

LIVING WITH DEMENTIA IN RETIREMENT VILLAGES

**Aged & Community Services NSW & ACT
Seniors Housing and Retirement Living –
The Next Wave**

22nd October 2014

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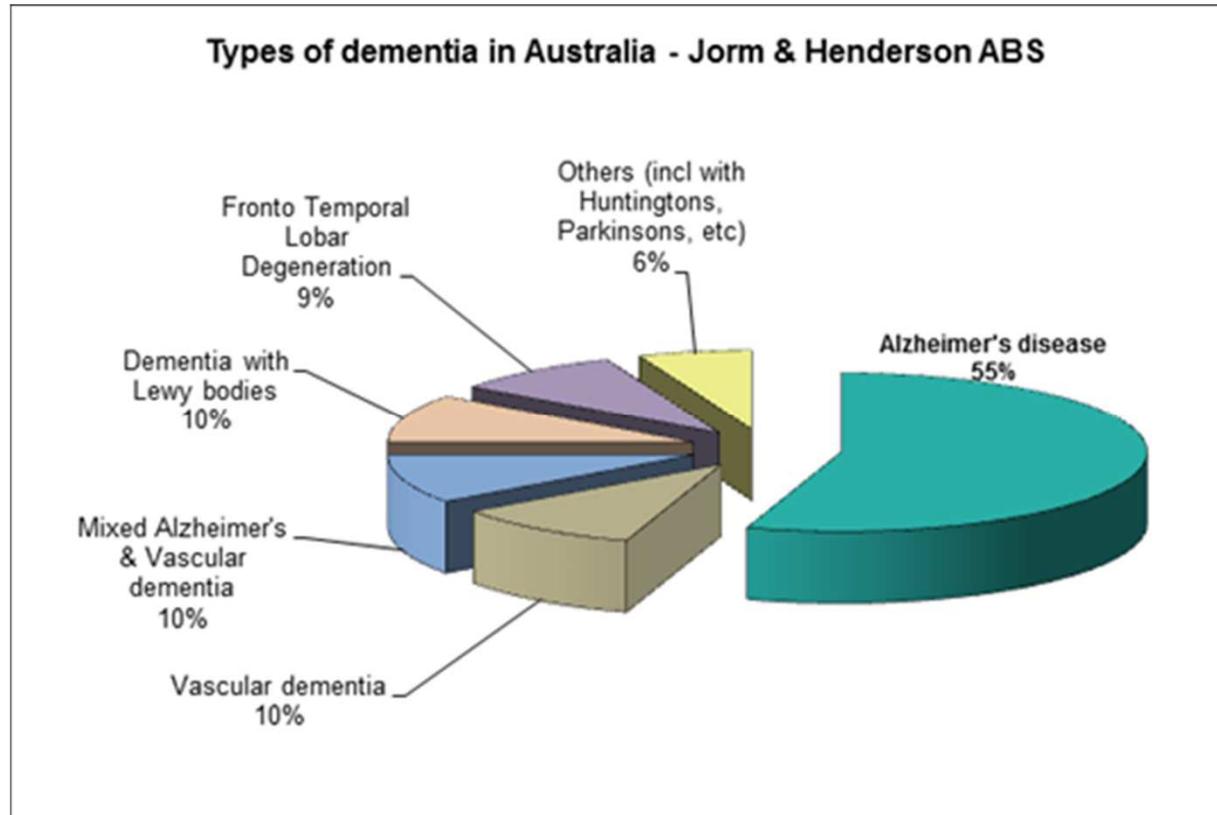
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WHAT IS DEMENTIA?

- Umbrella term that describes the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning.
- Dementia may cause a loss of memory, intellect, rationality, social skills, physical functioning and what would be considered normal emotional reactions.

TYPES OF DEMENTIA



There are over 100 different types of dementia.

The most common type is Alzheimer's disease.

In Australia this accounts for around 50-70% of all types of dementia.

WHO GETS DEMENTIA?

Most people with dementia are older, but it is important to remember that **most older people do not get dementia.**

It is not a normal part of ageing.

Dementia can happen to anybody, but it is more common after the age of 65 years. People in their 40s and 50s can also have dementia. This is called **younger onset dementia.**

PREVALENCE

Doubles every 5 years past 60 years:

| | Prevalence | |
|-------|------------|--------|
| Age | Male | Female |
| 60-64 | 1.2% | 0.6% |
| 65-69 | 1.7% | 1.3% |
| 70-74 | 3.5% | 3.3% |
| 75-79 | 5.8% | 6.3% |
| 80-84 | 12.1% | 12.9% |
| 85-89 | 21.1% | 24.4% |
| 90-94 | 31.5% | 35.7% |
| 95+ | 37.2% | 47.3% |



Source: Access Economics:
Projections of dementia prevalence
and incidence in NSW 2009 - 2050

EARLY SIGNS OF DEMENTIA

- Often subtle and vague
- May vary a great deal
- Common symptoms include:
 - Progressive and frequent memory loss
 - Confusion
 - Personality change
 - Apathy and withdrawal
 - Loss of ability to do everyday tasks

ALZHEIMER'S AUSTRALIA NSW

- Peak body for people with dementia and carers in NSW
- Part of a federated organisation – National and State and Territory offices

DEMENTIA HELPLINE: 1800 100 500

www.fightdementia.org.au

- Mission: to minimise the incidence and impact of dementia through leadership, innovation and partnerships - in advocacy, policy, education, services and research

LIVING WITH DEMENTIA IN RETIREMENT VILLAGES

Co-funded by IRT Research Foundation and Retirement Living Council

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DEMENTIA IN RETIREMENT VILLAGES... WHAT DO WE KNOW?

- The number of Australians living in retirement villages is expected to increase.
- At the 2011 census, 135,900 older Australians (approximately 4.5% of the population over 65 years) were living in retirement villages (ABS, 2013).
- However, other reports suggest that there are 160,000 or more retirement village residents (RVA & Deloitte, 2010).
- In the 2006 evaluation of the Retirement Villages Care Pilot, 10.5% of participants in the pilot had a diagnosis of dementia (AIHW, 2006) BUT the rate or prevalence of dementia in retirement villages is unknown...

WE DON'T KNOW THAT MUCH!

THE NEED FOR THIS PROJECT

Little is known about the experience of people with dementia in retirement villages or what retirement village operators and committees do to support residents with dementia.

The retirement village industry has indicated that it expects to play an increased role in supporting residents as their care needs progress, but generally there is a lack of understanding about dementia and how to support residents with a diagnosis.



INNOVATIVE

The first research project to examine the issue of dementia in retirement villages in Australia.

It will address gaps in knowledge about the experience of retirement village residents with dementia and operators experience of residents with dementia.

The research findings and recommendations will assist retirement village operators and community aged care providers to respond to the needs of residents with dementia.

RESEARCH AIMS

- Investigate the experience of living with dementia in retirement villages
- Ascertain the extent to which people with dementia are supported to age in place through the provision of community care services and informal support from the village community
- Identify how operators can best support residents

KEY RESEARCH QUESTIONS

1. Are retirement villages **supportive environments** and suitable for ageing in place for people with dementia?
2. How **accessible** are **formal and informal supports** for people with dementia living in retirement villages, including community care services?
3. What **policies and practices** do retirement village operators/resident committees have for **supporting** residents with dementia to **age in place** and what **barriers** do they face in supporting residents with dementia?

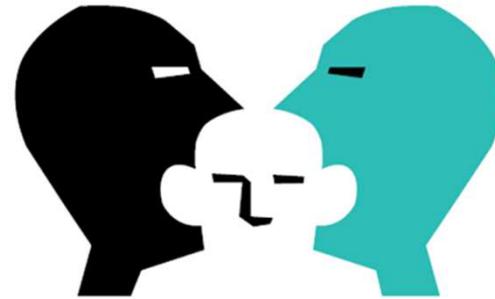
RESEARCH METHODOLOGY

Focus groups: Completed

RVRA (9 participants)

RLC (3 participants)

ACS NSW (8 participants)



Interviews: Ongoing

Retirement village residents with dementia and/or family carers

Online survey: About to start

Retirement village and community aged care staff

PRELIMINARY FINDINGS

- Limited threshold of informal support, esp. for people living alone
- The 'dump and run' – families expecting that the village will look after their relative with dementia
- Retirement villages not designed for people with dementia
- Assessment of potential residents for dementia – some operators are screening out people with dementia if they don't have a spouse

PRELIMINARY FINDINGS

- Major concern for operators - existing residents who develop dementia and families who won't acknowledge it
- Need for staff training on dementia
- Implications of aged care reforms for village operators – concerns that villages will become de-facto low care, with the removal of low/high care distinction in residential aged care.

NEXT STEPS

- Complete data collection and analysis
- Publish Discussion Paper in mid-2015
Then Research to Practice Guide later in 2015
- Other research dissemination and knowledge translation activities in 2015



THANK YOU

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QUESTIONS & DISCUSSION

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