

NATIONAL AGED CARE ROYAL COMMISSION

'Cruel, ugly killer lurking in shadows': Dementia victims speak out

By **Matt Bungard**

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Early onset dementia sufferers have pleaded for governing bodies and aged care facilities to provide more support for victims of the disease during the final day of public hearings in Sydney for the Royal Commission into aged care.

Trevor Crosby, 69, who was diagnosed with Lewy body dementia four years ago, told the commission on Friday he first noticed something was up when he wasn't his usual self while on a group holiday.



Trevor Crosby at the Royal Commission on Friday.

"At the time I thought it was just old age - pity it wasn't. When I received my diagnosis I was dumbfounded," he told the royal commission.

"I choked, I cried, all my defences had been smashed. I felt helpless, pathetic. 'I'm going to die', I said."

He entered into a support group run by Dementia Australia called "Living with Dementia" that lasted eight weeks. Afterwards, he said, gaps started to appear in his life.

If he had been diagnosed earlier, Mr Crosby said he would have had access to an assistance program that helps people with dementia but that program has a rigid cut-off of 65.

“The killer here is I was 65-years-old-and two months when I was diagnosed. Had I been diagnosed earlier I would not have missed out,” he said. “I feel I could have benefited.”



Kate Swaffer at the commission.

Mr Crosby praised his wife Jill for supporting him but said she needed help and suggested a "flying squad" of nurses who travel around relieving personal carers of dementia sufferers.

“Having a peer support program would make it easier for Jill - I’m sure there are lots of well qualified nurses that would be able to help,” Mr Crosby said.

Asked what the most important thing the commission needed to know was, Mr Crosby said that he believed far more could be done to try and find a solution.

“I want a cure, I want to continue to live,” Mr Crosby said. “There is no getting away from dementia. It is a cruel, ugly killer lurking in the shadows of my life. It destroys the very fabric of humanity, the brain.”

Retired nurse Kate Swaffer, who holds a masters in science in dementia care, told the commission she was diagnosed with a rare form of early onset dementia at age 49.

“Everyone around me basically told me to give up my life and go home and prepare to die,” said Ms Swaffer, who is also the chairwoman and chief executive of Dementia Alliance International.

She has used her own experiences, focus groups and feedback from both aged care residents and their staff to come up with a list of 18 things that people living in aged care facilities want.

This includes open access to the outside world, the use of technology and access to group classes for exercise and well-being.

“The built environment is really important in late stage dementia,” she said. “There’s some really simple design principles we need to put into any aged care facilities.”

When she was asked if the voice of people living with dementia is adequately heard and addressed in current government policy, she replied: "Absolutely not."

Professor Henry Brodaty from the Centre for Healthy Brain Ageing at the University of NSW told the commission that some aged care residents feel trapped.

"They feel they're prisoners. They say 'I'm a prisoner here'," he told the commission. "Sometimes they are in a locked section of the nursing home and physically cannot escape".

The professor spoke of a thesis by one of his PhD students, which found that 50 per cent of residents had zero social relationships.

"No one actually sits down with the person and spends time with them."

The next public hearing of the Royal Commission begins on June 17 in Broome and will focus on aged care for indigenous Australians, person-centred care and the delivery of aged care in remote locations.



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