James 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. James's late wife, Maria, had young onset Alzheimer's disease. As a couple, they found themselves on an unexpected path, moving through the different stages that followed her diagnosis.

James: Maria and I first met in the very romantic surroundings of the Elephant and Castle in South London. We were both working for the Labour Party at the time in the run up to the 1997 General Election, so that's actually how we met. My first impressions of Maria was very vibrant, she's a lot of fun, very [00:01:00] humorous.

I think I asked her for a drink and we went to a pub in Camberwell. What struck me was a sort of mixture of feistiness, warmth, and vulnerability as well. And that, for me, that was a very appealing mix. Maria was different. Very interested in activism and in social change. She was actually born in the Caribbean, in Trinidad and Tobago.

And she moved to the UK in the early 60s, when she was around 4 years old. Actually growing up in Kilburn. I don't think it was easy. I think some of our fellow citizens weren't always as welcoming to people coming from the Caribbean from that generation as they could have been.

Jim: A man after my own heart, James has been an actor for over 20 years, [00:02:00] and Maria had a host of different careers that she excelled in.

James: She worked as a teacher, then she moved into acting. And she's very self-deprecating about that, but she achieved a lot. She did a variety of theatre work, some interesting television work as well. We both shared a real passion and love of soul and funk and jazz music. She introduced me to Soca and Calypso actually, and both Soca and Calypso have got a rich tradition in Trinidad and Tobago.

I actually loved how she also just had a real interest in people. She was a very empathic person, and that was reflected in the depth of her friendships. That would help us a lot down the line, you know, in terms of some of the things we had to face. [00:03:00]

Jim: In 2014, after 17 years together, Maria was diagnosed with young onset Alzheimer's disease.

James: What I would say is I had an awareness that people who were younger were affected by dementia. I was sympathetic, but I think, you know, like a lot of people before you're directly affected by a health condition, you think, Oh, I'm really sorry, but that happens to other people.

The early signs and symptoms weren't obvious at all. With hindsight, Maria was a very adept person, often presenting, you know, quite confidently. And so, her loss of confidence, I remember she left her [00:04:00] full time workplace, and then she actually got a succession of different jobs, I think she would have been adept at, but which, for whatever reason, she would just have a struggle with.

I thought maybe she's just having a difficult phase in her life.

Jim: Maria began to have trouble with orientation. She'd lose her way, get lost in places she normally would have moved through with ease.

James: And I thought, actually, there's some stuff going on that isn't typical. Before Maria was diagnosed, there were a couple of close friends of hers who got in contact with me.

I had a difficult call to make and said, look, You know, we're worried about Maria, uh, having that conversation that actually is very helpful for me in terms of feeling empowered to take action to, for example, seek [00:05:00] support from, from our GP. We went on a kind of little mini break to Edinburgh. I remember sitting in a park, having a conversation with Maria.

Suggesting we should go to the GP, maybe just explain what's happening and seek some support. And that is extremely difficult as a couple. In hindsight, I think she was worried that if I felt that she was unwell with something like dementia, that I would leave. I think that was a fear for her. That's a tough thing to reflect on.

Jim: With James’s support, Maria did go to her GP, and she was referred to a memory clinic.

James: I thought they were very good in being cautious about what it could be. For example, we thought it might be linked to the menopause, or it might [00:06:00] be linked to depression, and they were very cautious about making any assumptions before they, you know, had clear clinical evidence.

Jim: But, by the Spring of 2014, Maria was officially diagnosed with young onset Alzheimer's disease. She was 56 years old, James was 45, and now they had to prepare for a new chapter in their lives. Several new chapters, really.

James: I met a specialist dementia nurse. and she divided the disease into three phases.

She said that phase one was all about maximising independence, and that's a really good phase. Phase two, which I found the most difficult, is about maximising safety. And phase three, towards the end, is around [00:07:00] maximising your loved one's comfort. And of course the lines blur, that's where it's tricky, but it is useful and what you want to do is maximise phase one, the independence phase, as much as possible.

So, yeah, what we sought to do is to, it's very simple really, is to do as many things that are as enjoyable as possible. In the first six to twelve months after Maria's diagnosis of young onset Alzheimer's disease, She did incredibly well.

Jim: James and Maria were able to enjoy precious time together in Paris, celebrating his mum's 80th birthday.

James: It was very special because we were really operating as a couple, rather than me being a carer, so still enjoying, you know, that sensuality, that intimacy. [00:08:00]

Jim: And it wasn't just about these big events, like going on trips and holidays. It was about finding small ways to make the most of everyday life.

James: We used to get one another a card to celebrate our first date anniversary.

And during the first phase of the illness, I remember Maria bought me two cards, but she wasn't sure she bought me one already, so she bought me two. There are things like that that are very poignant and sweet. Later, when we're in, if you like what I talked about, phase two, When things are getting more difficult, we managed to go to Porto on holiday, which is a place that we'd always really wanted to go to.

And it was both immensely satisfying and also for me, actually, immensely stressful. [00:09:00] You'd have a very good hour and then you might have a very difficult hour. We had a lovely flight on the way back. It was beautiful and you could see Northern Spain and it's a really lovely experience. But I remember thinking, you know, that will be the last time we go abroad together.

In some respects, you know, I'm quite, um, I'm not embarrassed, but it feels naive retrospectively, because I remember, uh, yeah, six to nine months after the diagnosis, I actually thought, well, I think we might be all right, you know, I think there might be some clinical advances, we're a strong couple, I think we might buck the, the expected pattern.

And obviously now, with what happened, that seems very, very naive. But the hope is that there'll be a couple down the line who'll be thinking that. [00:10:00]

Jim: Over time, the impact of the disease meant that Maria had to stop working.

James: It put pressure on us as a couple, because then I was, if you like, the sole person working. And we were initially, you know, in quite a comfortable position before, but that flipped things around. So I'd often come home, I'd be tired, sometimes sleep deprived actually, retrospectively, through worry.

And you know, I look back on that and I can remember getting irritated. I certainly would have said things that I wouldn't choose to say. I enjoy my work, but I also, on a practical level, I had to continue working. So, there would be people who'd come around and take Maria out and go to an art gallery.

And this, actually, this carried on for, for years, which was really lovely. It [00:11:00] enriched Maria's life. It also calmed her. my anxiety or I feel very positive then going into work knowing that Maria was having a good time. Later on, when things were more difficult, I mean, I just, you know, I realise the depth.

of friendship that existed. Literally, at the beginning of each working week, I would have a list of about 15 different friends. And I'd be trying to fill the slots where we couldn't access enough home care for Maria. I had a whole raft of friends, almost acting like a kind of rotor, um, coming round, spending time with her, taking her out.

And that was absolutely vital, because I, I would have struggled to continue working [00:12:00] if that hadn't been in place. The socioeconomic impact for us could have been very, very serious.

Jim: James and Maria had now solidly reached what he would call phase two. A shift in priorities, where James would have to do a lot more to support Maria, putting strategies in place to ensure her safety.

James: She wanted to maintain independence, but lacked the capability, because of the disease, to do that. It would be really tough. I mean, it would lead to, publicly, you know, some quite heightened exchanges between us. It's things you take for granted, like sort of topping up our Oyster cards. So, I knew there was a particular newsagent near the station where the guy was really [00:13:00] patient.

And sympathetic. So I thought, we go there every time to do that. Because that will allow Maria some space and allow her to do that.

Jim: In 2016, James and Maria connected with Maggie, a local Admiral Nurse. That's a specialist dementia nurse supported and developed by Dementia UK. Admiral Nurses provide free advice and support to families caring for a loved one.

Maggie was there for James and Maria from 2016 right up until Maria died in 2023.

James: She came into our lives just as things were getting difficult. When I got effective professional support, it also reduced pressure sometimes that I felt I was putting on friends to help. A lot of people facing dementia and potentially other diseases actually will [00:14:00] recognise that services are often fragmented and difficult to access. And having Maggie as an advocate actually to try and access social service provision, was really significant before she came into our lives. I mean, throughout a lot of 2016, it just felt like crisis management.

So I always felt one step behind and just under a huge level of stress, actually. Once she was there, I felt, I'm not on my own, actually, I'm not just doing this on my own. Having somebody who's professional, articulate in those situations, really important. The other thing I'd say is, actually, when we met Maggie, there'd be a lot of laughter, you know, there'd be a lot of fun, she has a great sense of humour.[00:15:00]

You know, back in 2014 when Maria was diagnosed, my first thought was right, Maria's not going into a care home. That's not going to happen. In one sense, I'm glad I had that thought. And I think we did really well to maximise the time together that we could live together as a couple. But it's such a brutal disease.

And in the context of this disease, the problem is not actually residential care. The challenge is finding good residential care.

Jim: This can be especially difficult when the person has young onset dementia. Some care homes don't even accept people under 65. Maggie, the Admiral Nurse, was there for James as he faced that responsibility, finding the right care home for Maria.

James: I mean, that was critical. It's so difficult visiting somewhere with that emotional [00:16:00] weight around you and asking sort of articulate questions and having somebody there with you doing that, you know? Asking questions like what is the ratio of care workers to residents, for example. Our Admiral Nurse was actually much wider in terms of a choice of home for Maria where she would be happier.

She, she had a positive influence on me in that regard. I think that my initial thought of where Maria should, should go wouldn't have suited her as well. I've talked a little bit about not being able to leave Maria alone at all. You think about the implications of that as a couple, it's very, very difficult to sustain living together.

under those circumstances. You know, the joy of being a couple, of being with somebody you [00:17:00] love, the intimacy, the sensuality. Now, the reality of what the disease does is then you're having to engage with perhaps the sharp end of your lover's personal care. And that's quite brutal in practice. And I'm not.

a trained care worker, so I wouldn't say I'm particularly skilled, and it is a skill in managing that. When Maria went into residential care, one of the benefits of that was that when I visited her, we could focus on enjoyment, on contact, on doing stuff that was, you know, that was fun. In the context of phase two and three of dementia, it enables you to have more compassionate contact of real value.

I would, uh, [00:18:00] Check her out for meals. Music played a big part. Yeah, I used to come in and be the selector and play a lot of retro, uh, soul and funk tunes, which some of the young care workers had never heard of. Yeah, I found with Maria, her emotional engagement, you know, even when she often wasn't very verbal.

was really great. One of my godsons came with us for a visit and, you know, the look of, uh, contentment and serenity, um, from Maria when my godson was there. Um, yeah, it's very powerful. So these are really precious times.

I remember in the last couple of weeks of Maria's life, stress is, is very, very high, very difficult. Um, and I, you know, I had [00:19:00] to continue working. That was a practical necessity. And I was often doing that, coming at the hospital in the evening, and, uh, really challenging periods. But I remember having a meeting with our aboral nurse, with the nurse on site, And they were talking about how they would maximise the chances of Maria being in comfort, you know, with the final phase of her life, how they try and find a way of achieving that.

Jim: They also talked about ways to support James as he juggled work and visits with Maria.

James: And it was a very strange paradox because nobody wants to be in a position where they're discussing, you know, their partner's final phase of their life. Because of the level of care we were getting, [00:20:00] I felt kind of strangely uplifted.

I thought, this is amazing. You know, it's part of me that thought this is, this is just amazing. What one friend of mine described as ‘professional love’.

I'm conscious that I've talked quite a lot where I've used the term luck. I've talked about being lucky with my relationship. I've talked about lucky to enjoy a lot of my work. I've also talked about luck in terms of us accessing services. And actually I think being lucky with your relationship, great.

Being lucky with work, really good. Being lucky. In terms of, for example, getting access to a smooth diagnosis path, I'd really like not to be lucky with that. I'd like that to be a regular experience for people. Being lucky in terms of [00:21:00] accessing an Admiral Nurse, again, I don't want to be a minority in that.

I want to be normal in that regard, that to be a normal experience for people. I think taking that luck factor out, um, would be fantastic, so that it's, it's just a normal experience for people to get good services when they're at their most vulnerable.

In the early phases of the disease, the period when Maria was doing well, I mean, it was, you know, It was remarkable, actually, because we'd sometimes go to social events and people would have no idea. I remember going to, like, a work social do, and one of the actors said to me, Oh, God, it was so nice to meet your missus.

She's lovely. You know, I thought, wow, it's fascinating. He's got no idea. So, and it's important to be able to experiment and enjoy that. [00:22:00] It obviously becomes more difficult as the disease progresses. And one simple tool that I used, and I didn't realise at the time how significant it would be is, Maria was having a tough day one time, uh, in terms of her morale as the disease progressed, and I wrote her a letter, sort of just talking about some of the things that she'd achieved, things that reflected, uh, her humanity, her values.

I'd talk about things like the way she supported her mum through her mum's Things like, for example, her positivity. In the face of sometimes pretty hostile reception because of her cultural background. [00:23:00] She had a really easy screen presence, uh, with her telework. So I kind of referred to that. So I, you know, mentioned these different things that some of them were, if you like, obvious achievements.

Some of them were about achievements in terms of humanity. As things progressed and she was getting some home care, care workers coming to her flat, I'd stick it on the wall and try and make it as visible as possible so that they could see the person that they were supporting, uh, and not the disease. I did the same thing with it in the care home that she was based at.

And then, you know, the final phase, the final kind of couple of [00:24:00] months, really, of her life, I did the same thing. In the hospital, I remember that the last couple of hours that I spent with her, you know, we had that up on the wall. And one of the nurses, who's fantastic on the ward, she came in and I just saw her reading it. That action definitely had an impact.

Jim: Maria died in 2023, aged 65, nearly nine years after she was diagnosed.

James: In terms of remembering Maria, I think of, you know, her values, of solidarity and generosity, of fun. of vibrancy, of warmth. [00:25:00] In some ways, doing something positive like this is a way of moving forward and celebrating the person, you know, celebrating Maria at a very simple level, by doing something constructive, doing something for the future.

From a couple's perspective, Particularly, you know, for people, if you're having a rough time and your loved one doesn't seem to be the person that you, that you met or that you dated, or you had that, all that romance with what I would say is two things. And I respect that this is difficult, is nothing negates the good times that you had.

And I recognise dementia sort of manifests itself in lots of very, very tough ways. But the person that you're with, they never lose their [00:26:00] values. They never lose their humanity. No matter what the disease is, is doing.

Jim: A huge thank you to James for being so generous in sharing his and Maria's story. You or someone you know might even be on a similar journey right now. Two of Dementia UK's Admiral Nurses, Hilda and Vic, are here now. To share a bit more advice on something, James touched on the process of finding the right residential care for someone living with 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: We've just heard James talking about moving [00:27:00] Maria into a care home. I think it is fairly normal for carers to feel a degree of resistance when someone's going into, into care because there's a lot of emotions involved in that.

So people may feel guilty about that. They may feel actually, is this the right decision they're making? There's that, there's a massive fear of the unknown because It's, it's changed. It's a shift. It's something different for your loved one. And, and actually, how does that, how does that feel? And then I think the other thing that is often a big thing for carers is that they, they're very involved in someone's care when you're caring for someone with dementia.

By the point that you're needing to consider residential care replacement, you're actually, very involved in the day to day care and support somebody and relinquishing that control and saying to somebody else, I trust you to take over this caring responsibilities is a big thing for people. It's difficult.

It's one of the, the transitions that I think as Admiral Nurses, we, we support people with a lot actually is how do you, [00:28:00] how do you make these decisions about when placements the right decision and how do you do that in a way that feels supportive and the right for support for everybody involved.

Hilda: I think that's particularly difficult as well, when family members might have a different viewpoint.

And I think with, with James, it was trying to judge which is the right time. And sometimes it's about the promises that you make to people, particularly pre diagnosis. Oh no, you'll never go into a home, you'll never do that. And it's very difficult then to kind of go against that when it comes to the stage when you need to make that decision.

So all of the things that you said Vic, absolutely agree. I think sometimes the media plays a part in frightening people rigid about what happens in care home facilities as well. So there's that fear of, so what happens once that person leaves me and goes through that door? What I would normally say when I'm working with a family is the right time to have that discussion is right at the [00:29:00] beginning of when the person gets the diagnosis.

Where you start discussing the advanced care plan, what would you like to happen if, so would, do you consider going into a care facility? If you did go into a care facility, what would you like? to happen. Where would you like to be? So I think having the discussions early is really important. It gives you time to all get on the same page about things as well, doesn't it?

Vic: And I think for me, there's also if there's obvious safety concerns, you know, actually, if somebody is no longer able to live in their own home safely, and you start to think actually, there, there is some real concern. safety concerns here, or, or perhaps their health needs have escalated and someone's become more unwell due to their dementia or another condition that they're living with and you, and actually it's no longer safe and sustainable for someone to stay at home.

And then I think the other thing that it's worth thinking about is actually the impact that caring has on families. Because we know sometimes that the person with dementia, you know, you may all think actually it's probably better for them to stay at home, [00:30:00] but actually the family get to a point where they could be saying, we're exhausted, we're tired, we're not managing to do the things we need to do whilst providing the level of care and support that our loved one needs.

So there's lots of things that come into play around that, isn't there? In terms of choosing a good care home, what advice would we give around that?

Hilda: I would always say go with your senses. So go in there, what does the place smell like? When you look around, are people occupied? Are they doing things? Do the people look happy?

Do the staff look happy? Listen to see what's going on within that care setting. A care setting that's too quiet would concern me just as much as a care setting where I walked in and there's three televisions all on different channels in the same room. So it's about getting this feel of what's happening.

When you're going into that environment, by using your senses, by asking questions, ask the staffing ratio, for instance, ask what the turnover of staff is, [00:31:00] because there's some care homes that turnover of staff is very rapid. That would kind of alert you that there might be some issues as to why people are leaving that environment as quickly as they are.

I would try and talk to some of the other residents that are there and some of the visitors that are there to find out what they think about the care home. I would ask what activities are on offer. I would be asking about whether somebody could come home for the day or come home for a week or go on holiday for a week and then come back.

So all of those things are what I would be looking for if I was looking for a care setting. With some of the families that I've worked with, uh, we've looked at homes that have got residential settings as well as daycare settings as well. So gradually moving that person from a daycare setting into a longer term setting often works a lot more effectively.

Vic: I think my final thoughts on this conversation is actually, we know moving somebody into, care is, is difficult. We know it's a significant decision and, and [00:32:00] actually our Admiral Nurses can help with that. People can, can book an appointment with an Admiral Nurse or speak to an Admiral Nurse and we can help people kind of plan through and think through that transition and actually how to do it.

So I would consider reaching out to an Admiral Nurse if actually you do need some more support around this.

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 [00:33:00] listening.