Living with dementia in retirement villages

This Help Sheet provides information for people living with dementia, their families and carers about Australian retirement villages. It outlines what retirement villages are, reasonable expectations for village residents living with dementia, and where to go for further information and advice.

What is a retirement village?

Retirement villages are accommodation models specifically designed for people over the age of 55. They generally provide units and common areas that promote and facilitate social interaction and support.

There are more than 2,200 retirement villages in Australia¹ and many variations in their design, management and operation. Villages vary in size (as small as 10 units to as large as over 200 units on site) and there are differences in the business models of retirement villages. For example, villages may be run for-profit or not-for-profit, operated by a large corporation, a non-government organisation in the church/charitable sector, or as a small family business. Some retirement village operators provide leisure activities and services, such as domestic assistance and limited low-level care services, whilst others merely provide accommodation.

There is a common misconception that retirement villages are the same as residential aged care facilities. Retirement villages are not the same as residential aged care facilities. Retirement villages have traditionally been developed to house older people who can live independently, while aged care facility residents require daily assistance with personal and nursing/health care. Also, entry to residential aged care is based on an assessment of care needs, while entry to retirement villages is generally based on capacity to pay. Some retirement villages can cater for more frail residents, with basic housekeeping and meal services included in the weekly fee. However, the level of care someone can receive and the amount they pay for it will vary from one village to another. There are different contracts for entering retirement villages and different payment arrangements. It is recommended that you seek independent legal and financial advice before moving to a retirement village.

Retirement villages are not a substitute for residential aged care, especially for people with dementia, as they are not able to directly provide the specific care and support they need.

Living in a retirement village

The majority of residents enter retirement villages in their early-to-late 70s for health and lifestyle reasons². The average age of retirement village residents is currently 81³. Retirement villages have become a popular accommodation option for people seeking independent living with access to amenities, security and healthcare support, and increased social networks⁴. Australian research has found that residents perceive retirement villages to have a greater sense of community, security and independence than the general community⁵.

Regulation of retirement villages

Retirement villages are regulated by State and Territory-based legislation primarily concerned with consumer protections, with different Government departments administering the relevant legislation in each State/Territory (see the further reading section of this Help Sheet for links to the relevant department in your State or Territory).

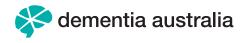
Current legislation regulating retirement villages does not address requirements, responsibilities or obligations with regard to the health status of residents other than generally requiring residents to be able to live independently. Responsibility for providing options to address chronic health issues, including dementia, is the concern of individual operators.

Relevant rights and responsibilities

The Retirement Village Acts in the Australian State and Territories are designed to protect a resident's security of tenure in the event of a financial failure

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and have disclosure requirements for operators to ensure residents know what they are entering into. They also set minimum requirements for conduct in administering village accounts and annual meetings.

The Retirement Village Acts do not offer protection around the management of resident health conditions (including dementia) as they have traditionally been 'independent living' environments and work from the basis that a resident is capable of living independently in the village.

The onus, therefore, is on the resident to access supports to maintain their independence needed to live in a village. Residents or their advocates can ask questions of the operator as to how they can assist in facilitating support or in providing support for resident health conditions such as dementia. It is also worth checking if there are any restrictions on home modifications permitted to units.

Make sure you clearly understand your rights and obligations as a resident, and the financial arrangements of the retirement village. Before signing a contract to enter a retirement village, you should obtain the following:

- copy of the resident contract
- copy of the village rules
- notice of your rights under your State or Territory Government's Retirement Villages Act
- copy of financial information relating to the operation of the retirement village, including departure fees
- other relevant information such as dispute resolution process, floorplans and re-marketing procedure when you leave the village

Support for dementia in retirement villages

The variable nature of retirement villages across Australia means that it is difficult to generalise as to whether villages are suitable accommodation options for people living with dementia⁶. Some are very good and provide supportive physical and social environments for people with dementia and their carers. However, others do not have the appropriate environment or level of support required to enable the independent living of people with dementia.

Operators are constrained by their on-site experience, the breadth of their broader operations in health and aged care, and the extent of their village's connection to support services. If you currently live in a retirement village ask your operator how they can assist you.

If considering a move to a retirement village, it is very important to consider whether a move will best suit the individual circumstances of the person with dementia. Think about the suitability of the living arrangements, ask lots of questions and check whether the operator is able to provide a better and more supportive environment than the person's current home. It may be better for people with dementia to stay in the familiar environment of their home, as a move may trigger or exacerbate symptoms of dementia.

The Commonwealth Home Support and Home Care Packages Programs (see **myagedcare**. **gov.au** for further information) are government funded services available to support people with dementia to remain living in their home or retirement village.

Some retirement villages will provide such services at an additional cost; others may assist you to access external services (such as home care packages); while in other villages it is the responsibility of an individual and their family to arrange any additional support they may need.

Plan for future support and care needs

The diagnosis of dementia for residents already residing within a village does not automatically mean that they will require immediate transition to residential aged care. Their ability to remain at home can be extended with appropriate home care and support services, and open discussions with the village manager and health professionals should help facilitate this.

However, residents with advanced dementia will likely need to move into residential aged care as their condition progresses and their care needs become too great to be met within the village. Residents and their families should plan ahead to ensure that their wishes are met and that the move to residential aged care is smooth and well-supported.

Key questions to consider

- What commitments has the village operator made in writing to support people with dementia?
- Will the retirement village help meet your future support needs? For how long and to what level?
- Does the village already provide a supportive environment for people with dementia?
- Are you able to modify the environment and living areas to help support your future needs?
- Does the village have, or have access to, staff who are knowledgeable about dementia?
- Is there a co-located aged care facility, or a partnership with one, should you need this in the future?
- Reflecting on the answers to the above questions, will this option be better than staying in your current place of residence?

Further reading

These resources may assist you in making the decision to move to a retirement village, or, if you live in a retirement village and have recently been diagnosed with dementia.

- Living with Dementia in Retirement Villages, Alzheimer's Australia NSW Discussion Paper 13, August 2015
 - nsw.dementia.org.au/files/NSW/documents/ Discussion_Paper-Dementia_in_Retirement_ Villages.pdf
- NRMA Living Well Navigator Retirement Living: Your Checklist
 - mynrma.com.au/media/lwn/LWN_checklist_ RetirementLiving_2015.pdf
- Retirement Living Council Retirement Living: Helping seniors enjoy retirement retirementliving.org.au/village-life/
- Retirement Villages Guide and Directory itsyourlife.com.au/retirement_villages_guide.asp
- Relevant Government Departments in each State and Territory:

Consumer Affairs Victoria

consumer.vic.gov.au

Office of Fair Trading New South Wales fairtrading.nsw.gov.au

Queensland Department of Housing and Public Works

hpw.qld.gov.au

Consumer Affairs and Fair Trading Tasmania consumer.tas.gov.au

Northern Territory Consumer Affairs consumeraffairs.nt.gov.au

The Office For the Ageing (SA Health) sahealth.sa.gov.au/officefortheageing

Consumer Protection Western Australia commerce.wa.gov.au/consumerprotection

Office of Regulatory Services Australian Capital Territory

ors.act.gov.au

References

- 1 McCrindle, M. (2013) McCrindle Baynes Villages Census Report, Accessed 20/05/2015 http://www. mccrindle.com.au/ResearchSummaries/2013/ McCrindle-Baynes-Villages-Census-Report-2013-Executive-Summary.pdf
- 2 Retirement Village Association & Deloitte (2010) Caring for Older Australians – Submission to the Productivity Commission, RVA Australia Ltd.
- 3 PWC/Property Council (2015) Retirement Village Census
- 4 Gracia, N., Moyle, W., Oxlade, D. & K. Radford (2010) Addressing Loneliness in a Retirement Village Community: A pilot test of a print-delivered intervention, *Australasian Journal of Ageing*, 29(4): 179-182
- 5 Bohle, P., Rawlings-Way, O, Finn, J., Ang, J. & Kennedy, D. (2014) Housing Choice in Retirement: Community versus Separation, *Housing Studies* 29(1): 108-127
- 6 Miskovski, K., Chenoweth, L. & Moore, B. (2015) Living with Dementia in Retirement Villages, Alzheimer's Australia NSW Discussion Paper 13, August 2015.

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at **dementia.org.au**



For language assistance phone the Translating and Interpreting Service on **131 450**

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