

DEMENTIA GUIDE FOR THE AUSTRALIAN RETIREMENT VILLAGE INDUSTRY



**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
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Alzheimer's Australia NSW respectfully acknowledge the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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WHY WAS THIS GUIDE DEVELOPED?

While conducting research for the [Alzheimer's Australia NSW](#) discussion paper [Dementia in Retirement Villages](#) it became apparent that a lot of retirement village operators and managers do not have a sufficient understanding of dementia or of the implications for village management and future planning.

Alzheimer's Australia NSW recognises the historical legacy of retirement villages in providing accommodation for independent living seniors; however the industry itself has indicated that it expects to play an increasing role in the care and support of older Australians. As the peak body for people with dementia in NSW, Alzheimer's Australia NSW wants to ensure that the retirement village industry is well prepared and supported to respond to the needs of the increasing number of residents living with dementia.

HOW TO USE THIS GUIDE

This guide is intended as a starting point for CEOs, village managers, sales staff and others working in the retirement village sector to learn more about dementia and decide how they will respond to and address dementia-related needs in their village.

Alzheimer's Australia NSW recommends that retirement village operators make a decision as to whether or not support will be provided for people with dementia who reside in their villages, to identify the parameters of support, and formulate a policy statement which is clearly communicated to staff and existing and potential residents.

Issues that need to be addressed regardless of the decision made are identified in this resource, as well as additional actions that can be taken to establish dementia-friendly retirement village settings. Hyperlinks to further information are provided throughout the guide for readers wanting more information. Therefore it is recommended that the document be used as an online resource as this functionality will be lost if printed.

This guide is not intended to be legal advice. Operators should seek independent legal advice in relation to statutory and contract law as required.

WHAT IS DEMENTIA?

[Dementia](#) is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. Dementia is the single greatest cause of disability in Australians aged 65 years and overⁱ. Dementia is Australia's ninth national health priority.

There are many types of dementia. The most common form of dementia is [Alzheimer's disease](#), which accounts for 50-70% of dementia cases. Other types of dementia include [vascular dementia](#) and [fronto temporal dementia](#). Dementia is fatal and there is no cure. Dementia is currently the second leading cause of death in Australiaⁱⁱ.

Signs and symptoms of dementia

Dementia is not a normal part of ageing. Symptoms of dementia include loss of memory, intellect, rationality, social skills and physical abilities. Symptoms of dementia vary between individuals and the early symptoms can often be vague and subtle which makes [diagnosing dementia](#) difficult.

i Australian Institute of Health and Welfare (2012) Dementia in Australia

ii Australian Bureau of Statistics (2014) Causes of Death, Australia 2012

Early signs of dementia can include:

- Memory loss – particularly short term
- Difficulty performing familiar tasks
- Confusion about time and place
- Problems with language
- Poor or decreased judgement
- Problems misplacing things
- Changes in personality or behaviour
- Loss of initiative and apathy

Alzheimer's Australia [Help Sheets](#) provide more information about dementia, the various symptoms and advice for people living with dementia, carers, service providers and professionals. In addition, anyone can call the [National Dementia Helpline](#) on 1800 100 500 for information and advice.

DEMENTIA PREVALENCE

In 2015 it is estimated that there are more than 342,000 Australians living with dementia. Unless there is a major medical breakthrough (i.e. the discovery of a cure) there will be almost 900,000 people living with dementia in Australia by 2050ⁱⁱⁱ.

Each week there are an estimated 1,800 new cases of dementia in Australia. Almost one in ten people over 65 years have dementia and this rate increases to three in ten for people over the age of 85 years^{iv}.

WHY DOES THE RETIREMENT VILLAGE INDUSTRY NEED TO KNOW ABOUT DEMENTIA?

The context in which retirement villages operate is changing and the industry is required to respond accordingly. The driving social and policy forces underpinning this change include:

- Ageing retirement village population and the trend towards older age at entry. The average age on entry to a retirement village is 74 and the average age of current residents is 81^v
- Increasing number of people in Australia living with dementia
- Increasing number of single person households
- Changing consumer expectations that a move to a retirement village will be the last move a person makes in their life
- Increasing demand for care/support services in retirement villages
- Expanding provision of in-home care and support to delay progression through home care packages and entry to residential aged care
- Limitations of retirement villages with regard to knowledge of dementia and dementia-friendly design
- Dementia being hard to detect and diagnose
- A changing retirement village market as some operators alter their business models in response to all of the above.

iii Australian Institute of Health and Welfare (2012) Dementia in Australia

iv Australian Institute of Health and Welfare (2012) Dementia in Australia

v PWC/Property Council (2015) Retirement Village Census

Dementia is a health and social issue that the retirement village industry is responding to. It is essential that dementia be considered in the business models, philosophies and policies of retirement village operators. Alzheimer’s Australia NSW believes that this should be underpinned by the recognition of individual personhood and the right to live independently for as long as is possible.

RETIREMENT VILLAGE DEMENTIA PREVALENCE CALCULATOR

It is not known how many people in retirement villages have dementia as data is not collected on this. The [retirement village dementia prevalence calculator](#) can be used to estimate the number of residents in a village or portfolio of villages who may have dementia. To use the prevalence calculator, enter the number of residents, male and female, in the five-year age bracket cells in the white columns. The “rate” cells are fixed based on epidemiological prevalence data for dementia in Australia according to the five-year age brackets and by sex. The estimate will appear in the cells on the right with the total number and percentage shown in the bottom row.

Age	Rate (%)		Number		
	Males	Females	Males	Females	With Dementia
Under 30	0%	0%	0	0	0
30–34	0%	0%	0	0	0
35–39	0%	0%	0	0	0
40–44	0%	0%	0	0	0
45–49	0%	0%	0	0	0
50–54	0%	0%	0	0	0
55–59	0%	0%	0	0	0
60–64	2%	2%	0	0	0
65–69	2%	3%	0	0	0
70–74	4%	4%	0	0	0
75–79	7%	8%	0	0	0
80–84	11%	14%	0	0	0
85–89	19%	23%	0	0	0
90–94	37%	48%	0	0	0
95–99	37%	48%	0	0	0
100+	37%	48%	0	0	0
Total			0	0	0
			0		–%

ACTIONS THAT ALL RETIREMENT VILLAGES SHOULD UNDERTAKE

Regardless of whether or not retirement villages want to actively support residents with dementia, there are a number of actions that operators should undertake to ensure that organisational policies are developed and staff are equipped to respond to dementia.

DEMENTIA RISK REDUCTION

To help residents avoid or delay developing dementia, retirement village operators and managers can support healthy ageing approaches and provide dementia risk reduction programs in villages. Research indicates that living a brain healthy lifestyle can reduce an individual's risk of developing dementia. This includes looking after your heart, being physically active, eating well, keeping socially active, and challenging yourself mentally. The Alzheimer's Australia dementia risk reduction program is [Your Brain Matters](#)

CLEAR AND CONSISTENT COMMUNICATIONS

It is imperative that sales and operations staff communicate with prospective and existing residents in a way that is clear, transparent and consistent. There is confusion amongst consumers about what retirement villages are and the different types of services provided. Clear marketing and sales materials can help alleviate some of this confusion.

For prospective residents, communication must clearly explain what they can and cannot expect from the village, as well as their responsibilities and obligations. For existing residents, the threshold point of support in the village must be consistently communicated.

ENGAGEMENT OF RESIDENTS AND THEIR EXTENDED FAMILY

It is important that retirement village staff try to stay in contact with and engage residents who may be exhibiting signs of dementia. A sensitive and consultative approach may remove some of the perceived stigma a resident may be experiencing. It is also important to consider that symptoms commonly attributed to dementia may also be symptoms of other undiagnosed health issues. Further assistance can be sought in partnership with the resident to ensure they receive the correct diagnosis.

Equally important is to keep in touch with their extended family and/or nominated Power of Attorney/Guardian so they are aware of the impact of dementia on the resident and can support the transition to residential aged care if required. Retirement villages should have basic data for each resident for emergency contacts which identifies person responsible/ power of attorney etc., who do not live in the village so staff can communicate with them. Consent should be obtained for their information to be collected and in what circumstances they would be contacted.

It is also important that village managers consider how they can improve social engagement opportunities so that residents' families are engaged with the village community and staff, and are able to observe their family member in social situations which may draw attention to signs of dementia.



RELATIONSHIPS WITH LOCAL DEMENTIA EXPERTS AND RESIDENTIAL AGED CARE FACILITIES

It is important that village managers develop relationships with dementia experts in the local area who can support staff and residents in understanding and responding to dementia.

For information about home care and residential aged care contact the Commonwealth Government's [My Aged Care](#) on 1800 200 422.

Information about assessments for care services is available at [Aged Care Assessment Team \(ACAT\)](#)

If retirement village staff have concerns or need advice about the behavioural symptoms of a resident with dementia, they can contact the [Dementia Behaviour Management Advisory Service \(DBMAS\)](#) or National Dementia Helpline on 1800 100 500.

HEALTH ASSESSMENTS FOR POTENTIAL RESIDENTS

Pre-entry health assessments should be encouraged to identify, as much as is possible, a person choosing an accommodation model where the operator may not be able to support their care, lifestyle and safety needs. A health assessment may also help to overcome resistance from families and provide third party evidence that supports efforts to communicate to the resident's family that there is an issue they need to consider. In addition, potential residents should be interviewed by the village manager (who has a good understanding of dementia and the village's capacity to support residents with dementia), not just sales staff.

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. Individual circumstances will differ and a move to a retirement village could be beneficial if the operator is able to provide a better and more supportive environment.

EDUCATION FOR STAFF AND RESIDENTS ABOUT DEMENTIA

Retirement village operators need to build staff capability and capacity to recognise the symptoms of dementia and respond appropriately and according to any organisational policies.

Alzheimer's Australia provides nationally recognised dementia education for professionals, families and carers, and the community to understand dementia, the symptoms, and how to support people with dementia. For details of specific education services available in each State or Territory, please visit the Alzheimer's Australia [website](#) or contact the National Dementia Helpline on 1800 100 500.

PLAN FOR TRANSITION TO RESIDENTIAL AGED CARE

It should be emphasised that 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 may be extended with appropriate home care and support services. By having open and frank discussion with all parties, the residents and family may be more willing to trust advice offered by the retirement village operator.

Most people with advanced dementia will need to move into residential aged care as their condition progresses and their care needs become too great to be met within the village. Retirement village operators should develop a clear policy for staff and residents which outlines when a person with dementia needs to access a higher level of support than the village can offer. Alzheimer's Australia NSW research indicates that safety is the key threshold point, that is, when a resident with dementia is at risk or poses a risk to other village residents. This policy and further information

needs to be included in the handbook for incoming residents and new resident contracts.

The transition to residential aged care is a very difficult time for people with dementia and their families. It is made all the more difficult if families are in dispute or if members of the family are in denial about the diagnosis of dementia. The situation can be improved where there is agreement and coordination between families and retirement village managers. Alzheimer's Australia has a range of [Help Sheets](#) to assist families of people with dementia with the move to residential aged care.

If a situation arises where a resident and/or their family refuse to move from the village despite the organisation's policy statement, management will need to escalate the issue to the relevant Guardianship body in their State or Territory. Each State and Territory has a body and the names differ, however, an application can be made where the safety of a resident is at risk and the issue needs to be escalated to an entity with relevant legal authority. A tribunal will then assess whether an individual with dementia has the capacity to make their own decisions, or an existing appointed attorney/guardian is not acting in the best interests of the person with dementia. If it is deemed that they do not have the capacity, a substitute decision maker will be appointed. The substitute decision maker would then be responsible for finding appropriate accommodation for the person with dementia. This measure should be used as a last resort.



ACTIONS TO SUPPORT RESIDENTS WITH DEMENTIA

This section outlines some additional actions that retirement village operators who want to support their residents with dementia can take.

WHY SUPPORT RESIDENTS WITH DEMENTIA?

- Human rights perspective – people have the right to choose where and how they live and remain living in their own home for as long as is possible
- Business perspective – there is a growing market for innovative operators to provide retirement village accommodation that is suitable for people with dementia (which will also benefit other residents).

DEMENTIA-FRIENDLY RETIREMENT VILLAGES

Dementia-friendly communities understand, respect and support people living with dementia, enabling them to feel confident and contribute to community life. In dementia-friendly communities people are aware of and understand dementia, and people with dementia feel included and involved and have choice and control over their lives. Alzheimer's Australia NSW has published the helpful resource [Guide to Becoming a Dementia-Friendly Community](#).

Operating within a dementia-friendly framework requires innovation, support and collaboration. Dementia needs to be made a priority in village design, policy and structures, and staff need to be well-educated and motivated to support residents with dementia.

Retirement village managers will also need to educate existing residents about dementia, consult with them, and take them on the journey. This includes breaking down the [stigma](#), fear and misconceptions about dementia. The village culture and attitudes of residents are critical to creating a dementia-friendly retirement village.

BUILDING FOR DEMENTIA

Well-designed built environments can play an important role in supporting people with dementia and facilitating their independence and inclusion. The design of both individual units and the village layout including communal facilities, gardens and public spaces need to be considered.

Operators developing new retirement villages should design and build with dementia in mind. Alzheimer's Australia NSW acknowledges that retro-fitting old stock can be challenging but even small changes to the environment which support people with dementia are possible.

Information about building and designing for dementia in terms of the interior design of units can be found at the [Dementia Enabling Environments website](#).

For information and guidance about how village environments can be designed or adapted to be dementia-friendly spaces, start with the following resources:

- [Building Dementia and Age Friendly Neighbourhoods, Alzheimer's Australia NSW discussion paper, July 2011](#)
- [Designing Outdoor Spaces for People with Dementia](#) edited by Annie Pollock and Mary Marshall

PROVIDING CARE AND SUPPORT

Operators need to make a business decision about whether and how they will offer additional support and care services in their villages, and how this will be funded.

The concept of [service integrated housing](#) describes the various forms of purpose built housing for older people where the housing provider also delivers, or arranges for the delivery of support and care services^{vi}. This is a useful concept for the retirement village sector.

The provision of care and support may include all or a combination of the following elements:

- Employment of health and wellbeing staff
- In-house home care or relationship with community aged care service providers
- Carer support and respite
- Technology for monitoring and community connection
- Assisted living / serviced apartments.

PEOPLE LIVING ALONE WITH DEMENTIA

Without the support of a co-resident carer, people living alone with dementia may need additional support to maintain their independence. This cohort is the most challenging to respond to. They may be a long-standing resident who develops dementia, a person with dementia whose carer passes away or transitions to residential aged care, or a new resident whose dementia was not identified on entry. Each will require a different response and the response will be informed by decisions made by the operator in relation to their adoption of the above guidance.

Telehealth and monitoring technologies can assist in enabling a resident with dementia to live longer in a retirement village setting. The cost of these can be included in a home care package.

Advice for supporting people living alone with dementia is provided in the [Living Alone with Dementia Guide for Service Providers](#) developed by Alzheimer's Australia NSW.

CONCLUDING STATEMENT

As the number of people living with dementia increases, it is essential that retirement villages are equipped to respond to the needs of residents with dementia. Alzheimer's Australia NSW hopes that this guide is a helpful resource for all staff in the retirement village sector and is an impetus for action and continuous improvement.

For more information about dementia, visit the Alzheimer's Australia website (<https://fightdementia.org.au/>) or call the National Dementia Helpline on 1800 100 500.

vi Australian Housing and Urban Research Institute - Integrating housing, support and care for older people: a national and international analysis <http://www.ahuri.edu.au/publications/projects/p20287>

OUR OFFICES

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Coffs Harbour:	02 6651 6415
Forster:	02 6554 5097
Hunter:	02 4962 7000
Port Macquarie:	02 6584 7444

SYDNEY REGION

North Ryde:	02 9888 4268
St George/Sutherland:	02 9531 1928
Blacktown*:	02 9805 0100

**NATIONAL
DEMENTIA
HELPLINE**
1800 100 500

This is an initiative of the Australian Government

SOUTHERN NSW

Bega Shire:	02 6492 6158
Eurobodalla Shire:	02 4474 3843
Bateman's Bay:	02 6492 6158
Cooma, Bombala & Snowy Mountains Shires:	02 6452 3961
Yass, Young, Goulburn, Queanbeyan, Harden, Upper Lachlan & Palerang Shires:	02 6241 0881
Moss Vale:	02 4869 5651
Wagga Wagga:	02 6932 3095
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