

Stay with me

“Hello, I’m from the memory service. I’m looking for Mr. Sheppard?” The door swings wide open and a relieved smile beckons me inside. “Oh yes doctor we’ve been expecting you. My husband’s just in the living room. This way...”

I follow the corridor round to the right, my brogues squeaking on the well-polished oak floorboards. The walls are covered in photographs – individual portraits of people I assume are parents or grandparents, stunning vistas and group photos of a laughing couple at the centre of what look like elegant cocktail parties. Most of the photos are dominated by a tall and striking man, gazing confidently at the camera.

At the end of the hallway is the living room, and I am greeted in the doorway by the handsome man from the photographs. His tall frame stands proud, a sharp silhouette perfectly framed by the doorway ahead. My eyes adjust and I see he is dressed in an immaculate charcoal grey suit and silk tie. He turns towards me and briskly extends his hand.

“This is a wasted trip for you.” He says gruffly. “Unless you’ve got a cure for old age.”

It’s a familiar script. I reply as I always do.

“Why don’t we just have a chat, Mr. Sheppard? I can do a short memory test and we can take it from there?”

He gestures towards the sofa and I settle down as he says, “Please, call me Artie. I always look around for my father when someone says ‘Mr. Sheppard’!” He takes the chair by the dining table as his arthritis make it difficult for him to get up from a lower seat.

I ask him to tell me a bit about himself. He tells me he is a retired accountant who enjoyed travelling and living abroad. He had a stable and loving family and a few romantic relationships but said he didn’t date much – “Nobody was that interesting. Until that party my dad threw when I got my exams – you remember that?”

“How could I forget? You charmed me off my feet, with your suit and your exotic travel tales...”

“So you’ve been together since...?”

“It was 60 years last summer.” I look away as they share an intimate smile.

They continued to travel together and Artie found work abroad as an accountant. They had returned eight years previously when Artie’s arthritis and hypertension were becoming difficult to manage and his mother’s health was also in decline. His memory problems started about a year prior to my visit.

“It’s nothing major...you know, forgetting appointments or where I put things and I don’t think it’s got any worse.”

“No, darling, there was that time you turned the fridge off completely. We had rotting food and puddles and you couldn’t explain what happened. You said you were cleaning but why would you turn the fridge off?”

“That was one time for goodness’ sake! Can’t a man have an off day?!” Artie is sitting, jaw and fists clenched and I try to smooth things over – “Well, why don’t we do a memory test and see how things go?”

The testing does not go well and Artie struggles with even the simple questions. I am surprised as he was so articulate and confident - his educational and occupational achievement must have helped him mask his cognitive difficulties for years. He gets progressively more irritated and needs a lot of cajoling and persuasion to complete the test. Normally by this stage I would be reasonably confident in a diagnosis of dementia but the apparent lack of decline in his function and the possibility of a mood disorder, given his mother’s recent death, make the diagnosis uncertain. I tell him his score on the memory test was low but we need to do some blood tests and a brain scan to investigate the cause. He reluctantly accepts this plan while insisting there is nothing wrong, then apologises for not being able to come to the door to see me off as his legs are quite painful.

“Oh, don’t worry darling, I’ll see the doctor to the door.”

I say goodbye and then head back along the long corridor. As we walk, I am suddenly taken by the arm and moved out of earshot with some urgency, as Artie’s arthritis gives me the space to hear another side of the story. I wait patiently, while the pictures surrounding me reflect multiple perspectives on the furtive glances towards the doorway and the words spill out in a hurried whisper.

“Sorry doctor but don’t be fooled by Artie. He’s really good at talking but there IS a problem and I know it. It’s not just appointments and losing things - though that is definitely getting worse. And it’s not just that one time he’s turned off the fridge. But it was the thing that happened a few weeks ago when we were walking past Holborn police station - that’s why I asked for the referral.”

The story is interrupted by more glances towards the doorway. Then it continues, louder and more determined.

“With his arthritis, he needs to hold onto me even though he has a walking stick too. We were walking past the police station and he saw a police officer. He suddenly dropped my hand and told me to go ahead. I said “What are you doing Artie, you’ll fall” and he said “Look we don’t want any trouble – I don’t want them seeing us together. You know they’ll just harass us for no reason.””

I stare blankly for a moment, trying to work out the significance of this.

“You see, he thought we were back in the 70’s. We used to have problems when we went out together back then. The law changed in 1967 but gay people weren’t really accepted for a long time after. It’s part of why we lived abroad. I mean, those other places also criminalised homosexuality but at least as outsiders we were mostly left alone. Artie thought it was back then and we shouldn’t walk together.”

It’s clearly a painful memory and I thank Gerald for sharing that information with me. I promise him I will take it into account and give them a diagnosis when we next meet. On my way home, I reflect on how long they have been together – longer than I have been alive. And how a prejudice once enshrined in law that stigmatised them so many years ago continues to reach out from the past to haunt their lives.

I get the results of Artie’s blood tests and brain scan a few weeks later and schedule a clinic appointment.

"I'm afraid your brain scan shows a lot of brain shrinkage, especially in the area called the hippocampus which deals with memory. Given your history and the results of the brain scan and memory tests, it seems that you have Alzheimer's dementia." I look at them both, waiting for a reaction, ready to describe treatment options and health optimisation. Gerald is sitting motionless, lips pressed together tightly, hands clutching his knees - but Artie is staring blankly out of the window.

"Artie?" I say.

"Thank you doctor. I know you've done everything you can for him and he seems to be getting better."

"Sorry, I..."

"I'll bring him to the next appointment as you said." Artie turns back to look out of the window.

Gerald leans forward, his voice strained. "He thinks this is the appointment he went to for his brother John. He had cancer and Artie took him to all the appointments – they had no other family you see. He does this sometimes – he goes off into the past, relives events. It's happening more frequently now...."

He leans back and tries to force a smile. "It's not always bad though. The other day he was walking around in shorts because he thought we were back in our holiday home in Zanzibar. Sometimes it must be nice for him, you know, reliving past events, talking to old friends. I try to think of it as time travel." His voice tails off to a whisper. "I only wish I could go with him."

The three of us sit, words trapped by the silence. We share the same space, but not the same time. Eventually, Artie turns to Gerald and says "I want to go home." I arrange to meet them again to talk about treatment options.

When we meet again, it is clear that Gerald is under tremendous strain. He talks about how frustrating it is, having to answer the same question repeatedly, having to remind Artie to take his medications or go to appointments.

"With other people he can still be really charming but with me he's so irritable. I don't know what I'm doing wrong." I reassure him that he is not doing anything wrong and arrange for him to see our psychologist for support. When I check in with him a few months later he says he is coping better, mostly by making time to do things for himself that don't involve Artie.

"But it feels like a betrayal, you know, going out and doing things without him. I went to that wildlife photography show the other day. Artie would have loved it but I just knew he wouldn't have coped with it the way he is these days. I keep telling myself I have to look after myself so I can look after him. But still..."

I next see Artie waiting to be picked up from his cognitive training session. He has been coming weekly for four weeks now but the therapist said he has not been doing well and this is reflected in his appearance. The sharp suit and tie have been replaced by a threadbare and stained shirt and tracksuit bottoms. I barely recognize him, but when I do I go and sit next to him.

"Mr. Sheppard? Artie? How are you?"

He looks at me blankly. "Are you waiting to go home?" I ask.

He looks away then turns back to me, eyes filling with tears. "I shouldn't have said what I did. Now nobody talks to me. I'm all alone."

"Isn't Gerald here with you? Is he on his way to pick you up?"

He doesn't seem to hear me.

"Artie, can I make you some tea while you wait?"

He turns away from me, sighing and mumbling to himself.

I look around helplessly, desperate for something to do or say. Thankfully, I see Gerald striding through the front doors. He is out of breath and rushes to Artie.

"So sorry darling, parking was just a nightmare and I didn't want you to have to take the bus again. You nearly fell last time."

Artie turns slowly towards this familiar voice. When he sees Gerald, his whole face lights up and I see a glimmer of the dashing man I had met such a seemingly long time ago.

"You came! You came! You always do!"

He gets shakily to his feet and clasps both of Gerald's hands in his. They lean against each other, foreheads touching, oblivious to everything around them. I feel like an intruder and slip away. I know they have both been through so much, buffeted by forces they cannot control. But for that one moment at least, they are both anchored to each other and content.

I have seen so many patients make their journeys from noticing their first symptoms of memory loss, to getting a dementia diagnosis and treatment. I have often watched helplessly as they drift away, lost beyond the point at which medicine can play a role. But the families who accompany patients on their journey have shown me how much more there is to dementia care. For in love, compassion and the remembrance of things past, patients find what drugs can never give them - hope and dignity.

I have come to realise that the true heroes of a story are sometimes not the ones in the centre of the picture frame.