

Rose and Carl: a GP's reflections

Hilton Koppe shares the story of Rose and Carl*, and the learning that arose from supporting this couple and their extended family, in his role as their GP, for over a decade as Rose's dementia progressed

It was one of those conversations that I wished I had been able to record. It would have made a great example of how to maintain a person's dignity in the face of advanced dementia.

Rose was being admitted to a residential aged care facility. I was her GP. We were having a conversation with Rose's two daughters and the care staff about the goals of care for Rose's admission.

We got round to the question of what to do if Rose had a serious illness from which there was little chance of recovery or if the only treatment available would require hospital admission.

"I can see no point in any of that," Rose said. "When your time is up, your time is up. I've had a good life. What's the point in prolonging it?" Rose was very clear about this. She didn't know what day it was. She didn't know where she was. She would not be able to recall a random name and address. She might not have been able to take a sheet of paper, fold it in half and place it on the floor. Or correctly respond to other prompts from cognitive screening tests. But she was still able to express with absolute clarity her long-held views about end-of-life care.

A colourful life

I had known Rose and her husband Carl since they moved to our region to be closer to their daughters a decade earlier. Rose and Carl spent their early married life in inner Sydney, living in a community of artists, actors, American servicemen on R'n'R, nightclubs, drinkers, prostitutes. They lived a colourful life in that milieu.



Image courtesy Dementia Training Australia, from the video *GP Home Visit*

They moved to suburbia when their children came along but retained their sense of mischief. It was a delight to get to know them. I already cared for their daughter's family, so when they arrived it was a precious opportunity to be a real family doctor.

Planning for the future

Early on in our time together, it became clear that Rose was developing dementia, most likely a mixed pattern of Alzheimer's and vascular. Her cognitive and functional decline was exacerbated by significant visual impairment. A comprehensive dementia management plan was put in place. Her vision was optimised, cardiovascular risk factors minimised, medications reviewed and optimised, including the addition of an anticholinesterase inhibitor. With the family's involvement, we began discussions about planning for the future, including preparing a Delirium Action Plan to assist Carl and

the family to know what to do if Rose developed delirium (using a locally developed form, listing key information and contacts).

We also put in place a plan for Rose to visit me on a regular basis. This gave us an opportunity to regularly review our management plan and its objectives. It was an opportunity for "just in time" education on dementia for Rose and Carl as well as guiding them towards what was likely to occur in the coming weeks or months.

An uneasy truce

Carl was extremely protective of Rose. As her dementia progressed and her reliance on Carl for support increased, his protectiveness increased. "We don't need any interfering do-gooders coming into our home," he'd say.

Try as I might, I could not convince Carl to accept extra help. His views were in line with many working class folk of his generation: "I made a vow to care for Rose. Till death do us

part! I'm not letting anyone lock her up."

We came to an uneasy truce in this battle. Carl agreed that their daughter Jo could join them in their visits with me. Rose was delighted with this arrangement because each visit to me was followed by coffee and cake at her favourite café. And we agreed that they would continue to come for visits at least monthly, more often at times of need.

An advocate and conduit

Throughout this time, my objective was to keep Rose central to all discussions and decisions. Even during times when Jo or Carl needed to be involved in helping with decisions about treatments, I would continue to speak directly to Rose as much as possible, while at the same time acknowledging the input from Carl or Jo.

Together we managed this dance through heart failure, bowel cancer and repeated urinary tract infections. I saw

*The names of the people in this article have been changed to maintain their anonymity. Permission has also been granted by the surviving relatives for their story to be shared in this format.

Resources for GPs

DTA resources for GPs

Dementia Training Australia (DTA) offers a range of free resources aimed at GPs, including a compendium of links to helpful organisations and resources titled *Dementia Resources for General Practice* (go to <http://bit.ly/GP-dementia-resources>), two online courses ('Recognising, diagnosing and managing dementia in general practice', and 'Demystifying dementia'), and three webinars ('Diagnosing dementia in general practice', 'Demystifying Dementia', and 'A structured approach to managing dementia in general practice'). In 2021, DTA is hosting a new four-part series of webinars aimed at GPs. The first was held on 25 March (on 'Changed behaviours associated with dementia utilising a stepwise patient-centred approach to management'); the second will be held on 27 May and will focus on legal issues relating to dementia, including capacity: <https://dta.com.au/>

People With Dementia: A Care Guide For General Practice

This substantial, practical 2019 resource from the Cognitive Decline Partnership Centre is aimed at GPs and covers communication, behavioural and psychological symptoms of dementia (BPSD), elder abuse, dementia in

people with an intellectual disability, dementia prevention, and supporting carers: <http://bit.ly/GP-care-guide>

Dementia Outcomes Measurement Suite

The website for the Dementia Centre for Research Collaboration hosts this hub of validated tools for the assessment of various aspects of dementia by health care professionals, including a range of tools available for cognitive screening: <http://bit.ly/outcomes-suite>

The Silver Book

The 2019 edition of the RACGP *Aged Clinical Book* (referred to as *The Silver Book*) includes sections on 'Dementia', 'Behavioural and Psychological Symptoms of Dementia', and also on 'Short-term pharmacotherapy management of severe BPSD'. Each section includes information on general principles, practice points, clinical context, and 'In practice': <http://bit.ly/silver-book>

Dementia Australia: Clinical Resources for General Practice

A range of practical information on dementia, with links to a range of resources for GPs: <http://bit.ly/clinical-tools-resources>

I was expecting the eerily familiar odour of grief as I entered their home, but was also struck by how disorganised and dishevelled it looked. The medications that I had been assiduously prescribing for Rose were jumbled in an old shoe box on the kitchen counter. No wonder some of the drugs didn't seem to be working as I had expected! Who knows if they were even being taken?

They must have barely been coping. I could now understand why Carl forbade visits from non-family. He must have been terrified that they would take Rose away if they saw how they were living. I wished that I'd done a home visit earlier. Might some of their problems have been avoided if I really knew their domestic situation?

After Carl died, the impact of Rose's cognitive decline on her ability to function became more obvious.

It quickly became clear that Rose was going to require 24-hour care. She needed assistance with all activities of daily living. She couldn't dress herself. She couldn't prepare a meal. She was unable to manage her medications. She needed help with bathing. Jo stayed with Rose for the next few days, but she had a full-time job and a young family, so it was not possible for this arrangement to continue. I was able to relieve some of Jo's guilt by helping her understand that Rose's requirements for safety and comfort were so extensive that it would require a team approach to meet her

myself as an advocate for Rose and a conduit between her and the other practitioners involved in her care – geriatrician, physiotherapist, occupational therapist, cardiologist, surgeon, ophthalmologist, pharmacists and more.

Despite her increasing ailments and progressive dementia, Rose always appeared happy, engaged in family activities and well cared for.

Until Carl died suddenly. The phone call came in the middle of a busy morning at my clinic. "Hello Dr Koppe, it's Constable Robinson. Your patient Carl Jones has been found dead at home. We need you to come down and certify him as deceased before his body can be moved."

It transpired that Carl had died two days earlier, beside his bed, out of sight. Rose thought he might have been having a

long session at the pub. It was only when their daughter Jo called in to check on her parents that Carl's body was discovered.

Going to certify Carl's death was my first visit to their home. It was a shocking experience. The sight of Carl, face down on the floor, his mottled complexion matching the stains on his favourite track suit, is a vision that continues to haunt me.



GP WEBINAR (RACGP accredited)

Capacity and decision making in dementia: a case based approach for GPs



Save the date

Thursday 27 May, 2021

7:00 – 8:00pm (AEST)
6:30 – 7:30pm (ACST)
5:00 – 6:00pm (AWST)

Presented by
Dr Marita Long

(MBBS Hons, B Med Sci,
FRACGP, DCH, Cert S, RH)



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needs. After two days, she did not need much convincing of what was best for Rose and the rest of her family.

Urgent respite was arranged which progressed to a full-time admission to a local residential aged care facility. And that remarkable end-of-life care conversation.

A moment of recognition

Rose's condition declined rapidly. I recall visiting her just before she died. She looked shrunken. Her bed appeared to now be too big for her body. She was staring at the ceiling when I arrived.

"Hi Rose, it's Hilton," I offered as I sat by her side and gently rested my palm on the back of her hand. She looked up at me and for a moment there was a sparkle of recognition in her eyes before her gaze returned to whatever was occupying her attention before I walked in.

It reminded me of one of my last visits to see my father before he too died from dementia.

"Hi dad, it's Hilton," I offered as I sat by his side and gently rested my palm on the back of his hand. My dad looked up at me and for a moment there was a sparkle of recognition in his eyes. "I used to know someone who looked just like you," he said before his gaze returned to whatever was occupying his attention before I walked in. ■



■ Dr Hilton Koppe is a general practitioner from Lennox Head. Since 2016, Hilton has been working with the

GP Education Team at Dementia Training Australia (DTA) to develop and deliver innovative education programs to assist with the recognition, diagnosis and management of dementia in the general practice setting. Hilton also runs creative writing workshops for doctors and health professionals with the goal of deepening their compassion, overcoming professional isolation and reducing the risk of burn out. Hilton's writing can be found in a range of publications including *Grieve*, *The Examined Life*, *Pulse*, *Chrysalis*, *The Universal Doctor* and *More Voices*.