



Alternative transport needs and emotional adjustment for people living with dementia and their caregivers during driving cessation

Donna Rooney

Project Coordinator | Occupational Therapist

Dr Theresa Scott

Principal Investigator

NHMRC-ARC Dementia Research Development Fellow

Living with Dementia and Driving

Giving up driving can be a significant challenge for people living with dementia.

- ❖ Depression and anxiety
- ❖ Isolation
- ❖ Grief (loss of identity)
- ❖ Family conflict
- ❖ Unsafe and unlicensed driving



What is driving?

- A practical activity

“means of getting from point A to B”

“hard work and concentration”.

- Source of enjoyment

“I loved it, my hands on the wheel, my bottom on the seat, any excuse! The joy of driving!”



What is driving cessation?

Practical loss

- Change to daily routines (behaviour change)

Symbolic loss

- Life transition – changes to individual roles and personal identity



Meaning of driving cessation – behaviour change

“I would have to plan more”

“I could no longer go out anytime. Now I have to plan, consider if it’s really worthwhile. Now I have to stay home.”

“I could adapt my lifestyle because of the bus and train service available, but [there would be] a big loss of flexibility and independence.”

Meaning of driving cessation – life transition

“I’d sink into nothingness” “I’d be a prisoner in the home”.

“To the bad. To the big depression. It’s hard to make adjustments and they need to be made so quick.”

“It completely changed my lifestyle. I used to be out a lot. Where I lived I used to know everyone but all of a sudden that was cut off, from all the people I know.”



Image from [6minutes.com.au](https://www.6minutes.com.au)

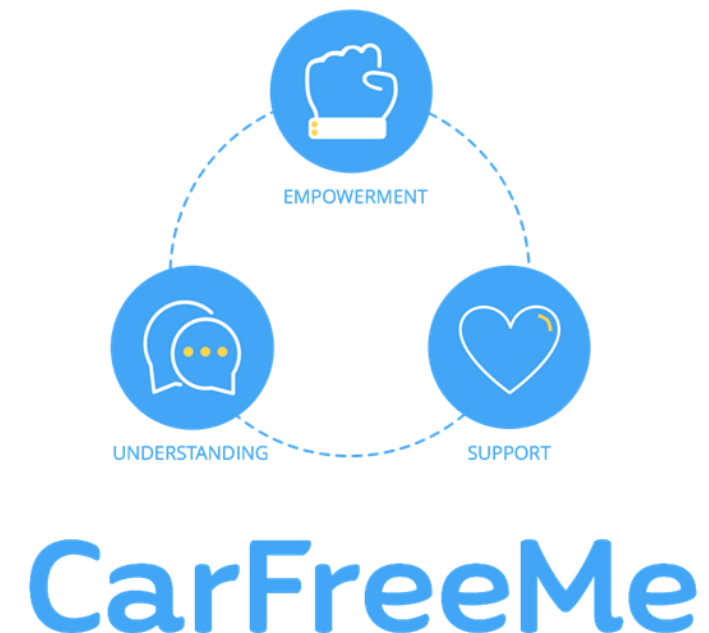
CRICOS code 00025B

What does driving cessation mean for most people?

- ❖ Combination of practical and emotional loss.
- ❖ Symbolic loss can be quite different for different people (loss of “independent adulthood”, car, roles).
- ❖ Need to be sensitive and empathic regarding symbolic loss
- ❖ Also need to acknowledge symbolic losses for people to accept practical assistance
- ❖ People living with dementia often describe driving cessation as ‘tipping the scales’

Living with Dementia and Driving Study

- ❖ Evaluate the effectiveness of an evidence based driving cessation intervention - CarFreeMe program
 - ❖ Community Mobility – life space
 - ❖ Quality of Life



CarFreeMe

- ❖ Support and education based intervention
www.carfreeme.com.au
- ❖ Seven one hour sessions, held once a week
- ❖ Flexible content - adapted to address goals set by participant.
- ❖ Session delivered by health professionals (occupational therapist/psychologist)
- ❖ via telehealth
- ❖ Individual, Group, Carer only Sessions



CarFreeMe Modules

Modules	Adapted CarFreeMe for People with Dementia
Module 1	Living with dementia This module focuses on the changes that may occur with dementia, and strategies to live positively.
Module 2	Balancing independence and safety This module gives information about driving safety, including how symptoms of dementia can impact driving. It provides an overview of things to consider as you retire from driving.
Module 3	Adjusting to losses and changes This module covers changes that may occur to your lifestyle and feelings of loss and grief that you may experience from retiring from driving. It also includes strategies you may use to help you adjust.
Module 4	Experience of retiring from driving This module covers what it can be like to give up driving. Stories of other retired driver and family members have been included to show different ways that people adjust to giving up driving.
Module 5	Alternative transport This module covers the range of alternatives to driving that you may be able to use and ideas of where to find out more.
Module 6	Lifestyle planning This module covers things to consider in planning for achieving a balanced lifestyle.
Module 7	Advocacy and support This module focuses on the services that are available to you and steps you may take to improve the service, and make service providers aware of your needs.
Module 8	Carer support (optional) This optional module gives carers and family members information on how manage conversations about driving cessation and also provides an overview of strategies to cope with care giving.

Order and focus of modules depends on participants goals and needs

Living with Dementia and Driving Study Participants

- ❖ People living with mild to moderate dementia
- ❖ People who are still driving, or have recently retired from driving
- ❖ Carers encouraged to participate as well
- ❖ No age restriction – **people living with younger onset dementia are encouraged to participate**



Alternative Transport Options

- ❖ Drive self ~16%
- ❖ Lifts from others ~ 43%
- ❖ Multiple transport options ~ 20%
- ❖ Walking locally ~ 9%



Modes of Transport

- ❖ Public Transport – buses, trains
- ❖ Govt or Council Transport Services e.g. FlexiBus, On Demand Services, Council Bus
- ❖ Community Organisations
- ❖ Taxis
- ❖ Uber
- ❖ Mobility Scooter



Barriers to Alternative transport use

Public Transport

- ❖ Proximity to stops
- ❖ Infrequent services
- ❖ Time involved and multiple modes required
- ❖ Unable to access independently
- ❖ Lack of experience

Barriers to Alternative transport use cont.

- ❖ Resistance to cease driving
- ❖ Awareness of and ability to access information
- ❖ Costs
- ❖ Distrust of service

Other concerns with alternative transport use

- ❖ Burdening others
- ❖ PWD previously main driver – partner now required to take on majority of driving
- ❖ COVID19 further impacting isolation and decreasing skills

“We don’t have the spontaneity... So easy not to do things

“I like to be independent”

Facilitators to alternative transport use

- ❖ Provision of good local public transport system
- ❖ Previous experience with Public Transport
- ❖ Access to trusted alternative transport options
- ❖ Door to door services

- ❖ **Support networks** such as caregivers, family or friends
 - ❖ Lifts
 - ❖ Researching and providing information

Adjusting to Driving Cessation

- ❖ Participants who sought information on alternative transportation earlier adapted more smoothly to post driving life.
- ❖ More difficult for those who were required to stop driving abruptly and felt the choice to stop driving was taken from them.

"It's unfair that the decision to stop driving is made for me"

Supporting the Transition to Retiring from Driving

- ❖ Acknowledge **issues of personal importance to the person** in relation to driving and retiring from driving
- ❖ Have the conversation early and often
- ❖ Provide information and support to access services
- ❖ Early referral to the CarFreeMe program
 - ❖ Participants are supported to explore future transport options and in their emotional adjustment to driving cessation

Case Example:

Changes in participant self rating of performance and satisfaction of individual goals

Goal	Pre Intervention Scores		Post Intervention Scores	
	Performance	Satisfaction	Performance	Satisfaction
Driving Skills	1	2	7	8
Taxi Subsidy Scheme	2	2	8	8
Community Transport	2	2	8	8

‘Your time and this program have given me the tools to make the decision.’

‘I think what I am doing is the way it should be done, I am phasing in the no driving, I don’t have to do it but I am.’

Contact information

Thank you for listening!

Donna Rooney

- ▶ E: donna.rooney@uq.edu.au
- ▶ T: 07 3365 6392

“I still mourn my car, I kept trying for two years to get my licence back. I was obsessed with driving.”

