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Photo: Kelly Barnes AAP

## 'If she would just pass away it would all be over': Carers tell their story at the royal commission Mildura

By: Conor Burke in News, Top Stories August 1, 2019 1 Comment

"I just cried silently all the way home so Don couldn't see. And I just thought, 'Well maybe I just end it for both of us,'" said Rosemary Cameron, describing a low point she experienced as an informal carer.

Cameron, 69, is a carer for her husband Don, who is living with Lewy body dementia, and she was one of many carers who told the commission of the realities of informal care in Australia.

As of 2015, almost 2.7 million Australians identified themselves as informal and unpaid carers – that's 12 per cent of our population. Of those, around 420,700 are primary carers of people over the age of 65.

Females make up 68.1 per cent of all primary carers, and this has a massive impact on income and employment opportunities for women. Deloitte Access Economics estimated that carers provided 1.9 billion hours of care in 2015. This is equivalent to each carer providing 673 hours per year or 13 hours per week.

Cameron and her husband have been inseparable since the days when they first started to go to the movies together aged 14, eventually raising a family and running a business together for 25 years.

She spoke to the commission about the problems she faced when attempting to place Don in short term respite.

In her statement, she remembered the time her family were evacuated as a fire precaution.

"This was a very difficult time, trying to cope with Don and trying to manage animals, etc. We were sent to the oval in Gisborne, so I contacted the local aged care facility to ask if they could keep Don for the day as it was difficult for me to care for Don as he was confused and wandering, and I was not able to leave our possessions and pets with the car in 40 degree heat. They refused. I had to manage the best way I could until we were cleared to go home again," she wrote.

When she eventually managed to get Don into respite, nurses bombarded her with calls daily and argued with her over medication.

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"I was then told that either I agreed to the locum medicating with whatever he/she chose to give him or I 'come and take Don home'. Therefore, Don's stay was cut short and I had no choice but to take him home and manage as best I could."

She also told the commission that other attempts to gain respite often resulted in cancellations, leaving her "exhausted" and unable to give Don the best care possible.

Her statement went on to detail the poor understanding of his condition that Don faced as he was placed in mental health units where repeated attempts to sedate him were made without permission.

Cameron recalled the desperation she felt at times, after multiple attempts to get proper help failed.

"I thought if I can't look after him nobody else certainly is showing me they can do that too and I just cried silently all the way home so Don couldn't see. And I just thought, 'Well maybe I just end it for both of us'. You know, I thought, 'Maybe I will put the exhaust pipe in the back of the' – you know, the pipe, it was just this irrational thought," she said.

Cameron urged the royal commission to consider committing to more staff in aged care as well as increased knowledge about dementia.



Don Cameron Photo: Royal Commission

"I just feel that PCAs, while they have their role, they are not equipped to deal with a lot of the situations that occur. And I think I feel that if I would have had somebody who knew and understood dementia more, if the staffing was adequate and they had adequate training, things could have been very different."

The commission also heard from carer Elaine Gregory, a mother and grandmother from Mildura who looks after her mother.

The immense workload of acting as a full-time informal carer did not occur to Gregory until she was in the thick of it.

"Yes, I don't think I realised how it was 24/7. It was just constant all the time with working out what avenue, and each day there seemed to be another issue. So, you would be chasing up another avenue of things," she said.

Dealing with Veterans' Affairs (her father was a veteran) was one issue, working out what packages to choose, organising people to come over and help out with her mother, all the while dealing with teenagers and running her own business, made caring a challenge.

Looking back, Gregory feels support from ACAT was lacking and, at times, the weight of the responsibility got to her. She told the commission that GPs and doctors weren't much help either and any information she found was by herself.

"I got to the stage with Mum, I – you're beginning to think, 'Oh my goodness, if she would just pass away it would all be over'. And I knew that wasn't the right attitude to have with it all, so I knew that I needed – just needed someone to come and say, 'Hey, is everything all right with you?'"

The frustration that came with unpaid caring had flow-on effects to other aspects of family life.

"I probably didn't show it in front of her, but I would go home frustrated and just think, 'Oh my gosh. Why is it me all the time?'"

"I probably took it out on my husband and children," she said.

Dorothy Holt, a retired registered nurse who spent 25 years in aged care, acted as a carer for her mother for 12 years.

Even with her clinical training, the rigours of informal caring coupled with a day job proved difficult.

"She didn't do anything for herself. She wouldn't get up and initiate having a cup of tea or initiate eating a meal. You'd have to just put that all [together] for her, and just keep her eating it," she said.

Holt told the commission that the idea of taking a home care package was confusing and expensive for her mother, so the caring fell to her, but this meant that her income fell significantly.

"Probably the biggest help would have been if the carer payment was somewhere equal to what you were earning beforehand because, like I said in my statement, my income dropped a lot.

"I could still meet my mortgage and I could still pay my bills but the rate I was paying my mortgage off really slowed down," she said.

Holt had similar problems with ACAT as Gregory encountered, and eventually the stress of caring took its toll on her health and ultimately her marriage.

"I'd put some of it down to the marriage breakdown but not all, because you certainly didn't have a social life by then," she said.



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The next hearing of the royal commission is in Brisbane from August 5 to 9.

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**ONE COMMENT**

*Mag*  
August 1, 2019 at 11:40 am

Working in Aged Care as a RN is dangerously difficult.  
 1 RN for over 100 Residents.  
 No EEN .  
 Insufficient medications competent pcas most recently 1 for 108 Residents.  
 Unpaid overtime every single shift often an hour or more.  
 No time to even do the basics properly.  
 No meal breaks.  
 Not enough medical supplies.  
 Computer systems that are so slow as to be unstable.  
 1 pca to 9 Residents if you are really lucky.  
 Insufficient activities people.  
 Restrictions on continence aids.  
 Ambulance services who abuse Aged Care staff, treating them as uneducated idiots with no skills or knowledge.  
 Demanding to know why Residents don't have NFR orders.  
 Doctors who are paid too little for the time and effort they spend.  
 Nurse's paid ridiculously low amounts.  
 Pressure to pick up extra shifts.  
 All the while the company makes a fortune.  
 On the whole the Nurse's in Aged Care are passionate and caring, professional and Knowledgeable but have no time and no support.  
 It's our passion that keeps us there but at some point we will all have to walk away or be broken by the system.

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