

THE QUARRY

Julia Grace Roscoe

Stolen Memories

Julia Grace Roscoe shares a very personal account of what it's like to lose someone to Alzheimer's disease.

We're just getting old. That's what my Nan used to say. She denied for so long that anything was wrong with my Pop. He was forgetting things. Things like the day, the month, and the year. Sometimes he would forget what he was doing. Sometimes he would be in the shower and he would forget actually getting in the shower. He would forget where the toilet in his own home was. Once he even forgot who I was. Still, Nan insisted they were just getting old. But instead of old meaning wrinkles and grey hair, for Pop, it meant becoming dependent on someone to look after him. And the worst part, it meant losing his memories.

Alzheimer's disease is a disease of the brain, which gradually impairs higher brain functions such as memory, thinking and personality. It is the most common form of Dementia, and affects one in 25 Australians over the age of 60. There is no cure.

In the early stages of Alzheimer's, symptoms may be too subtle to notice. Depending on the affected areas of the brain, early symptoms include memory lapses, problems finding the right word for everyday objects, difficulties making decisions, confusion and personality changes.

I never wanted to leave Brisbane. Growing up, my sister and I were very close to Nan and Pop. When we moved to Sydney, we would fly up to visit them every school holidays. I've got a picture on my dressing table of my sister and I with Pop. He is holding both of us over his shoulders and we're all laughing. My sister and I have our faces huddled in Pop's neck. I'm five or six in the photo.

Pop's initial diagnosis was pretty vague, as with most cases of Alzheimer's. Diagnosis is about 90 per cent accurate, but there is no definitive test. The only way to confirm the presence of the disease is with a post mortem on the brain, which for an Alzheimer's patient shows damaged cells called 'tangles' and 'amyloid plaques' in the spaces between the cells. The plaques are made up of a protein called 'A-beta'. The build up of protein is what is thought to cause the damage as it basically rusts the brain. Research has shown that the protein converts oxygen to hydrogen peroxide, which bleaches and corrodes the parts of the brain linked to memory and reasoning. In Alzheimer's disease, the brain cells cannot connect and 'talk' to each other. Ultimately, the connectors disappear entirely in the part of the brain where thinking occurs. Drugs aimed at inhibiting the production and toxic effects of the A-beta protein are in development, but it will be some time before they are widely available.

Pop was first diagnosed in June 2009. He was 80 years old. The doctor's report read: 'The history is basically one of gradual onset and gradual decline of short-term memory over about three years or so. I note the CT head, which shows considerable deep white matter ischemia* and normal full blood count. I have talked to John and his family about the diagnosis of Mixed Alzheimer's & Vascular Dementia. He is interested in trialling Cholinesterase Inhibitor so I have prescribed Reminyl.'

We were told that Reminyl might help to slow down the changes in his memory but it would not cure him. The doctor asked if he wanted to trial it anyway, and he agreed, though he had no idea what he was agreeing to. We were willing to try anything that might help, so he was put on a three-month trial. Reminyl is used to treat mild to moderately severe cases of Alzheimer's. It is supposed to increase the amount of Acetylcholine, a substance which transmits messages between brain cells, and which patients lack. The aim is to help improve or stabilise the symptoms and perhaps even slow the progress of the disease. It didn't help Pop. The doctor didn't think it would. The drug comes with some awful side effects, and Pop experienced

nausea, vomiting, diarrhoea, muscle cramps, tingling in his hands and feet and he became more and more depressed. I was staying with Nan and Pop one night during the Reminyl trial. When I said goodnight to him he hugged me and said *goodbye*. That was the only time I ever saw him cry. He had tears welling in his eyes as he said,

‘I don’t want to wake up in the morning.’

He looked scared. His dressing gown was drowning his frail frame, and I watched him, hunched over as he shuffled off down the hallway until I couldn’t see him in the darkness anymore.

When the doctor told him he had Alzheimer’s she asked if he knew what that meant. He said he did, but we knew he didn’t. When we left the clinic he couldn’t even remember why we were there. He was also diagnosed with Vascular Dementia (VD), which occurs due to problems in the supply of blood to the brain. It is the second most common form of Dementia after Alzheimer’s. Symptoms between the two are difficult to differentiate because a large percentage of people with Alzheimer’s also have VD. Mixed Alzheimer’s is a condition in which abnormalities characteristic of more than one type of Dementia occur simultaneously. In Pop’s case, the abnormal protein deposits on the brain associated with Alzheimer’s coexist with blood vessel problems associated with VD. The main difference between the two is the progress of the disease. Alzheimer’s patients tend to experience a more consistent rate of decline in all cognitive abilities. Pop’s symptoms progressed quickly, consistent with VD. The most common cause of VD is a stroke, which is a type of vascular disease. Often patients can experience a number of small strokes, which may go unnoticed. This may have been the case with Pop. The doctor thinks it’s more likely to be related to his past as a boxer, which is now known to be a risk factor due to the trauma inflicted on the brain by blows to the head.

About a month after the doctor’s visit he started asking for his mother all the time. He stopped recognising himself in photos taken in the last 30 years. In Alzheimer’s disease, short-term memory storage is damaged first. Humans have two types of memories, short-term and long-term. Short-term memory is programmed in a

part of the brain called the temporal lobe, while long-term memory is stored throughout extensive nerve cell networks in the temporal and parietal lobes.

Pop would ask for Nan all the time too, but he got agitated because the woman he remembered was 40. Nan was 80. He was also becoming delusional; he kept saying that Nan was an imposter. He said there was a strange man sleeping in his bed. Nan would just shake her head and tell him to stop being daft. He had good days, and bad, but now the bad started to be more often than the good. He needed help choosing clothes appropriate for the weather and time of day. Sometimes he would put his pyjamas over his jeans, or socks over his shoes with his shoes on the wrong feet. He couldn't remember where he lived, or where he went to school. He could still distinguish between familiar and unfamiliar faces, but he was increasingly having trouble with our names.

I don't know how Nan did it. He was almost totally dependent on her at this stage; she was looking after him full-time. He couldn't even go the toilet without her help anymore. I remember once when I was there he started shouting at her, saying he wanted to be with Jeanie. He was waving his cane stick at her and shaking his head. It might have been funny, except for the look on his face. It was screwed up and he kept gasping. He couldn't work out what was going on. For the first time I noticed the deep lines etched on his face. The lines of a life lived. His grey wispy hair was thinning, and so was his face. It was drawn and he had deep purple colouring around his eyes.

'I'm Jeanie, I've changed my hairdo,' Nan said to him and she gave him a lolly. It was like watching a mother and her son, not a wife and husband.

'Come on dear, I'll make you a cup of tea.'

This scene played out fifteen times that day.

Before Nan could get any help, she had to qualify for respite from the Australian Government Department of Health and Ageing. Respite Care provides a chance for both the carer and person being cared for to take a break. Respite can be in the home with care ranging from a few hours a week to overnight care, in a Day Care Centre which provides full or half day care, or, in a residential aged care home for two or three weeks. Nan desperately needed help, though at first she didn't want any. But she couldn't leave him alone anymore, and being there with him all the time was taking its toll on her. The last time she left him on his own he urinated on the kitchen floor because he couldn't remember where the toilet was.

To qualify for respite, someone from the National Respite for Carers Program came to assess the situation and determine whether or not Nan needed help. Mum was there on that morning and she sat with Pop and he read to her.

‘He read the same thing over and over again. He read the same sentence a dozen times, and then moved onto the next paragraph and did the same thing. He never turned the page. He had no idea what he was reading, but every now and then he would throw in the grandchildren’s names,’ she told me.

During the test, the nurse asked Pop his age, birthday, where he was living – he had no idea. He thought he was 40, and had only just moved to Australia. They moved here from England in 1961. He couldn’t copy a picture of a cube. He tried over and over again but couldn’t get it. He was a builder by trade; he could easily have drawn a cube. He couldn’t name everyday items shown to him, like an apple. He couldn’t remember how to spell, not even his own name, he wrote ‘Jhon’. But what he could still do blew the nurse away. When asked to count backwards from 100 in multiples of seven, he rattled the numbers off correctly and without giving it so much as a second thought.

Mum and dad had already been researching nursing homes for Alzheimer’s patients, because we all knew what was inevitable. High-care nursing homes are for people who need 24 hour nursing care. This may be because they are physically unable to move around and care for themselves, or because they have a severe Dementia-type illness or other behavioural problems. Residents in high-level care receive specified care and services including assistance with daily living. A year or so earlier Nan and Pop had downsized, and moved into a smaller home across the road from the hospital. Pop was always in the hospital for some sort of check up – he had chronic back and knee pain – so it made sense to move there. The hospital also had a high-care nursing home attached to it.

On Boxing Day 2009, just six months after the initial diagnosis, we were left with no choice but to put Pop into the home. While some families celebrated the holidays, lazing about in the wringing heat, with bellies full of left over Christmas turkey, Pop had chased Nan around the house with his walking stick, threatening to

hit her if she didn't find his real wife. Mum and dad found Nan hiding under her bed, terrified. Pop kept demanding to know who she was and what she wanted. He was too far gone now, there was nothing else we could do. He was on the edge of an abyss, and he wasn't coming back.

The home is a large rectangular building. Inside is a maze of rooms, sectioned depending on the level of care needed by the patients. The high ceilings and wide corridors are painted stark white, and the smell of disinfectant lingers. The bedrooms are all the same, a bed in the middle, a desk on one side, and an ensuite. We tried to make it feel like home for Pop. We put photos of the family around the room and on the desk. The younger grandchildren drew pictures that we hung on the wall. Nan brought in blankets and towels, books and music. But he knew it wasn't home, and he kept asking when we would take him home.

I used to go and sit with him for hours. I would read to him and feed him. It was like feeding a baby. He would dribble and I had to wipe his face with his bib. Sometimes we would go out and sit in the garden. We would bring his dog Princess over too. He loved her, and she adored him. She would sit beside him for hours. The garden wasn't much of a garden, the trees were lean and straggly and there were some sad looking bush shrubs lining the fence. But the grass was always perfectly manicured, and was a luscious shade of dark green.

Aphasia is the inability to communicate effectively, and occurs in all Alzheimer's patients eventually. Pop couldn't hold a conversation anymore, so he would sometimes just mumble or grunt. If I asked him something he would nod, but I don't think he even understood what I was saying. Sometimes he wouldn't say anything at all. But he would smile at me. I used to wonder if he even knew who I was.

It's been just over three years since his initial diagnosis. The Alzheimer's Association says that most people with the disease die within four to six years of diagnosis. However the disease can last up to 20 years. Pop is now bed-ridden and sleeps most of the time. He cannot bathe himself; he cannot even turn in his bed. He is into the late stages of the disease, slipping in and out of death. These stages can last

up to several years. It has him in its grips and there is nothing we can do except make sure he is comfortable. He no longer recognises any of us. He doesn't even recognise himself. He cannot chew or swallow. He is incontinent and has had several urinary tract infections. His skin is a deep shade of purple, he is frail and his skin bruises so easily that they only bathe him once or twice a week. There is no dignity in Alzheimer's disease.

Pneumonia is often the cause of death in patients. Difficulty swallowing often causes people with Alzheimer's to inhale food or liquid into their airways and lungs, which can lead to pneumonia. The doctors say Pop has liquid on his lungs. I have an aunt who is a nurse in a high-care home. She said pneumonia is the best way to go, because what is to come is much worse as the body starts shutting down. I feel guilty for thinking she is right, but grieving for someone with Alzheimer's is a long process. My sister has refused to see him since he has been in the home. She says she doesn't want to remember him that way. I haven't seen him in nearly twelve months. I don't know if I'll see him again. Mum asked me the other day how will I remember him? I want to think that I won't remember him like this, that I'll remember all the good things. But I'm afraid the trauma of the disease may have tainted my memory. I suppose that's the hardest thing - watching him every day just go, so that now he's nothing like the Pop I knew. The chaos of the disease has created someone who we don't even know anymore, and worse, someone who doesn't know who we are.

* ⁱ Brain ischemia is insufficient blood flow to the brain. Chronic ischemia of the brain may result in a form of Dementia called Vascular Dementia.