

# A family's perspective on care

**Ben Johnston** and his family, from Melbourne, share their experience of dementia and lessons learned with other families and caregivers. Ben's experience motivated him to work in the care sector and he is now Country Manager of *Homage Australia*, a technology-enabled caregiving and health service launched in Australia in 2021



In hindsight, the signs were there. One of the defining moments of our dementia journey was the day Dad's house was broken into. Someone had entered his home, he said, and taken a box full of his personal financial details. He'd spent the entire day at the local bank branch cancelling all his credit cards, closing bank accounts and opening new ones to protect his and the family's affairs.

That evening I went to visit Dad to assess the break-in. There was no damage to the windows, no forced entry to any doors. From my perspective it didn't look like a robbery at all, and yet Dad was adamant that was the only possible explanation why his financial documents were missing. In the lead-up to this event, Dad had seen cars stopping regularly outside the house; he was convinced that someone was watching him with the intention to financially ruin him.

After a 15-minute search of the house, I was able to locate the supposedly missing box. Dad was relieved. I didn't doubt that Dad thought it had been stolen, but I certainly felt sorry for Dad and the banking staff who'd assisted him that day and completed a lot of unnecessary work. I could only imagine the stressed state Dad would have been in when he arrived at the bank.

A barrister by profession, Dad was naturally sceptical about anyone or anything and he always presented a strong case. Over a few years, he repeatedly told increasingly elaborate stories similar to the break-in incident, which involved many examples of people trying to hurt him,

including the people who loved him the most.

Every element of life was now a worst-case scenario. Going to the footy had been something I used to love doing with Dad, but I started to feel exhausted every time we went. Conversation while watching the game was always dominated by his constant, heightened anxiety over financial and marital matters.

Eventually, I retreated from the relationship. We didn't speak to each other very much for about six months. I told him he needed to speak to someone professionally; although he initially dismissed this idea, eventually he started seeing a psychiatrist.

After a month or so, with

Dad's consent, I spoke with the psychiatrist, who explained: "I think (your) Dad might have a cognitive issue. He is very good at building an argument and rationalising his own thoughts through his professional skills, but I think there might be other issues here."

## Acceptance just the first step

From that moment on, my frustration turned into understanding and kindness towards Dad. Even though he wasn't officially diagnosed with early onset frontotemporal dementia until about 18 months later, at age 66, it set the scene that while Dad might feel or behave a certain way that was unusual or seemed improbable, there

was a context for understanding him.

While accepting Dad's diagnosis helped me change my approach to our interactions, in reality I was grieving, almost as if he had died, knowing he wasn't going to be the Dad who had been there to support me all my life.

The hardest part was wanting to spend time with Dad socially, but feeling nervous about how he would react or behave in social settings. Sometimes he would become unexpectedly angry with me, especially when we were out; and he would approach strangers, assuming they would talk to him. Dad wouldn't like it when I asked him to come back or to join me,

## Gateways to support

### My Aged Care

My Aged Care is the gateway for accessing all Commonwealth Government-funded aged care services: home-based, respite and residential care. Contact can be made via telephone, online and now in person with face-to-face services available in many locations across Australia. Details: [www.myagedcare.gov.au](http://www.myagedcare.gov.au) or phone 1800 200 422.

### Carer Gateway

The Carer Gateway is another Commonwealth online hub, with the focus on emotional, practical and financial support for carers. Emergency respite care can also be accessed through this gateway. Details: [www.carergateway.gov.au](http://www.carergateway.gov.au) or phone 1800 422 737.

### Dementia Australia

Dementia Australia is the national peak body for people impacted by dementia and it offers information, education and support services across Australia. Details: [www.dementia.org.au](http://www.dementia.org.au) or call 1800 100 500 (Dementia Australia's National Dementia Helpline).

### Aged Care Navigators

Aged Care Navigators help older people and their families to navigate the aged care system and access services. Find out where your nearest service is located by contacting COTA Australia, which is leading a consortium of 20 organisations across Australia in delivering the Aged Care Navigators service. Details: [www.cota.org.au](http://www.cota.org.au) or phone 1300 268 228.

### National Disability Insurance Scheme (NDIS)

The NDIS offers a wide range of practical support for people under 65 who have a disability caused by a permanent impairment (including cognitive and neurological). Details: [www.ndis.gov.au](http://www.ndis.gov.au) or phone 1800 800 110.

### ReThink Respite

This website offers information about the different types of respite care available in Australia for people living with dementia and their family carers, including resources to help with decision-making and planning. Details: <https://rethinkrespite.dementiaillawarra.com/>

instead often telling me to go away and to leave him alone.

### How proper care helped

Care was the saviour for our family, particularly for my step-mum. Without any support, she couldn't leave the house, not knowing if Dad might walk off and become lost. Her life became fully dedicated to Dad and, over a period of 2.5 years, my siblings and I watched her own health decline. Support was needed to give her a proper break – to socialise, shop and simply to have some time to herself, with the assurance of knowing that Dad was safe.

We accessed help through the Commonwealth Home Support Program (CHSP). Initially, it was for just a few hours each week, but it made such a difference. Our greatest learning as a family was that, in addition to the person living with dementia, you also need to ensure the primary carer is taken care of and given the support they need. We knew Dad was fine, but it was my step-mum who needed the help. So, as a unified family, we made the decision together to ensure she was supported in every way we could.

Most of the care that was accessed through the CHSP was for social support for Dad, to keep him engaged and give my step-mum some respite. Carers would come to the house to spend time with him and do things that he enjoyed – working through a crossword, enjoying a cup of

## Points for practice

- A person living with dementia will experience changes in their relationships over the course of the illness with close family, and friends too.
- Family carers of people living with dementia often describe feelings of loss and grief, even while the person with dementia is alive. When supporting carers, it's important to listen well and to recognise and acknowledge these painful feelings.
- Family carers also have support needs, and they may need some help recognising this and accessing assistance.
- Continuity of care – having the same care staff available to support a person with dementia – can make a big difference to the person, especially during times of change.

tea together and looking through family photos. Because that was the main purpose of their visit, they were able to be patient with Dad, listen to his stories and give him their full attention, instead of being distracted by all the things that needed to be done in the day.

The carers also provided another form of companionship by keeping Dad company as he walked the neighbourhood streets and stopped to buy a cup of coffee. This gave the family invaluable peace of mind as we knew Dad was getting out and about – something which he loved – and that he was safe and not alone.

We also used respite care. On a few occasions Dad did refuse to go into the respite care centre when my step-mum dropped him off, or he would go in, but then become distressed and have to be

picked up. However, when it was successful, it gave the family a much-needed break and also time to reflect upon Dad's needs going forward. Eventually, it became necessary for Dad to move into full-time care – at the care home where he had been attending day respite. Unfortunately, Dad was not able to be part of the decision-making process. While it was a difficult decision, it was necessary to reduce the impact on my step-mum and ensure her health and wellbeing was prioritised equally to Dad's.

### Supporting transition into care

Dad had built a lovely relationship with one of his home carers, and they were able to support him during his move into the care home. The carer kept Dad calm during the move but also visited him

regularly during the settling-in period. For Dad, this carer was a familiar face whom he trusted when we weren't there. It was invaluable to him in an environment that was relatively new, and a reminder to us that it is okay to rely on support and facilities that are set up to help in this very situation. Dad has remained at this facility ever since and we have peace of mind that he's being well cared for.

### Care is personal

The biggest takeaway from this entire experience is that care is personal and the care needs are different for each individual. Likewise, the impact of the care experience on each family member is different – as we each have different emotional reactions to the situation. Many of us play the role of caregivers within our families – work that is challenging, both mentally and physically. It is important to ensure that family caregivers are properly supported and that their wellbeing is considered as part of the care plan.

There are now more support systems and resources available in Australia than ever before, enabling families to leverage professional help for both the person living with dementia and the family caregivers who support them. It is my hope that more Australians understand the support available to them to achieve a better quality of life for all impacted. ■

## Supporting people with dementia to stay involved in the community

A new international study has explored and compared participation in out-of-home activities among 163 people living with dementia in four countries – Canada (29), Sweden (35), Switzerland (35) and the UK (64).

Interviews were conducted with each individual participant, using Part 1 of the validated Participation in Activities and places OUTside the Home for older adults (ACT-OUT) instrument as the basis for the interview. ACT-OUT Part 1 contains yes/no questions regarding present, previous and anticipated future participants in activities at 24 places (for example restaurant, bank, sport facility, pharmacy).

Participants visited an average of 16 places (median) and they had abandoned an average

of 5 places. The Swedish sample visited a significantly higher number of places (median 18) compared with the Canadian sample (median 13). Across all countries, most participants (over 80%) still visited their local neighbourhood, restaurant, friend/family member's place, mall and doctor's office.

Places with the largest rate of abandonment were sports facilities (50% had stopped going, with no significant differences between countries), cottage, bank and forest. There were significant differences between country samples in the frequency of current participation and abandonment of certain activities: the hospital, dentist's office, cemetery, garden and forest. While overall, participants still visited a variety of

places, they had stopped going to places they had previously frequented, which is potentially concerning.

The authors say some of the differences across the four countries' samples may be explained in part by differences in access to healthcare services and to public transport. They conclude by arguing that their findings send an important message to stakeholders to specifically address older peoples' access to nature places and sports facilities as part of developing dementia-friendly communities.

Thalén L, Malinowsky C, Margot-Cattin I (2022) Out-Of-Home Participation Among People Living With Dementia: A Study In Four Countries. *Dementia*. First published April 17, 2022. DOI: 10.1177/14713012221084173