

More than memory.

[00:00] [background music]

Leigh Hatcher: [00:06] Hello, and welcome to the second of our Nerve podcasts, Hope Beyond Brain Disease. I'm Leigh Hatcher.

[00:12] This time, a condition in the brain that's likely to have the sufferer bouncing around between doctors and tests, try to identify a series of unusual and worsening symptoms. When they finally get a diagnosis, it's a condition called PCA, posterior cortical atrophy.

[00:31] Joining me is Rowena Mobbs, a neurologist at Sydney Cognitive, and Richard and Cheryl, who will explain what it's like to live on that merry-go-round with PCA.

[00:42] First, Rowena explains what exactly is posterior cortical atrophy.

Rowena: [00:48] I think it's one of the most fascinating, interesting types of dementias. It's very much a visual type of dementia.

[00:55] If you think about dementia, which is the umbrella term for a loss or degeneration of neurons within the brain, of which Alzheimer's is the most common type, usually, that would present with memory loss and even mood disturbance, often.

[01:09] Visual problems are really common in PCA. These are something that can greatly impact the person. It's, for example, gestures or dealing with objects in front of the person, and I think we'll here describe some of the difficulties with it.

[01:26] We think it is probably a form of Alzheimer's, but the jury is out. The pathology under the microscope is often similar.

[01:34] It impacts this area of the brain called the occipital lobes. They are where our vision, see, it's vision is within the brain. The neurons perceive vision. It's a really large area of the brain. It is certainly a major part of our existence, of course, and we need our vision. That, hence, the large area of the brain being taken up.

Leigh: [01:56] It is a rare condition and perhaps difficult for doctors to diagnose, recognize.

Rowena: [02:03] It is rare, and if we classify it as a type of Alzheimer's, we think it's in the realm of about 5 percent of patients with Alzheimer's disease, though, because of that factor of difficulty identifying this condition, it may be a higher number of patients, say 10 or 15 percent of Alzheimer's patients.

[02:21] Often these patients will have seen many different doctors, right from the GP through to eye specialists for these very visual problems. Even as neurologists, we don't always get it right. We don't always detect it early enough.

Leigh: [02:33] I'm sure we're going to hear that from Richard and Cheryl.

[02:36] Is there a cause?

Rowena: [02:37] Yes, there's always a cause. It's bound to be environment and genetics, to what degrees, we don't understand yet. It's bound to be complex, multiple different factors, pieces of that puzzle to cause the illness.

[02:52] As I allude to, we think it's a type of Alzheimer's. In that condition, we think there's a culprit protein called beta-amyloid, largely, although there are others. That may sort of clog up neurons or their connections and cause a dysfunction of the neurons, and eventually, those neurons can no longer cope and a loss of neurons.

Leigh: [03:12] I'm so glad to say that Richard and Cheryl are here to tell us exactly what it's like living with PCA. Richard's a former private pilot, justice of the peace, still runs his own removals company. Cheryl is a former nurse.

[03:26] What and when did you both start to notice something different in Richard? Who was first? Richard, I suppose it was you?

Richard: [03:34] I suppose about four or five years ago, I always had issues anyway, but I found it hard to drive at nighttime, and if it's raining and bad weather, I wouldn't drive at all. I'd been noticing slight deterioration for a long time.

Leigh: [03:47] You've been married 43 years.

Cheryl: [03:49] Yes.

Leigh: [03:49] I suspect, Cheryl, you probably knew something was different before Richard realized you realized, if you know what I mean.

Cheryl: [03:58] I think I did. It was shaking of the head when he was trying to focus on something, a little bit of stumbling, and just that, and you're playing bridge, he couldn't see the cards properly. He'd come home, he'd be all dejected.

[04:12] We went to the optometrist, who we've seen for many, many years prior, and over a couple of years period, she made him three or four different pairs of glasses for bridge playing, for reading, for driving, for normal everyday seeing. She finally said to me, "Cheryl, this is not Richard's eyesight. It is a cognitive issue."

[04:33] Therefore, we went to the GP, spoke to her about things. She didn't do a lot at that point of time. As Richard had glaucoma and was being treated for it, an eye specialist, I spoke to him on numerous occasions. He couldn't answer my questions, but he didn't tell me where to go.

[04:51] I knew there was a problem, and I really thought Richard had a brain tumour and I would have been happy if he'd had a benign brain tumour to cause all these problems.

Leigh: [04:59] See, that's interesting, because you're kind of after a tag, aren't you?

Cheryl: [05:03] Everything was all over the place. There wasn't a straight road in any of this. I asked the eye specialist for an MRI. He sent us back to the GP, who did it. Then we were referred to Dr. Mobbs, which would have been in late 2014.

Leigh: [05:19] How long was this whole process, from when these changes started to happen, the merry-go-round of doctors?

Cheryl: [05:25] The merry-go-round started in September 2014. We'd been to eye specialists and we'd then just got to Dr. Mobbs.

Leigh: [05:32] Richard, how did you feel when you were finally diagnosed with PCA?

Richard: [05:36] It's a bit of a shock in the beginning, losing your driver's license, because I've been driving for 55 years and suddenly you can't drive anymore.

Leigh: [05:45] Or fly anymore.

Richard: [05:46] Or fly anymore, because I've got a pilot's license. It took me years to get one and suddenly you can't fly anymore. There's not much you can do, you just have to adapt yourself to the situation. Fortunately, I discovered Uber and taxis.

Leigh: [05:58] Lots of ways around.

Richard: [06:01] Lot of ways around it, it's just adapting.

Leigh: [06:04] This may seem an unfeeling question to ask, but was it a good thing to finally get that tag, that diagnosis?

Richard: [06:12] I suppose it is, because I thought it was just my glasses. I didn't think the optometrist was any good, because she couldn't fix my glasses. Not telling her I couldn't see much.

Leigh: [06:22] You ended up having lots of glasses.

Richard: [06:25] Lots of glasses, and then drove the lady insane. I have to accept these things, I'm 72, nearly, so, things happen.

Leigh: [06:32] Cheryl.

Cheryl: [06:33] Throughout this process, Richard has always been in denial, despite what he's just said. What he blamed his issues on, he was on hormone therapy for prostate cancer, and he's quite convinced that that is what had caused the eyesight issues.

[06:49] A lot of this is denial on Richard's, I have to contradict him quite a lot, because...

Leigh: [06:54] He's such a bloke.

Cheryl: [06:55] He is. I mean, Richard's on a different plane to all of us, he always has been, the most literal person I've ever known. But I mean, everybody loves him, and he's very intelligent.

Leigh: [07:04] What would you say it was like for your relationship through all this merry-go-round and all this uncertainty?

Cheryl: [07:12] Over the years, Richard would never go to a doctor. I always had to fight with him to have just normal checkups or whatever. I'd always go with him because he would lie to me about the outcome.

Leigh: [07:21] [laughs]

Cheryl: [07:23] Anyway, I've always been with him. In the last 10 odd years, he's been very, very good. In the beginning, with all this merry-go-round, he did buck the system, and I have to be careful who I book in, when I book them in, and how often. Now the last 12 months, all that's eased a bit. It has eased, which makes life a lot easier.

[07:45] Someone said to me a few weeks ago, "What do you do, Cheryl?"

[07:49] I said, "Well, I look after Richard."

[07:52] She said, "Well, don't be so stupid. What else do you do?"

[07:55] It's the truth, I do, he's the most important person, the top of the tree of the people that I look after.

Leigh: [08:02] If you think about it, if he's lost a large part of his vision, that requires a lot of help and a lot of understanding.

Cheryl: [08:08] It does, but I've always done a lot for Richard, because he's been very lateral and not very handy in the home or practical anything, so I've always had to do all those things. I'm getting tired, because I'm getting a bit older and there's a lot of other factors in our lives now. We still have a good time. We think alike, we like the same things, generally.

Leigh: [08:29] 43 years of marriage.

Cheryl: [08:30] That's right.

Leigh: [08:31] Richard, what's this been like for you personally, and what's it been like with your relationship?

Richard: [08:35] It's been a bit frustrating for me, because now I have to listen to Cheryl all the time. Cheryl's an ex-nurse, so I go from doctor to doctor.

Leigh: [08:46] How helpful.

Richard: [08:47] I've never seen so many doctors in my life. I said, who am I seeing now? We've been together from the day we met, just about 45 years ago. From the day we saw each other, we've always been together.

Leigh: [08:59] Rowena, what do you look for, what do you listen for to come up with a

diagnosis of PCA?

Rowena: [09:03] With neurological conditions, you always start with the history, and that includes not just from the patient. As we've heard, there can be lots of contributing history from family and friends.

[09:16] We listen as doctors, first of all. We try to put together some clues. With PCA, there can be subtle, very slow changes. You have to listen over time, repeatedly see your patient and watch them over time. The classic things are perhaps a little bit of difficulty with numbers and letters, so writing, and then accounts, adding up, and interpreting numbers and letters.

[09:40] There can be difficulty interpreting just normal social cues, so somebody giving a thumbs up, for example, identifying that. Or with faces, recognising people. Difficulty with visual tasks like dressing, putting on clothing, writing and drawing pictures, recognising imagery on television or through IT, that can be really hard.

[10:04] Even, as time goes on, difficulty with using an iPhone 4 or walking through a doorway can be very hard. That's really impairing.

Leigh: [10:13] This was on your radar as you were listening to Richard and Cheryl.

Rowena: [10:17] Yes. I guess in a way, my job is easy here, because he'd seen multiple eye doctors, including a neuro-ophthalmologist, who's switched onto these conditions, as well. Nothing had been identified, although he has a history of eye troubles, and they're being treated as best they could.

[10:34] It was more than that, and I always, I have a radar for rare conditions and what's going on, is there something more, that sort of investigation approach.

[10:44] With Richard, I could see in front of me across the desk that he just wasn't holding the pen right or grabbing the pen right. If he walked into my office, he just was missing those sort of trajectory lines as he's walking. I'd be worried if he was flying my plane, to be honest.

[11:02] [laughter]

Leigh: [11:02] I might say that, too, Richard, I'm sorry.

Rowena: [11:04] If you don't look you don't find. I must observe the patient every time they walk in the door, right from the get go.

Leigh: [11:11] Richard, can I ask you, can you put into a form of words what it's like to have this condition? What's it like today for you?

Richard: [11:19] It's very frustrating. You always have to rely on other people to do things for you. I find it hard to read on the computer, like, I can't even send an email. All that is hard. All the things I used to do, I can't do anymore.

Leigh: [11:34] Faces.

Richard: [11:35] Faces is the hard one. Recognising people, and when I go somewhere, people talk to me and I don't know who they are.

Leigh: [11:43] You're looking at me, describe what I look like to you.

Richard: [11:46] Oh, I can see you quite clearly now. You've got glasses. Maybe if you walk in next week, I won't recognise you.

Leigh: [11:53] Wow. Cheryl, what's that like? What's that been like to live with?

Cheryl: [11:58] I suppose it is traumatic. Because it fluctuates so much, sometimes I think, "Well, am I [inaudible] I'm missing something, or our family, our children don't know the depths of this.

[12:11] I tell them things when we're going out, watch your father, take him here, do that. Then Richard always says to them, "Oh, don't worry, I can see like a hawk." That is what he says all the time. I think, "Well, what's Cheryl going on about if he can see like a hawk?"

[12:24] Then he's had a couple of falls in front of them and trips and things, so they do know, but they don't know the greater depth of it all. What first happened, we were at the club, and our twin daughters were coming.

[12:36] Anyway, Richard went up to another table, and there was a little girl there, and he thought it was one of our twins, and he was talking to her. The little girl got upset and frightened and her mother was there and I thought that they thought he was not a very nice person.

[12:51] I had to go up and explain the situation, that he could not see who that person was. He really upset this child, unintentionally. I thought, my god. Our twins are identical, and even I find it hard at times. I always say, "Well, which one are you?"

[13:12] They don't mind and they know and they're very helpful and supportive to their grandfather. It's getting a little bit scary when you're out in the big world. If you're at home, doesn't matter.

Leigh: [13:21] Rowena, is there a treatment for PCA? What can you do for people in this position?

Rowena: [13:26] The treatment and cure are two different things. Firstly, with treatment, we can try to treat classic Alzheimer's in a way and sort of give a tablet which largely is used for memory, and memory can be part of this condition, and so the thing called cholinesterase inhibitors.

[13:42] That can be helpful to a degree, but it doesn't slow down or cure the condition, unfortunately. Then we're in the realm of management, and that's a huge topic, and often a very underrecognised, and I would hesitate to say, but sometimes ignored topic for

patients.

[13:58] With management, again, it's sort of listening well and understanding their own circumstance individually, as patients and families. Then getting them to a point of care, so continuing that relationship and rapport.

[14:11] Then getting them to people like occupational therapists, who can go out to the home, have a look, check the environment and make modifications. Not just as far as vision and falls goes, but cognitively, so how they can function well and think well in their own environment, and then extending out to the community, say, going to an ATM, [inaudible] how to put in PINs and so on.

[14:32] Supporting them through physiotherapy if there are mechanical arthritis sort of factors, etc., and sometimes the brain condition can affect movement, and other supports. Psychologically, because that's a huge part of treatment, too.

Leigh: [14:45] Yes, shaping their expectations otherwise.

Rowena: [14:47] Yes, partly, and also, resolving stress, because underlying stress in all of these conditions can make the symptoms worse, and it makes life very hard. You're going through a lot already to deal with their condition, let alone how the family's going to take it, financial consequences, or whatever it is, to sort out.

[15:07] Sometimes seeing a clinical psychologist or a counselor, psychotherapist, can be helpful, as well.

Leigh: [15:12] Can I ask you a personal question about these two?

Rowena: [15:14] Sure.

Leigh: [15:15] That they're up for talking about this, what do you think about that?

Rowena: [15:18] Pleasingly, my patients often surprise me with their talents and skills through dementia.

Leigh: [15:25] They're great...

[15:27] [crosstalk]

Rowena: [15:27] [inaudible] .

[15:27] People are very good in different ways, and they have intelligence in different ways, even though in some capacities, they might be affected.

[15:33] With Cheryl and Richard, even today, I'm often hearing that talent, the different aspects of them as people. Often, these days, people are very switched on. The old classic was, we thought older people and people with dementia could not use IT.

[15:50] That's certainly not the case. I don't have a single patient without an iPhone. [laughs] They watch TV, they're engaged in the world, and they've got lovely social

groups, often. That's a big part of the person...

[16:01] [crosstalk]

Leigh: [16:03] They're still living life.

Rowena: [16:04] They are living life.

Leigh: [16:06] It's a big point...

[16:07] [crosstalk]

[16:07] [laughter]

Rowena: [16:07] They have relationships, they're living life just as a well person would in lots of ways.

Leigh: [16:13] Well done to you, too.

[16:15] Richard and Cheryl, can I finish with this question? How are you dealing with this day-to-day and what's the future look like for you?

Richard: [16:22] Fortunately, I've got a lot of sense of humour and I can always laugh and take things by stride all the time.

Leigh: [16:29] That's a gift, actually.

Richard: [16:30] You need that, otherwise, it's so very humiliating when I crossed the road at some time ago, and this young girl grabbed me, "I'll take you across the road," she said. You have to accept all these things.

Leigh: [16:41] What a happy thing.

Richard: [16:42] A lot of people are a lot worse off than I am, so I can't complain, really.

Leigh: [16:46] Cheryl, what's the future look like for you?

Cheryl: [16:48] Now it's looking a lot brighter and more settled. We know more, what to access, and just get on with life. The first thing Dr. Mobbs ever said to us was get out there and enjoy your life, live your life. We've done that, we travel. We've already had three cruises this year with another one coming up.

Leigh: [17:10] Bravo.

Cheryl: [17:10] The next year we've got one booked, and the following January, one booked, plus little things in between.

[17:14] Richard has always been a doer, and he's been skydiving, he's abseiled off the harbour bridge, he's flown little planes. Thank god for all that, because he's got all that to look back on. We have got wonderful friends and they're all so supportive. We love living

in our community. It is not that bad. We're just going to get on with life.

Richard: [17:38] I've also got a fantastic atmosphere in the office. We've got an incredible culture.

Leigh: [17:43] Yeah, good stuff.

Richard: [17:44] Everybody laughs and everybody's happy. The trouble is I don't even recognise half the people who work for me anymore, especially the drivers. You don't see them that often, and I talk to them. I said, "Who are they?" No idea who they are, but anyway, everybody knows me and we all laugh. Very supportive office.

Leigh: [18:02] You're a magnificent couple, and great advocates, actually. I'm so pleased that you've been up for this podcast. What a great conversation. Thank you so much, indeed.

Cheryl: [18:11] Thank you.

Richard: [18:11] Thank you.

Cheryl: [18:12] This is all up Richard's alley. He thrives on it.

[18:16] [background music]

Cheryl: [18:16] He'll be telling everybody for weeks about it.

Leigh: [18:18] Spread the word, Richard.

Cheryl: [18:19] He does. Trust me, he does.

Leigh: [18:22] Thanks for joining us on our Nerve podcast, Hope Beyond Brain Disease. I'm Leigh Hatcher. There's a whole host of information and resources at www.sydcog.com.au.