



# “Don’t mention the ‘D’ word”: Dementia and driving retirement in rural NSW, a qualitative case series.



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**Background:** The inevitable transition from driver to passenger following dementia diagnosis threatens psycho-social well being. The prediction of a ‘Tsunami’ of dementia for the north coast of NSW warrants exploration of driving retirement experiences in rural areas where there is little public transport, great distances to travel and a notorious stretch of the Pacific Highway.



**Aims:** This project aimed to increase understanding of the experiences of people with dementia, their family and carers and other key decision makers living in a rural area in relation to driving retirement.



**Method:** This project used qualitative methods. Case studies were developed from in-depth semi structured interview data and from a review of medical records of participants with dementia. The data was coded and emergent themes linked to theoretical frameworks. Participants were six people with dementia, their family and carers and those who they identified as involved in their driving retirement (including general practitioners, aged care assessment team nurses and occupational therapist, a community case manager, a medical specialist, and a NSW roads and traffic authority manager).



**Results:** Major themes about driving retirement were derived from the data.

**No-one did anything!** Participants with dementia and their families and carers described a lack of support and guidance from authorities, and health professionals described a lack of time, resources, collaboration and clear guidelines to inform clinical decisions and interventions.

**I was like a cornered rat.** Participants described anger, anxiety and conflict with potential or actual damage to relationships.

**No-one faced me.** Participants with dementia felt that they were not included in decision making during driving retirement and that their emotional needs were not met. Clinicians described lack of time, resources and the skills to provide person centered care.



**I felt like I had had my arm cut off.** Participants described a loss of independence and difficulty functioning within the structural and institutional environment.

**Don’t mention the ‘D’ word.** Participants with dementia described experiences of outsider status, stigma and deviance.



**Conclusions:** There is a lack of guidance and planning for driving retirement in dementia care and inadequate resources to address the conflict, loss of identity and loss of independence associated with driving retirement.

*For the full report on this project visit our website, follow the link to the Rural Research Capacity Building Program and click on ‘view completed projects’*



Helen is an occupational therapist working in an aged care assessment team based in Coffs Harbour. Helen became interested in driving and dementia after completing post graduate training in occupational therapy driving assessment and rehabilitation. Helen holds a masters degree in health science (occupational therapy).



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