbs and absorbed [00:02:00] everyone's stress around her. Very glamorous, which I've always loved about her as well.

**Aqib:** She always had one of these very solar personalities. People could feel her warmth and many people in her vicinity would always feel warmer for it, if that, if that makes sense. She was the middle child, one of eight, I believe. But she was also very much the glue for her own family, amongst her siblings.

Everyone would come to her. And it extended beyond her family to, I would say, her in laws and her friends. She's always been a very foundational sort of person, in that sense. It doesn't mean to say, though, for all the warmth and the truly, you know, sort of unfiltered love, loyalty, love, all of these things.

She was, of course, still a disciplinarian. As my sister said, she was born in Pakistan, and that's where she was. I think at the age of 23, she became a Headmistress. One of the youngest Headmistresses, chosen, as we were told, above all of the other [00:03:00] teachers with tenure and rank, which I think speaks something towards her general people management skills.

I wasn't maybe as good as my sister, and she wasn't averse to, you know, disciplining me as needed growing up. Apparently I used to threaten to call Margaret Thatcher to report her.

**Shahbanu:** You did.

**Aqib:** I, I have no memory of this, but apparently even then I was very, very against corporal punishment.

**Shahbanu:** "I'm going to phone Maggie Thatcher now!"

I always felt that whenever she walked into a room, she lit it up. My father was often away traveling, and even at university, I would be like, Mum, why don't you just come up and stay with me? So, we'd get an inflatable mattress, and she'd be in my room, and once or twice the fire alarm went off, and everybody's looking around going, "Ah, who's this who's come out with everybody else?"

And even the porters got to [00:04:00] know her. She had the ability to fit in anywhere.

**Aqib:** One of my big regrets, as I'm sure for many children, because we never think about this when we're younger, is spending more time with her. Because she was obviously not just our mother, but in many ways she was a friend. We have the same sense of humour, we find the same silly things absolutely hilarious, and it could be anything from a word or a phrase or someone's expression and we will lose it.

**Shahbanu:** She's very much a person of, go with the flow as well. If a problem happened, she wouldn't dwell on, Oh my gosh, why has it happened? What's happened? She'd be like, OK, now we have to fix it, solve it, what's next? And so that's something that I am especially also

trying to really remember, because now it's all about finding solutions which suit her.

To help her [00:05:00] still be as independent and feel as normal as she can every day. I'm not, 100 per cent sure that she understands the extent and the seriousness of her situation. At the beginning, and even now, she says, Oh, I'll try harder to remember. I'll try harder to remember. And don't worry, I'll remember next time.

And we know that's not going to happen, but we just go along with it. We've put up notices, like at the front door, it's got a whole list. Have you got your keys? Have you got your phone? Is your phone on loud? Have you got your wallet? It's trying to find what can we do to help her so she can just be as normal as she thinks she is.

**Jim:** It was the end of 2021 when Aqib, Shahbhanu and Shama's journey with dementia really began.

**Aqib:** I certainly was aware of what dementia is, but [00:06:00] the impact? Absolutely zero sense of how profound it can be on the person and on the people around them. Once we realized that it could be this. Then, of course, immediately, you start trying to read and understand.

**Shahbanu:** My knowledge and information about dementia had mostly come, I would say, from the media. Newspaper reports or TV reports about, we're thinking about doing this to help people live with dementia, or There's this treatment. That was the extent, and like Aqib, I didn't understand the impact on the person and the impact on the family and how progressive and degenerative it can be.

**Jim:** It started with small changes. But those changes seemed to appear overnight.

**Shahbanu:** It felt like a switch had been flicked.

**Aqib:** Yes, that was, that's absolutely the way to think about it. That's how we always used to joke about it, as if something had happened. [00:07:00] What struck me in particular about the early signs was the repetition.

She would just ask, so what were we doing? What, where were we going? What's the name of that person again? But the, the questions weren't one shot. So once you gave the answer, the question kept coming. And it would come at least two or three times. The repetition of those questions became increasingly and alarmingly frequent.

It's part of the larger, sort of, impact, which is the reliability of a parent gets compromised, and that's something that I think initially even, For Shani, and certainly for me, to imagine that that could be what's happening, given that, especially as a child, your parent is normally the one who prompts you, certainly for me, I was, I was the more useless of the two of us, but having that sort of function even being mildly impaired was quite surprising.

Why am I reminding you? I'm the one who's usually needing to be reminded of things. [00:08:00]

**Shahbanu:** You had this strong, amazing woman who looked after everything, absolutely everything, and suddenly, she wasn't being that person anymore.

**Aqib:** Forgetting small details, needing constant and repeated prompts. It was because of that that we started even first our discussion of this and even our arguments over this.

Shani had one type of reaction and I had another.

**Shahbanu:** When we noticed the changes, I pushed it deep down. I didn't want it to be that. I thought about it, but I didn't want it to be that. So I tried very hard to convince myself and Aqib that it's not that, it's not that, it's just, you know, normal memory loss.

She's a bit tired. She just needs to rest more and she'll be better. I was definitely more [00:09:00] in denial and a bit more head buried in the sand. I had the gut feeling. I knew it couldn't be anything else, but I really didn't want to believe it. It would change everything and that was too scary to think about.

So, I buried it and I pushed it down.

**Aqib:** I had a very different response in the sense that while I was equally horrified at the prospect of this, I'm a bit more pragmatic maybe in that sense. Like I said, I didn't accept it, but I realised that something needed to be done about it as soon as possible. And I think that was the key divergence between us.

For me, therefore, it became a lot more practical. We are very close, I think, as a brother and sister, but that's not to say that we don't argue, and I don't know if that's a function of our closeness, that we argue, yes, we argue a huge amount of, I would say the important things, and of course the smaller things when we were young, [00:10:00] but this

experience that we're going through right now is absolutely testing our relationship.

**Shahbanu:** I would say that we argued a lot when we were leading up to the diagnosis. There's still disagreements that we have over the best approach and how to care for Mum, what's best for Mum.

**Aqib:** Both of us were very horrified at the prospect of this, but I think I leaned into it much faster. I said, look, this, this looks and sounds like this, as in this isn't just maybe traditional ageing and forgetfulness that, you know, many elderly people go through.

I was, I think, a lot more wary of the sinister nature of what this disease could be.

**Shahbanu:** And the consequences. And the impact on us as well.

**Aqib:** The irony is that my sister is super organised, but I'm a lot more strategic in my thinking, and a bit more long term. So I already started thinking that, okay, we are not set up to deal with this.

So we need to know as soon as possible what's going on, and then realise that if we have to make [00:11:00] changes to the way we do things, everything from our vocabulary and our mindset, through to, if I'm brutally honest, I mean, I've had these conversations even at the beginning with Shani about, do we then need to maybe think about, buying a wheelchair, should we have that ready?

Walking sticks? Hospital beds in the house if we don't want to put her in care? I came to this so much heavier in a way than Sharni did and I realised that traumatised her even more a little bit. Throughout that period that's when we were probably interacting and arguing and just trying to make sense of it ourselves.

I would be sending Shani all these links, like read this, read this, this will prove my point. And she would send me links going, no, it's just stress, don't worry, it's just about stress. So we would just be going backwards and forwards in this way. But the reality is, is that I have to give full credit to Shani.

This is also the awful thing in my case. I'm quite a bit lazier than my sister. I knew that if I convinced her, everything would start to go into action. [00:12:00] We're lucky to have this dynamic in a way, which is, makes it sound so awful as if I'm like some ideas person, you do

everything. It's not like that, but, I just knew that if I could convince her that everything would, the ball would start rolling in that sense.

**Jim:** And in the end, it was Shabanu who brought up the symptoms with their mum's physician at the beginning of 2022. By this point, both of them felt sure a dementia diagnosis was coming. So they moved on to next steps. What could they do to support their mum?

**Shahbanu:** Because we knew so little about the practical aspects and the impact, of course, everybody goes to Dr. Google. And you're looking around, you're looking around, you're reading so much, you don't know what to read, you need to check the dates of what you're reading because things can be old. And so we came across the Dementia UK website and their Admiral Nurses.

**Jim:** Admiral Nurses are specialist dementia nurses.

[00:13:00] They offer free advice and support to help families that are caring for someone with dementia.

**Shahbanu:** I sent it to Aqib and he said, great, let's make an appointment because we need outside help. We need someone to explain what's going on, even what's going on in her head, so that we can understand how her brain has changed and how it's now operating.

Virtual appointments had been set up. So I was able to liaise with Aqib and say, Are you going to be free? And then we got our first appointment. And I think it was with Admiral Nurse Ruby, I think it was her name. That was very, very important. She used a bookcase analogy to explain what's happening with mum's brain, how the books on the top, i.e. the newer memories, if you shake a bookcase, they're the first ones that are going to fall off. Memories at the bottom, your earlier memories, those are the heavier books at the bottom, that's going to be [00:14:00] stronger. And it was those just straightforward explanations using simple analogies. That really helped us to then change our thinking and change our vocabulary and how we talk to mum.

**Aqib:** To have someone explain it to you in an extremely empathetic and very, very kind way made all the difference. And actually, I think that was probably the first time that even we got on the same page. Because before then, I would be getting annoyed with Shani to say stop asking her or getting annoyed with her, stop being frustrated with her.

And I, of course, would occasionally get frustrated with Mum too, but I would always be, you know, picking Shani up about it because I think she

was still maybe a little bit more in the, no, no, no, she's fine, she can snap, I can snap her out of it, sort of.

**Shahbanu:** Yeah, there was a little bit of that.

**Aqib:** I can snap her out of it, this isn't anything serious.

But I think talking to Ruby, understanding that this is absolutely something very serious. And there is a pattern to it. And that we're not the only people who are noticing these things. [00:15:00] I think that made a huge, huge difference.

**Shahbanu:** I think that definitely then when it came to the diagnosis appointment, We were calmer.

Yes, yes, we were calmer and we weren't, we weren't going to fall to pieces in the, doctor's office. It was definitely calmer and not necessarily easier, but we were better prepared for when she actually said it. And then, then it became a matter of, okay, how do we help? How do we help? How can we keep her quality of life as good as possible for as long as possible?

**Jim:** Shama was referred to a memory clinic.

**Shahbanu:** That's where the doctor sent her for an MRI for her ECG, and did the Addenbrooke test for the first time. It's a test divided into certain categories, so recall date, name, address, drawing things like drawing a [00:16:00] clock face, identifying items, took a lot of background information from mum, so her education level - she's a Masters.

They asked us separately about what we'd noticed, and then the test score and all these things taken together was probable Alzheimer's.

**Aqib:** Because we are different, of course, like all brothers and sisters, it does mean that we find ourselves with different opinions, different views, different approaches, and trying to muddle through that and obviously respect each other's views and points and understand where we might be coming from is a big part of it.

It's been difficult and so I think we've probably argued more now than we have when we were children.

**Shahbanu:** Yes, yes.

**Aqib:** I mean, we know each other's buttons better than anyone else.

**Shahbanu:** Oh my gosh, yes we do.

**Aqib:** And we know [00:17:00] how to push them. We've never gone so far as to break anything, but we absolutely clash. And we know also why the other person might be saying what they're saying.

And that is a source of also challenge as well, because I might understand that my sister might be wanting to do something because she has some other sort of context for it. And I might disagree with that even before this incident that we're dealing with. So it becomes very easy in a way to, sort of, also spiral a little bit in that sense when it comes to these confrontations.

But the one thing that we've learned, and we learned it quite quickly, was that actually we have to, we have to reach a detente. We have to figure out something. It's not the case that we can just end on an argument and storm out. Especially if it's related to Mum. On other things, that's fine. But in this situation, we can't leave it hanging and end on a note which actually is not [00:18:00] productive.

**Shahbanu:** A lot of times, we will have a disagreement or an argument, and then it'll finish. And then I'll say something like, Oh, did you see the snail on the ceiling outside in the terrace? And then it's like, back to normal. We're talking about other things. We've got to keep things normal, especially around her because we don't want her to pick up on any stress and tension and be upset because sometimes it feels that if she's upset, her memory feels poorer sometimes.

So we just want her to feel happy and safe and relaxed. That's the number one, I think, aim the whole time everywhere and everything that we do.

We have to 100 per cent trust and rely on each other when it comes to everything to do with Mum.

**Aqib:** That's actually a very good point. I think the reason why we're able to bounce back is because I think the trust [00:19:00] is complete in a way that, you know, not that siblings are the only relationship that can have that sort of trust, but because we're very close and it's a very deep trust and we know that we're doing this for someone who we both care about so deeply. It really is about the method, not a lack of trust in that sense, which would actually make our relationship and our ability to cope with this much more complicated if we didn't have that trust in the first place.



**Jim:** Aqib and Shahbanu have had to learn new ways to interact with their mum.

They've realised it's not always helpful to contradict her when she makes mistakes or forgets things. And they're careful not to let her feel shame over those things, or let those moments erode the trust that exists between them.

**Aqib:** You suddenly have to be even softer in your reactions, you have to be that much more patient, which is again, an increase in patience is such a huge thing for someone like, I think, for myself.

For anyone, to suddenly actually [00:20:00] increase patience is one of those things which is very difficult to do even in a normal situation, uh, let alone a situation which is so emotionally charged. I think we've learned a lot of patience, but we're not saints.

**Shahbanu:** Yeah, exactly, exactly.

**Jim:** Aqib and Shahbanu have come up with some creative ways to keep their mum active, physically but also mentally.

**Aqib:** She's doing a GCSE in English again. Just because we thought that it might be good to do some reading comprehension, just to keep the brain engaged. So she does that every Monday. We just found this absolutely phenomenal tutor, she's wonderful, Amy.

Brilliant. She is someone who is so patient with mum, she sets her homework. It's true, maybe Shani and I do about 99 percent of it for her, but you know, we're sitting with her going through it. It's a, it's quality time.

**Shahbanu:** And she often says, have I done my Amy homework?

**Aqib:** Some things are getting through, but it's mainly just to try and keep the processes as prolonged as possible.

And I think that's a [00:21:00] function of just the fact that, you know, She has been so important to us. We are struggling with the idea of letting her go. And so all of this is a fight. And I don't think we've quite accepted that we won't win. But we will do our best in that sense.

**Shahbanu:** To delay it and keep her recognising us for as long as possible. That's a horrible thing. When I bring her breakfast in the morning, I give her a morning kiss and open the curtains. You know, will

she remember who I am? So that's really, scary. And as time goes on, it creeps into the back of your mind a lot more, much more.

**Aqib:** Shani and I are very willing to bear quite high costs to ourselves and our time, not just because of the sort of [00:22:00] affection and love that we feel, or even a sense of the fact that she's given us so much.

But it's also just sheer selfishness. We aren't prepared to let go of our mother that easily. As Shani says, I can hear your voice breaking, because mine does too, at the thought of her not recognizing her. Whenever I travel, I That is absolutely my number one fear. And I, I slightly resent, you know, the periods when I'm away because I realise that there is a ticking clock.

But I think that mix of sacrifice and selfishness has absolutely determined the path that we're on at the moment. And we don't know how those costs or benefits are going to change and I think we're just re-evaluating them at every step.

If we were to share one thing, what would it be? with, you know, with those who are listening, it is just try and remember that while it's very, very [00:23:00] complicated, it's very, very scary, scary. It's very complex. Unknown. There's huge unknowns, there is still a huge amount of quality time. and enjoyment that you can derive even in this very stressful moment.

**Shahbanu:** Another thing which Ruby told us was that she was always still going to experience joy in the moment. So, watching something funny, she's going to laugh and she's going to enjoy that moment. She might not remember afterwards, which happens a lot, but she will have had that moment. She would have been happy and laughing and smiling or, you know, telling us off for something or something like that.

All those moments still happen. She just doesn't remember them. She and I watched a film. It was this silly heist film about a group of air stewards. And then I came back and said, Oh, I wanted to watch that film. I said, let's watch it again because she won't remember. And we watched it again. And what I thought [00:24:00] was adorable was that she laughed and made the same comments at the same points in the film that she did the first time.

Exactly the same comments she was making the second time around. I don't know if that's a memory in the way she's still enjoying the film again.

**Aqib:** If there's something that we've learned it's that you, you don't need the memory to share the moment. The biggest change that I think I've made, I'll speak for myself obviously on this, is just you know in terms of just being demonstrating as much affection as possible for her, more so than I probably would have done in the past.

It's almost like a positive reinforcement that even if she does make a mistake, and even if I lose my temper occasionally, or just, you know, trip her up on it, sometimes because I'm just a mean type of son, I'll make fun of the mistakes she makes as well. Just like I think most children do with their parents, but just reinforcing that with affection and reassurance.

Because one thing that [00:25:00] Ruby taught us was absolutely the emotional component of memories. The fact that the strongest memories are associated with the strongest emotions. So that links back to your formative memories, as well as Certain huge life events. There'll be these traffic lights throughout her life that she will always be stopping at.

We were told that she will remember having children, but she might not remember us. We hope that even if she doesn't remember us, our presence is enough to lower her heart rate and keep her calm.

**Shahbanu:** Yes, that she still has that feeling of, if I'm with these people, I'm okay. I'm safe.

**Jim:** Thank you to Aqib and Shahbanu for being so open about the emotional reality of caring for a parent with dementia. You, or someone [00:26:00] you know, might be experiencing something very similar right now. And two of Dementia UK's Admiral Nurses, Hilda and Vic, are here now to talk a little more about family dynamics and dementia.

**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:** So we've just heard from Aqib and Shahbanu and they talked beautifully about their family's situation and and actually sometimes families have differences of opinions.

It's common for families to feel that way and and that can be about everything can't it? You know, even the most loving family. It's normal that you're going to have differences of opinions you're going to have

different opinions about what's the best care for somebody and when you're living with this and you're in this situation, it's really important to acknowledge that, to say, look, we feel things are differently here, you know, that doesn't mean [00:27:00] my opinion is right and yours is wrong.

Mine's not better than yours. We're equals. And actually voicing those differences of opinions that we may have can just help to kind of address them. Otherwise, it can sit there almost like an elephant in the room. The other thing that I always say to families is the kind of key thing to do really quickly when you notice there's a difference of opinion, whatever it's about, is kind of recognise the common goal.

So you say to each other, okay, you think X, well, I think Y, but actually we both love Mum. We both want the best for Mum. And I know that Aqib and Shahbanu have done this beautifully. They, you know, they really worked together as a unit. I'd like to say families are all terrible. I don't know if that's quite true, but lots of families don't do it very well.

We have a conversation with somebody, but we're not really listening, you know, normally you're kind of waiting to speak. You're waiting for your turn to say something back. But if you actually actively listen to what that person's saying and you go, okay, you've had your chance to speak. This is what you think is the [00:28:00] right thing to do. How can we then plan so that your views and your wishes are considered as well, rather than it just being, I'm the older brother and I know best, or whatever it might be.

**Hilda:** Absolutely agree, Vic. And it's about, everybody has got a strength. So it's looking at the strength of the other family member. What is it that they're better at? Is it the finances? Is it the cooking? Is it the taking on nice trips, going to the garden centre, have a cup of tea, going in the garden and doing some gardening? So try and find something that that person can do that you probably can't do. It comes back to, as well, so where is the person that's living with dementia's viewpoints in all of this?

So if you have an advanced discussion about what that person wants for their life, and how they want to live their life, then you've always got that to fall back on. So when there is a difference of opinion, and that, I quite agree with you, Vic, in every family there is going to be some [00:29:00] difference of opinion somewhere along the line, You can draw it back to, yeah, but that's what mum, that's what dad said, that's what your brother or sister said at that time.

**Vic:** The other thing is kind of about setting boundaries. It's about deciding this is what I'm comfortable with. This is what I'm not comfortable with, whatever that is. And it's going to be different for all of us, isn't it? Actually knowing this is the thing that I don't really want to have to do.

And that could be because I'm working and it's, I have to travel 70 miles to go and deliver something or it might be because actually that's not something I feel comfortable doing as a person myself.

**Hilda:** I think where the callers to the Helpline in particular have a difficulty is when one family member lives near to the person they're supporting and then another family member lives, say, two or three hours away.

And there's this resentment as to why this other person that's living further away isn't actually doing their share. This comes back to look at what that person can do instead then because finances nowadays, you can manage that online, [00:30:00] you can do the shopping online, there's lots of things that that person that's living a little bit further away can actually contribute.

And sometimes it's about them contributing the money towards having a carer coming in to give a bit of respite. So the found others family member can go out and have a bit of a break. So it's about all of those things that people Help those communications to go a lot smoother within a family and bearing in mind that within families There's often disagreements over lots of things and sometimes the disagreement over what's happening with their parent is about something that happened when they were in their teens or in their 20s.

So sometimes going and speaking to an Admiral Nurse on the Admiral Nurse Helpline or Admiral Nurse clinic can actually dig down and find out what the real issues are because sometimes what's on the surface isn't the real issue at all.

**Jim:** This has been an episode of My Life with Dementia, a podcast [00:31:00] 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](http://dementiauk.org). You'll also find links to the website and other resources in the show notes for this episode.

Thank you so much for listening.