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DEMENTIA IN RETIREMENT VILLAGES

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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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ACRONYMS

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACS	Aged and Community Services NSW & ACT
ACT	Australian Capital Territory
AHURI	Australian Housing and Urban Research Institute
CDC	Consumer Directed Care
CHeBA	Centre for Healthy Brain Ageing
COAG	Council of Australian Governments
DMF	Deferred Management Fee
GP	General Practitioner
ILU	Independent Living Unit
IRT	Illawarra Retirement Trust
NSW	New South Wales
RACF	Residential Aged Care Facility
RLC	Retirement Living Council
RVRA	Retirement Village Residents Association
SIH	Service Integrated Housing
UK	United Kingdom
USA	United States of America

EXECUTIVE SUMMARY

“The retirement living sector is a successful model industry, providing a range of care options to facilitate ageing in place.”¹

How well do retirement villages facilitate ageing in place for residents living with dementia?

Retirement villages were not originally set up to support the care needs of residents and often the financial models of operators do not incentivise this. However, the nature of retirement villages is changing due to social, demographic, economic and policy forces which are influencing the types of services and supports desired by residents. As a consequence, the retirement village industry has indicated it will play an increasing role in caring for people as they age and village residents expect this.

The support needs of people with dementia in retirement villages are unknown and operators are uncertain about how to address this. Although people with dementia will likely reach a point where their care needs cannot be suitably accommodated in a village and a move to residential aged care may be necessary, in the meantime, access to appropriate supports in retirement villages, including dementia-friendly environments, social inclusion and community care, can help delay premature entry into residential care. Retirement villages yield savings for Governments through decreased and delayed entry to aged care and health services.

This discussion paper reports the findings of exploratory research¹ which aimed to investigate the extent to which people with dementia are supported in retirement villages and identify improvements to ensure that retirement village residents with dementia are able to age in place. Little is known about this issue and this project is a valuable first step in addressing the gaps in

knowledge about the experience of retirement village residents with dementia in Australia.

The research findings indicate that there is considerable variability in the suitability of retirement villages for people with dementia and the extent to which residents with dementia are supported to age in place. Although some retirement villages provide supportive physical and social environments that enable ageing in place for people living with dementia, others do not.

A key aim of this project was to examine whether retirement villages are able to provide a supportive environment that is suitable for ageing in place for people with dementia. The simple answer to this question is: *it depends*.

Significant variations in the design and operation of retirement villages exist and it is therefore difficult to make a generalisable statement about the suitability of retirement villages for people with dementia. The extent to which retirement villages support residents with dementia is determined by a range of factors including:

- The motivations and business model of retirement village operators
- A culture of inclusion of people with dementia in the village community
- The level of family member engagement in responding to progressive care needs
- The level of village staff understanding of dementia
- Village layout, building design and environmental features
- The type and severity of an individual's symptoms of dementia.

The expected increase in the number of retirement village residents living with dementia presents both challenges and opportunities for retirement village developers and operators. The industry is currently in a state of transformation, with some operators positioning themselves as providers of care rather

¹ A mixed-method research project was conducted to collect data from a range of key stakeholders. Representatives of peak bodies participated in group consultations, retirement village and community care staff across Australia were surveyed and a small number of people with dementia and carers living in retirement villages in NSW were interviewed about their experience.

than merely a housing option for older Australians. The time is ripe for retirement village companies to decide whether or not they will develop dementia-friendly retirement villages.

Operating within a dementia-friendly framework will require innovative, high-quality support and collaboration between retirement village operators, managers and staff, community service providers and a range of support agencies. Appropriate village design, policies and structures and well-educated and motivated village managers and staff would need to be made priorities. A forthcoming research to practice guide (to be published in late 2015) will provide guidance to operators who wish to create retirement villages that are supportive and inclusive of residents with dementia.

Overall, this research found that the variability in the operation of retirement villages leads to confusion for consumers and their families, and their perceptions and expectations of what level of support will be provided are often inaccurate. The research also identified a need for dementia education for retirement village staff and for Government policies which encourage retirement village operators to support the increasing number of residents living with dementia.

To address these issues, Alzheimer's Australia NSW makes the following recommendations:

Australian Government:

1. Allocate funds from the Department of Social Services' Dementia and Aged Services Grant to promote dementia awareness, risk reduction messages and healthy ageing in retirement villages.
2. Provide dedicated funding for developing dementia education programs specifically for retirement village operators and staff.
3. Provide pilot funding for capital grants to retirement villages to incorporate dementia-friendly/universal housing design principles and environments in new retirement villages.

4. Issue instruction that the MyAgedCare website provide information which clearly delineates the difference between residential aged care and retirement villages to avoid terminology confusion for prospective residents and families.
5. Department of Social Services prioritise allocations of home care packages which provide service integrated housing in retirement villages for people with dementia.

State/Territory Governments:

6. Incorporate reduced developer contributions in State/Territory planning policies for retirement villages that support people with dementia and/or developments that co-locate retirement villages and residential aged care facilities that incorporate dementia-friendly design and environments.
7. When the relevant legislation is next reviewed in each State/Territory ensure that greater clarity and transparency for consumers is achieved.

Retirement Village Industry Peaks:

8. Provide guidance to operators to improve transparency in communication between operators and residents and families.
9. Include dementia education in training delivered to retirement village managers with content development funded by Recommendation 2.
10. Encourage retirement village operators to develop housing that achieves the highest level in universal housing design.
11. Promote the World Health Organisation (WHO) Age-friendly guidelines to encourage wider community interaction with retirement villages.
12. Implement a communications strategy to reframe public perceptions and expectations of retirement villages, particularly in relation to their capacity to provide ongoing, high-level care and dementia-specific support.



PURPOSE

“The retirement living sector is a successful model industry, providing a range of care options to facilitate ageing in place.”ⁱⁱ

How well do retirement villages facilitate ageing in place for residents living with dementia?

The Australian retirement village² industry anticipates that villages will play a greater role in the care and support of their residentsⁱⁱⁱ. Older Australians also have increasing expectations of retirement villages. A key aged care sector publication recently noted this situation, commenting that:

“Retirement living operators can no longer be primarily concerned with bricks and mortar; to meet current and future consumer preferences, a wide range of health and aged services need to be available within their villages.”^{iv}

Such health and aged services, providing a continuum of care in an individual’s own home, must include support for people living with dementia. Yet feedback from the industry and consumers indicates that many retirement village operators and staff are uncertain how to support residents with dementia.

In light of this, Alzheimer’s Australia NSW conducted the first research project on this issue. This exploratory research aimed to investigate the extent to which people with dementia are supported in retirement villages and identify improvements to ensure that retirement village residents with dementia are able to age in place. The research findings will assist the retirement village industry to improve their capacity to respond to the complexities of dementia.

The project explored the following questions:

- Are retirement villages supportive environments and suitable for ageing in place for people living with dementia?
- How accessible are formal and informal supports for people with dementia living in retirement villages?
- What policies and practices do retirement village operators have in place to support residents with dementia to age in place?
- What challenges do retirement village operators face in supporting residents living with dementia?

This discussion paper reports the findings and implications of the research. The paper concludes with recommendations for Governments and retirement village peak bodies and operators. Future Alzheimer’s Australia NSW publications and knowledge translation activities will further assist operators as they negotiate the tensions between the policy of ageing in place and the cultural legacy of retirement villages as communities for independent older people with limited care requirements.

² The term “retirement villages” is used in this paper however such accommodation arrangements are also known as retirement communities, self-care units, independent living units and lifestyle villages.

BACKGROUND

Dementia: The social and policy context

Dementia describes the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning. Symptoms vary depending on the type of dementia and may include loss of memory, intellect, rationality, social skills and physical functioning. Dementia is fatal and there is currently no cure.

In 2015 there are more than 342,800 Australians living with dementia and, without a significant medical breakthrough, that number is expected to increase to almost 900,000 by 2050^v. Dementia is the single greatest cause of disability in Australians aged 65 years and older^{vi} and is currently the second leading cause of death in Australia^{vii}.

The social impact of dementia is great, with an estimated 1.2 million Australians caring for someone with dementia^{viii}. On average, symptoms of dementia are noticed by families three years before a diagnosis is made^{ix}. The financial costs of dementia are also significant and, by the 2060s, spending on dementia is set to outstrip that of any other health condition. It is projected to be \$83 billion (in 2006-2007 dollars) and will represent 11% of health and residential aged care sector spending^x.

Older Australians wish to age in place^{xi} and Australian aged care policy emphasises the provision of a continuum of care to support older people to remain in their own homes for as long as possible and avoid premature entry to residential aged care^{xii}. The ageing in place philosophy and practice is particularly important for people with dementia, as multiple moves can be disorienting and exacerbate their condition and increase the need for care.

Supporting people with dementia is of increasing importance for retirement village operators in the context of ageing in place policies, the growing number of people with dementia and the predicted increase in people moving to retirement villages.

The Australian retirement village industry and its residents

Retirement villages are specifically designed to cater to the lifestyle needs of people over the age of 55. They generally provide accommodation units and common areas that promote and facilitate social interaction and support. There are more than 2,200 retirement villages in Australia^{xiii}. In 2014, approximately 184,000 Australians, 5.7 per cent of the over 65 population, were living in retirement villages; this rate is projected to increase to 7.5 per cent in 2025, meaning that there will be more than double the number of residents currently living in retirement villages^{xiv}.

There are many variations in the design, management and operation of retirement villages. Villages vary in size (as small as ten units to as large as more than 200 units on site); some operators provide leisure activities and services whilst others merely provide accommodation; some villages only have independent living units (ILUs) with no additional support whilst others have a mix of ILUs and serviced apartments, for which domestic and some care services are provided.

There are also differences in the business models of retirement villages in Australia. Villages may be 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. Retirement villages may be co-located with a residential aged care facility (RACF) on site or a stand-alone village.

The number of Australians living in retirement villages has grown significantly over recent years and the demographic profile of retirement village residents has changed over the past two decades in terms of age and health status. Two-thirds of Australian retirement village residents are women^{xv} and the average age of residents is 78.7 years^{xvi}. Residents living in villages co-located with a residential aged care facility are older, on average, compared to those

living in traditional stand-alone villages; 81 years compared to 77 years respectively^{xvii}.

The majority of residents enter villages in their early-to-late 70s for health and lifestyle reasons^{xviii}. Retirement villages have become a popular accommodation option for people seeking independent living with access to amenities, security and healthcare support, with increased social networks^{xix}. Australian research has found that residents perceive retirement villages to have a greater sense of community, security and independence than the general community^{xx}.

Retirement villages have traditionally been regarded as providing an accommodation and lifestyle package for 'independent living' of older people with few health and care support needs. Indeed, ABS data^{xxi} indicates that retirement village residents are, on average, less likely to need assistance with core activities than people aged 65 years and over living in the general community. However, people are moving into retirement villages at an older age, and often stay for longer when their care and support needs are met within the village. Retirement village residents enter aged care on average five years later than people moving from their family home^{xxii}. The cause of this is most likely due to the health status on entry discussed above, but also the improved physical and mental health effects that retirement village living provides.

A recent report prepared by Grant Thornton (2014) for the Property Council of Australia and Retirement Living Council noted that, as services and supports provided in retirement villages are self-funded, there is generation of savings to governments. Their analysis estimates that retirement villages generate \$2.16 billion in savings to the health care system; \$1.98 billion of which is achieved by retirement villages delaying residents' entry into government-funded residential aged care facilities (RACFs). The analysis also estimates there is also a potential \$177 million saved through retirement village residents requiring fewer hospital and GP visits, earlier discharge from hospital and better mental health^{xxiii}.

The introduction of consumer directed care (CDC) in Australia will likely also increase demands on retirement villages, as clients choose in-home care supports to help maintain independence and age in place. The retirement village industry is acutely aware of the changing profile and increasing expectations of their residents, acknowledging that it expects to have a greater role in providing care and support to their ageing residents. Yet the historical legacy of "independent living" in retirement villages poses challenges for operators which must be addressed.

Regulation of retirement villages

Retirement villages are regulated by State and Territory-based legislation primarily concerned with consumer protections. However, there is variation in which Government department administers the relevant legislation. For example, in NSW the *Retirement Village Act* is the responsibility of the Department of Fair Trading, while in South Australia the equivalent Act is the remit of the Office for Ageing. In its review of the aged care system in 2011, the Productivity Commission recommended that the regulation of retirement villages should remain the responsibility of State and Territory Governments, separate to the regulation of aged care, however that nationally consistent legislation be developed through the Council of Australian Governments (COAG)^{xxiv}.

There are varying conditions for entering into retirement villages which may include contracts for title or leasehold tenure, rental or deferred management fee (DMF). This variation is accompanied by a complex array of payment systems that are intended to promote flexibility, but in effect do more to confuse residents and their families and fuel uncertainty.

Current legislation regulating retirement villages does not address requirements, responsibilities or obligations with regard to the health status of residents. Responsibility for how health issues, including dementia, are addressed remains the remit of individual operators.

Service Integrated Housing

Service Integrated Housing (SIH) describes a variety of housing types where the provider deliberately makes a range of support and care services available for older people. SIH may include retirement villages as well as manufactured home estates and boarding houses. The provision of SIH overlaps the community and residential aged care sectors and has been identified as the 'third component' of aged care in Australia^{xxv}.

SIH is an important concept for the retirement village industry as their client group has high levels of chronic illness and disability and increasing expectations that support and care will be available^{xxvi}. Jones notes that almost all providers of retirement housing are involved in SIH to some degree, highlighting that this raises considerations of responsibility for providers including who provides, who pays, what principals should guide provision, and what are the limits to the level of support provided to residents^{xxvii}.

Retirement village residents with dementia

There is a lack of information about the number of people with dementia residing in Australian retirement villages. Anecdotal reports from providers and industry experts suggest that there is an increasing number of residents with dementia, yet little is known about their experiences. An extrapolation using the average age of retirement village residents^{xxviii} and epidemiological data on dementia prevalence^{xxix} suggests that approximately 1 in 10 residents have dementia (estimate of 18,400 residents). Another study^{xxx} has identified that 22% of adults at age 71 have a cognitive impairment that is not at the threshold for dementia. Healthy ageing strategies and dementia risk reduction programs have been shown to delay progression of cognitive impairment into a form of dementia and would build on the lifestyle benefits retirement villages provide, whilst also decreasing/delaying costs for health and aged care. This project is a valuable first step in addressing this significant knowledge gap.

People with dementia will likely reach a point where care needs cannot be suitably accommodated in a retirement village setting and a move to residential aged care will be required. However, in the meantime, access to appropriate support, including dementia-friendly environments, social inclusion and community care are necessary to help people with dementia age in place in their own home (in the retirement village) for as long as is appropriate.

Previous research

Research^{xxxi} from the USA and Canada has focused on ageing in place in 'naturally occurring retirement communities', while in the UK research^{xxxii} has been conducted on 'extra care' housing and villages for people with dementia. The Hogeweyk village model, developed in Amsterdam, is a dementia-specific village design^{xxxiii} that has more in common with a residential aged care facility (RACF) than the current independent lifestyle portrayed in Australian retirement villages. However with increased demands of government 'ageing in place' policy on the retirement village sector, this model may offer valuable design elements to developers and operators.

Our review of the literature found some Australian research^{xxxiv} on retirement village populations, yet none on either the experience of living with dementia in retirement villages or how operators respond to the needs of residents who develop dementia. In June 2015 a report published by the Australian Housing and Urban Research Institute (AHURI) noted that there is a need for further research into barriers to ageing in place for people with dementia in retirement village settings^{xxxv}. These research gaps demonstrate the importance of this innovative research project.

METHODOLOGY

The research team conducted a mixed-methods research project³ during 2014-15 in the following phases⁴:

Peak body consultations

Group consultations were held with members from three peak bodies – the Retirement Living Council (RLC - three participants), the Aged and Community Services NSW/ACT (ACS) Retirement Living Advisory Group (nine participants) and the NSW Retirement Village Residents Association (RVRA - eight participants). These consultations were designed to provide an understanding of the key issues confronting retirement village operators and residents in relation to dementia.

Interviews

Semi-structured interviews were conducted with people with dementia living in NSW retirement villages and/or their family carer. Participants contacted the research team in response to recruitment material distributed by retirement village operators. The informed consent of all participants was obtained prior to conducting interviews. The interviews explored participants' experiences of living with dementia in a retirement village setting, including how they are supported by staff and residents, what could be improved and what they think will help them to remain living in their home for as long as possible. Thirteen people participated in interviews; seven carers (two of whom were caring for their relative with dementia in the retirement village and five whose relative with dementia had moved into residential aged care) and three dyads of carer and person with dementia.

Surveys

Online surveys were conducted with retirement village staff and community care providers throughout Australia. An invitation to complete the surveys was distributed to retirement village and community aged care staff across Australia via various networks including the Retirement Living Council (RLC), Aged and Community Services (ACS), Leading Aged Care Services (LASA), Alzheimer's Australia and the project advisory group networks. As a result of this distribution method the survey sample size and response rate are unknown. The surveys investigated staff experience of supporting retirement village residents with dementia and their opinions about the suitability of retirement villages for people living with dementia. 159 valid survey responses were received; 71 from retirement village staff⁵ and 88 from community care staff⁶. Respondents were from metro (44.5 per cent), regional (42.2 per cent) and rural (13.3 per cent) areas, and the majority of respondents (70 per cent) were from NSW. Forty per cent of retirement village staff respondents were employed by for-profit operators while 60 per cent worked for not-for-profit operators.

Project advisory group

A project advisory group was established to provide the research team with a greater insight into the retirement village sector; promote the research; assist in recruiting research participants; review the research findings and analysis; and contribute to the development of recommendations.

3 The project was approved by the University of NSW Human Research Ethics Committee.

4 Approximately 200 individuals participated in the research project.

5 Respondents included onsite village managers, leisure/life-style managers and welfare officers.

6 Respondents included case managers, coordinators, aged care workers, Aged Care Assessment Team (ACAT) staff, community nurses and care managers.



RESEARCH FINDINGS AND IMPLICATIONS

This section discusses the research findings and implications for retirement village operators. The discussion is divided into eight sections:

1. Misperceptions and wrong impressions
2. Retirement village staff knowledge of dementia
3. Access to care and dementia services
4. Provision of informal support by village communities
5. Ageing in place in retirement villages for residents with dementia
6. Transition from retirement village to residential aged care
7. Suitability of retirement villages for people with dementia
8. Challenges and opportunities for retirement village operators.

Misperceptions and wrong impressions

Participants reported that families often had unrealistic expectations that a retirement village would look after their relative with dementia, assuming that a move to a village setting equated to a move to residential aged care. Families then withdraw, relinquishing responsibility and expecting that the village and its community will provide the necessary support and care.

"We had a recent case where I was in constant contact with the resident's son and he flat-out refused to acknowledge that his mother wasn't coping. And in the end she was diagnosed with dementia but she was wandering the village at all hours of the night and other residents had to look after her, and she disappeared from the village. And for us it's heart wrenching to see that decline in someone and we want to do our utmost to try to look after and protect our residents where we can, but we're not in control of this person and that's where the family need to step in." (Retirement village manager)

"We have a lady [living in our village] who now has quite advanced dementia and she has a daughter in Melbourne and a son in Sydney but they don't want to know. They say 'it's your problem' to the management of the village and 'she's with you and you had better look after her'. But this is not the right environment for her but they refuse to do anything for her. And she is becoming very much a burden for a lot of people...but they are very hesitant to do an assessment because they have had the experience that family can become very litigious and don't want to play ball. So they are hanging on and hanging on but one day something will happen to the lady." (Retirement village resident)

"Occasionally I think there's a bit of a sense from families, 'well, mum and dad have moved into the retirement village, all the services will be there, we're fine now and off we go'. And to put it in really blunt layman's terms, sometimes you see those cases where it's dump and run, and it's really terrible." (Retirement village manager)

Some of this may simply be wishful thinking on the part of families, but a portion of the blame could be attributed to misperceptions derived from retirement village advertising and sales agents. There is also the issue of a certain laxness around the contextual definition of the word, 'village', which is sometimes used in connection with dementia-specific facilities and leads to confusion in care provision.

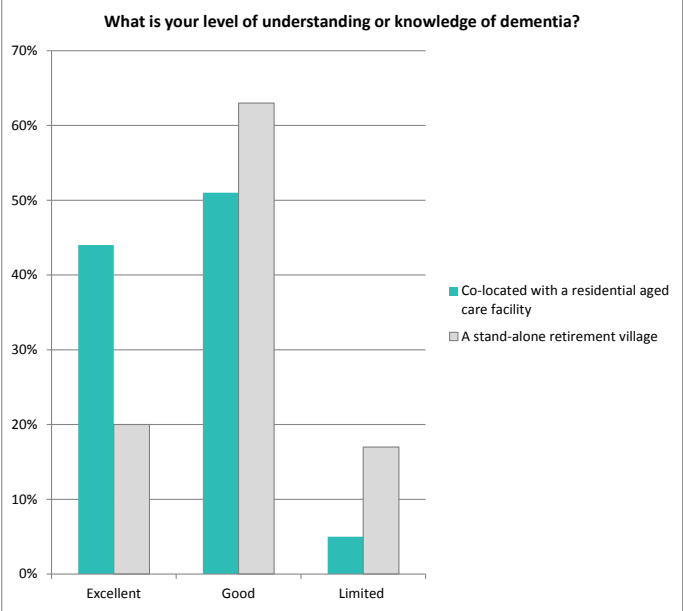
"The perception in the community is very blurred. People don't understand the difference between a retirement village and a nursing home. We were only 60 when we moved into our village and people used to look at us in absolute horror. We live in an apartment block; it's just like living in a strata unit. But people have this idea that once you go into a retirement village, you're going into care. And there's absolutely no care. And unfortunately sales people aren't upfront...Residents are given the wrong impression and families are given the wrong impression and there really needs to be quite a bit of education about the differences between retirement villages and care situations." (Retirement village resident)

A major concern identified by operators is when family resist acknowledging an existing village resident is developing dementia and refuses to work with staff in arranging suitable services and/or transition to a RACF. Staff consulted for this research all agreed that they walk a very fine line on this difficult issue and, lacking clear policy, currently address these issues on a case-by-case basis. The key concern is around the duty of care felt by staff towards their residents versus the requirement to respect residents' privacy. In addition, staff raised concerns about what role, if any, they should have in referring residents for a diagnosis of dementia and for care services, and/or assisting with the transition to residential aged care, if a family will not act.

Retirement village staff knowledge of dementia

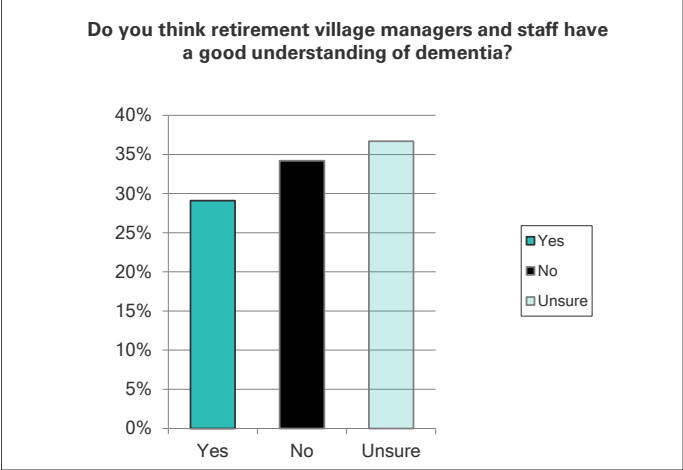
Of retirement village staff surveyed, 34 per cent rated their knowledge of dementia as excellent, 56 per cent as good and ten per cent as limited. Respondents who work at a retirement village that is co-located with a residential aged care facility rated their knowledge higher than those at a stand-alone village – 44 per cent excellent and 51 per cent good, compared to 20 per cent excellent and 63 per cent good, respectively (graph 1). It must be noted that responses to this self-assessment of knowledge are likely to be skewed due to people with an understanding of dementia being more likely to respond to a survey about dementia. In addition, respondents are self-defining what level of knowledge they have and such subjective measures need to be read with caution.

Graph 1: Retirement village staff self-rated knowledge of dementia – stand-alone and co-located village staff compared:



Less than 30 per cent of community care survey respondents thought that retirement village managers and staff have a good understanding of dementia (see graph 2). While retirement village staff may indicate positive expectations of their capacity to provide appropriate support for residents with dementia, it is likely their experience is limited. Community care staff would have more specific experience in this context and so are more likely to have a better idea of what level of knowledge is required to support people with dementia.

Graph 2: Community care staff:



"I think there needs to be a huge educational piece in the not-too-distant future and I think we [in the retirement village sector] have a responsibility to put that out and start to educate staff, right down to the maintenance staff."
(Retirement village manager)

This research found that there is a great need for dementia education and training for retirement village staff. Education would need to address, at a minimum, recognising early symptoms and communicating with people with dementia.

Access to care and dementia services

Over 80 per cent of retirement village staff survey respondents indicated that external services are accessed by staff or residents to support residents with dementia. Services accessed by staff and residents include ACAT (92.45 per cent), home care services (86.8 per cent), local dementia experts (75.5 per cent), and geriatricians (56.5 per cent). Allied health professionals and community support programs were also used by a small number of respondents.

This research suggests that people living with dementia in retirement villages are equally well supported by external services and community or home care packages as people living with dementia in the general community. Survey responses indicated that there are some difficulties in accessing services in rural areas, as would be expected in the Australian context. Previous Alzheimer's Australia NSW research^{xxxvi} has highlighted the challenges rural populations face in accessing home care packages and dementia-specific support. Some retirement village managers reported that they are hesitant to accept new residents with dementia because of uncertainty about the availability of care packages to support residents to live independently in the village.

Retirement villages generally offer building and garden maintenance, security and varying degrees of support for social engagement, but the availability of other supports and extra care services is highly variable. Some villages have a welfare officer who keeps an eye on vulnerable residents but others do not. There was a general impression that for-profit operators were less likely to offer care support than

not-for-profit, but also a perception of decreased staffing in the latter since the global financial crisis. This is seen particularly as a problem with families who 'dump and run' expecting village management to step-up. Residents with dementia in villages with minimal support services and who are virtually abandoned by their families can find themselves pressured to move.

"I think it would be difficult living in a village that didn't have the type of facilities that we've got because you might as well just be living in a unit in some cases if you haven't got support and activities." (Retirement village resident)

The current context of reform in aged care services presents opportunities for retirement village operators to deliver or broker aged care packages into the village for their residents. For operators who do this well it provides a competitive advantage in this growing market. The future liberalisation of the aged care market with individualised funding being allocated to clients, rather than aged care providers, furthers opportunities for retirement village operators to act as care facilitators.

Serviced apartments that provide additional domestic and care services within a village setting may be a suitable option for people with dementia. It is important that people with dementia have access to appropriate clinical, care and support services to enable them to remain living in their own home and delay premature entry into residential aged care. Retirement villages are well-placed to facilitate access to these services. For example, Ingenia Communities has implemented a 'care assist' program in their rental villages which is staffed by a registered nurse and a case manager. This free program connects residents to health, aged care and wellbeing services using local care providers. As at May 2015, more than 320 residents had used the program^{xxxvii}.

Provision of informal support by village communities

"Some of the other residents don't have a lot of patience. You know, if someone doesn't fit into their little world, they don't go out of their way to help. Other people are wonderful and very supportive." (Daughter of retirement village resident with dementia)

The small number of residents interviewed for this project indicated that their village community was supportive and helpful.

"Sometimes it scares me. That's why I can't go out on my own. I need to have my husband with me because I forget things. It is very frightening. And that's why I don't go out without him because I might get lost. I feel insecure because I forget easily and sometimes it's very irritating for me... But the other residents are very good. They ask us if we need any help. They are very helpful and they are very nice. They are very caring here." (Retirement village resident with dementia)

"He's settled in really well and it's been really good. The other residents have really embraced [my husband with dementia]. I don't want to impose his dementia on other people but I take him along to most activities. Like, he goes out for a walk twice a day and goes into the gym and everyone has been really good with him." (Wife of retirement village resident with dementia)

However, the popular concept of a supportive community is inevitably dependent on that community's character which may be more, or less, supportive of a resident with dementia and their carer/partner subject to the degree of disturbance felt.

"Other residents are entitled to live without intrusive behaviour. Residents seem to lose interest in residents with dementia as they don't get the responses they want/need from them e.g. forgetting outings, inappropriate conversations. Other residents can't make friends with them so if they have only known them in recent times they tend not to bother." (Retirement village staff)

When asked how residents with dementia are treated by other residents (graph 3) retirement village staff survey respondents trended towards positive responses but this was not the case across the board. While 70 per cent of respondents reported that residents are supportive, almost 60 per cent indicated that how a resident with dementia is treated depends on their personality and the symptoms of dementia displayed.

"If a resident develops dementia after living in the village, residents are more supportive than if they come into village with dementia." (Retirement village staff)

Qualitative survey data also revealed that residents may be more supportive and sympathetic if they have known a resident prior to the onset of symptoms of dementia.

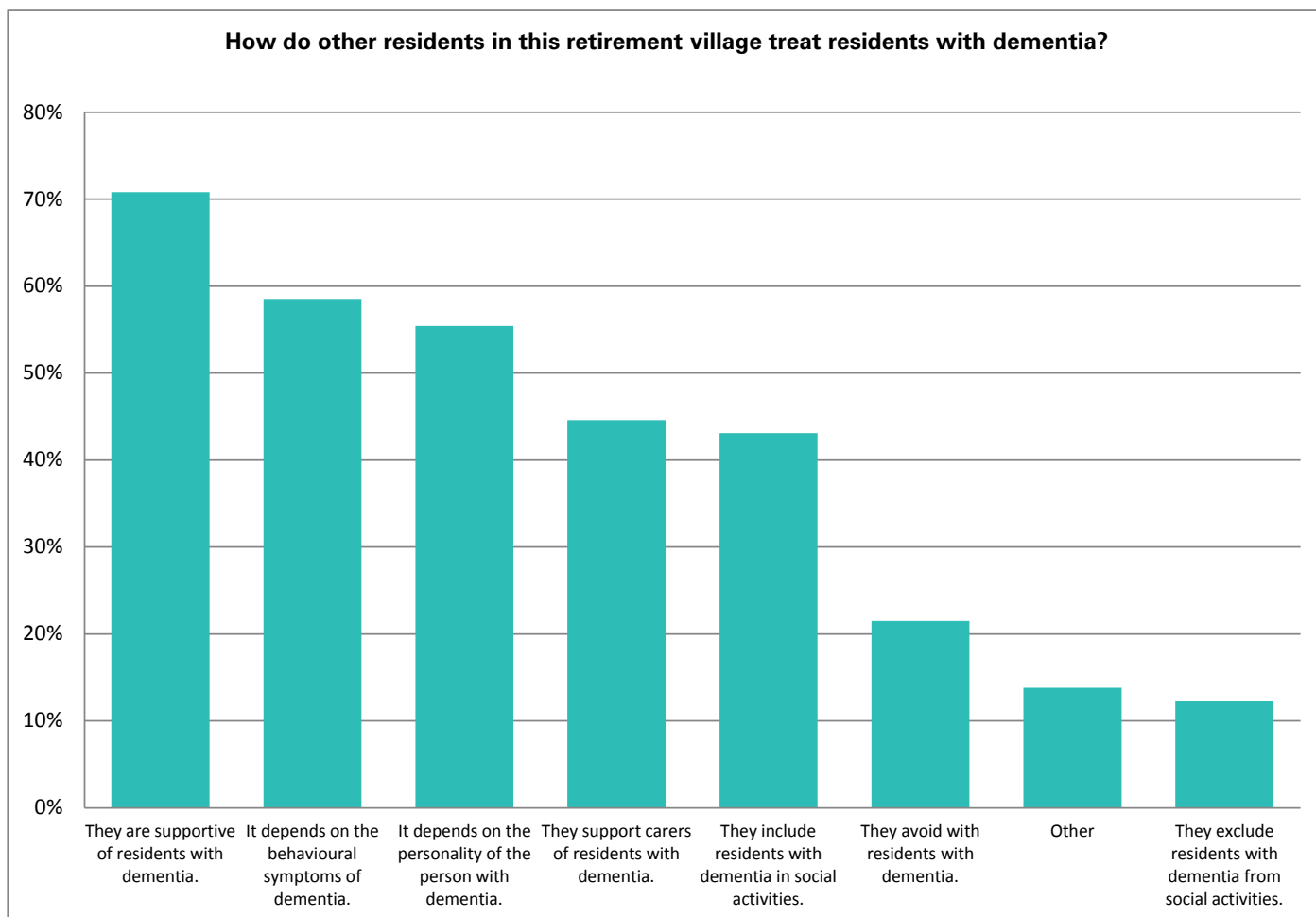
This research also revealed that although informal support from the village community is often strong during in the early stages of dementia, there is a threshold of support that other residents are willing to provide. Particular behavioural symptoms of dementia, such as disinhibition or aggression, are difficult for other residents.

"The residents are more supportive at the beginning and then get annoyed, frustrated and stop including the resident with dementia. They will suggest to me that the person should be moved into permanent care!" (Retirement village staff)

The group consultations revealed that other residents are more likely to support the spousal carer of a person with dementia than the individual with a diagnosis. For people living alone with dementia in retirement villages, support from the community can be limited, with the stakeholder consultations revealing that this cohort may transition to residential aged care earlier than those with a co-resident carer in the village.

"For people living alone, I think the security aspect is the worst and that terrible confusion of not knowing where you are. But if there is a partner, that can be handled better." (Retirement village resident)

Graph 3: Retirement village staff:



"There's a single lady here in the village with dementia who doesn't know why she's here. And I don't think our village is set up to look after someone like her with more advanced dementia. She probably needs a nursing home. She takes up a lot of staff time." (Retirement village resident)

"I don't think it would be easy for a person with dementia living alone in a village like ours. They're often regarded as an oddity, often some of their behaviours become quite concerning for some of the other residents so, in a way, you wonder if it really is a good environment." (Retirement village resident)

"Some residents can be overly concerned to the point of being a hindrance at times. Some gossip and feel as though the village is less prestigious with "these people" living there." (Retirement village staff)

"Dementia can make non-dementia people very uncomfortable and we have to cater for the greater number. They don't want to feel like they are in a nursing home." (Retirement village staff)

The research found evidence of stigma and exclusion of people with dementia in retirement villages which may stem from a lack of understanding of dementia. Group consultation participants in particular reported coming across exclusionary attitudes towards residents with dementia. The issue of exclusion and stigma also emerged in the survey responses:

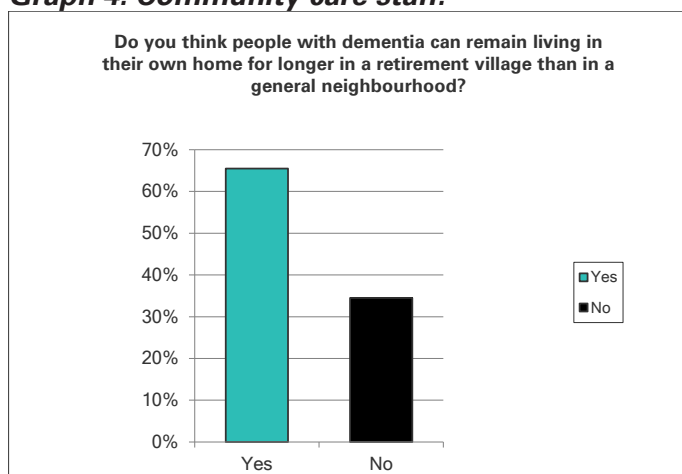
The much-lauded supportive community of the retirement village also has its limitations, dependent upon the character of both the community and the symptoms experienced by individuals with dementia. A person with dementia who has a partner is likely to receive more support and tolerance, especially if the dementia developed after they took residence, whereas a new resident who is a single person with an existing dementia diagnosis is likely to receive considerably less support. The presence of dementia within retirement villages is relatively new and has the potential to cause stigmatisation and for other residents to feel discomfort and less tolerant.

Ageing in place in retirement villages for residents with dementia

Sixty-five per cent of community care staff survey respondents think that people with dementia can remain living in their own home for longer in a retirement village than in a general neighbourhood (graph 4). They indicated a variety of reasons for this view including the sense of community amongst village residents, the social support generated in a village, the monitoring provided by on-site staff and access to services.

"If there is strong village community support and occupants and staff understand dementia and the supports being provided or available, it can be a safe and enabling environment."
(Community care staff)

Graph 4: Community care staff:



For the respondents who answered no, the key reasons that emerged were about the attitude of village staff and residents towards people with dementia and the unfamiliar environment of a village (that is, not the family home where the person with dementia may have resided for many years). The following quote from a survey respondent summarises the concerns about the attitudes of some operators towards people with dementia:

"The culture and attitudes of staff from the top down [limit the ability of people with dementia living in their own home in a retirement village]. Retirement villages are promoted with photos of 60-somethings having a fun, active time with others of a similar age; this is to attract buyers. As long as residents aren't "demanding" and don't "cause trouble" they are welcome to live there independently. But in the event of an event e.g. hospitalisation for a fall or becoming aware of dementia symptoms, there seems to be some

kind of thought that "it's time to consider moving into care". This belief undermines confidence in the individual and I believe hastens their decline, ultimately, via lack of support and information about their rights to remain in their own home."
(Community care staff)

A resident's tenure in a retirement village requires ongoing assessment for suitability to age in place and to maximise enjoyment of a chosen lifestyle. One of the factors identified in this research that will tend to influence the ability of people with dementia to age in place is the level and type of care and support requirements, especially for people with dementia living alone with limited family support.

Many retirement villages were designed with the expectation that people who develop disabling illnesses will move on into higher care facilities and therefore have limited capacity for residents with dementia. If the person with dementia has a partner there is greater support from the village community, but the community has limited tolerance for disturbing behaviours. While a single person with dementia is able to remain independent, has family support and can buy in services, they too are able to remain in the village. Yet without these supports they are more likely to need to move into a residential aged care facility prematurely.

"Our independent living villages are not equipped to deal with dementia and never have been, nor were they designed to be...and from the perspective of our staff and how our villages are currently structured, it is barrier to having someone live long-term with dementia in the village." (Retirement village manager)

Current variations in either the declared or undeclared capacity of retirement villages to support ageing in place for people with dementia, the degree of assessment of suitability of applications from people with dementia, and the availability of support for existing residents who develop dementia, render the decisions of consumers highly problematic. Retirement villages with a dementia policy and RACF onsite or in alliance may offer people with dementia confidence that they will be able to remain in their home for longer.

Transition from retirement village to residential aged care

For most people with advanced dementia a move to a residential aged care facility will be necessary as their care needs progress beyond that which can be safely managed in the retirement village.

"The retirement independent living industry does not address the complexities of old age. It is not interested in providing care within the facilities for clients with dementia. Its expectation is that these clients will move on."
(Community care staff)

The top three triggers identified by retirement village staff for a village resident with dementia to move into residential aged care were:

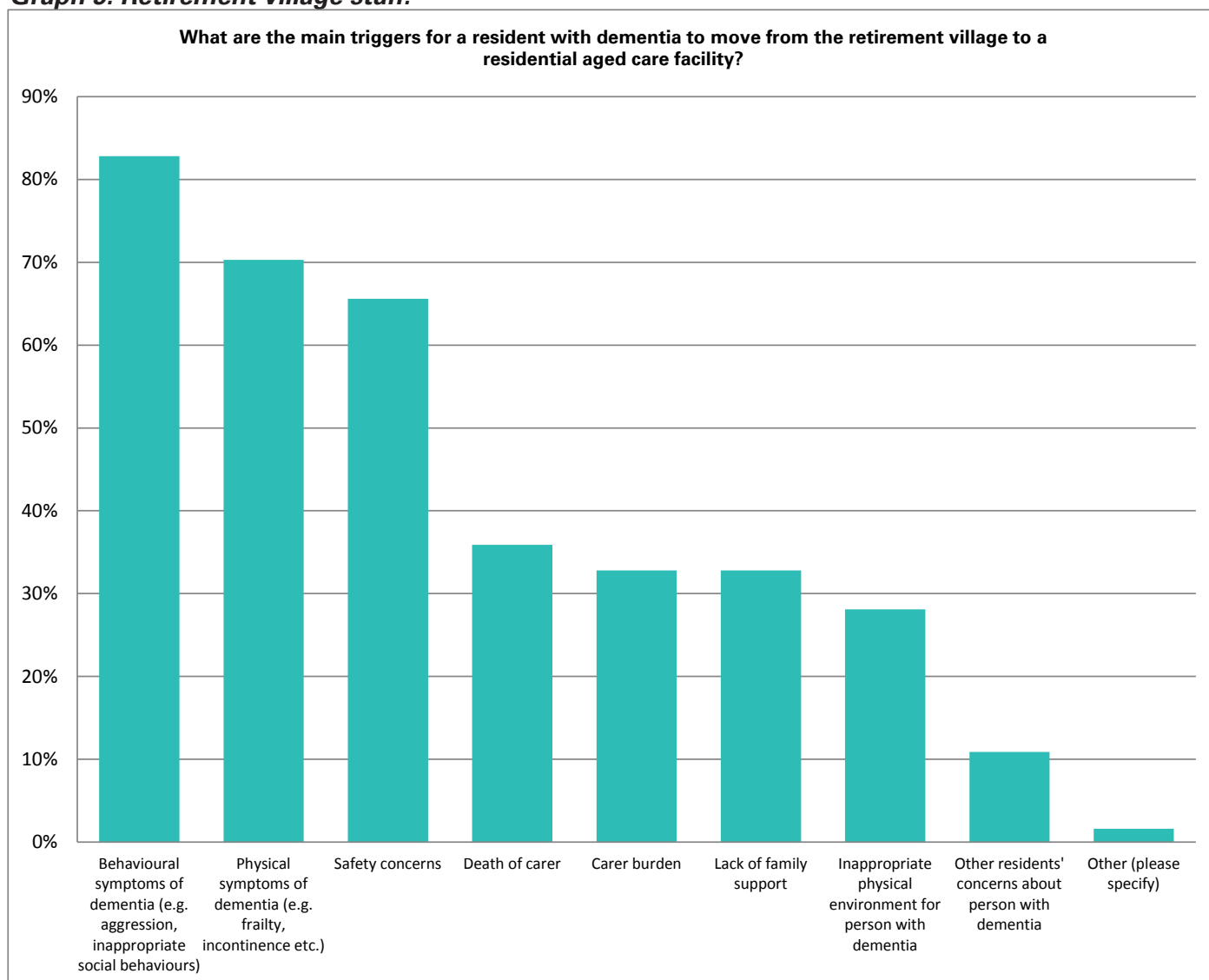
1. Behavioural symptoms of dementia

Staff felt that other residents have a poor understanding of dementia behaviour, do not know how to respond and feel uncomfortable when dementia becomes more evident. The general feeling is that people have bought into a retirement village for the lifestyle to enjoy their remaining years and have little interest in looking after a neighbour with advancing dementia, especially if the residents' family avoids that responsibility.

2. Physical symptoms of dementia

Retirement villages generally do not have

Graph 5: Retirement village staff:



sufficient staff, nor are those there sufficiently trained or obligated to provide dementia care. Therefore, if the person with dementia does not have, or loses, the support of a carer/partner there is currently often no option but to move into residential care.

3. Safety concerns

The layout and design of many retirement villages, especially older complexes, is often confusing and insufficiently secure to be safe for residents with dementia. People living alone who fear management detection of their progressive dementia symptoms may isolate themselves and therefore be at greater risk.

There is a perception that residents who live in a village co-located with a RACF will be guaranteed a place should the need for residential care arise. For most providers this is not possible (there are some notable exceptions to the rule, as in the example below) however there is a view that this is always the case. Indeed, waiting lists and occupancy levels are higher for retirement villages that are co-located with a RACF than stand-alone villages^{xxxviii}. For retirement village operators who do not also operator RACFs, there is benefit in partnering with aged care service providers. For example, retirement village operator, Stockland, recently partnered with residential care operator, Opal, to deliver a co-located model in Sydney^{xxxix}; while Living Choice has partnered with Estia on a similar offering in Queensland^{xl}.

Suitability of retirement villages for people with dementia

A key aim of this project was to examine whether retirement villages are able to provide a supportive environment that is suitable for ageing in place for people with dementia. The simple answer to this question is: *it depends*.

Our research indicates that although some retirement villages provide supportive physical and social environments that enable ageing in place for people living with dementia, others do not. Due to the significant variations in the design and operation of retirement villages it is difficult to make a generalisable statement about the suitability of retirement villages for people with dementia.

The extent to which retirement villages support residents with dementia is determined by a range of factors including:

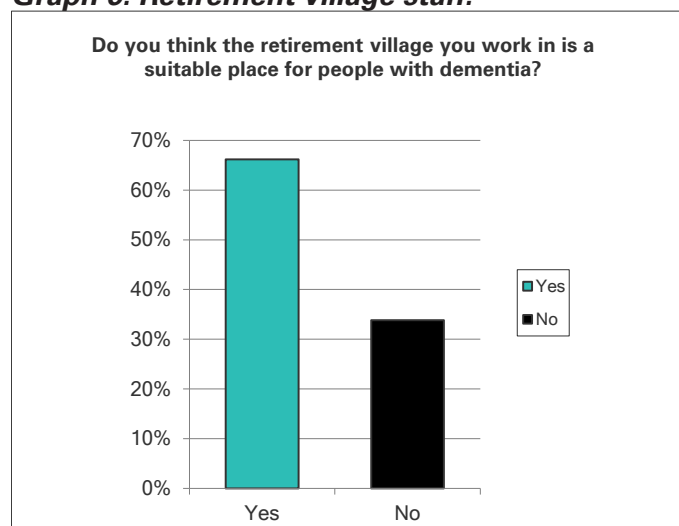
- The motivations and business model of retirement village operators
- A culture of inclusion of people with

dementia in the village community

- The level of family member engagement in responding to progressive care needs
- The level of village staff understanding of dementia
- Village layout, building design and environmental features
- The type and severity of an individual's symptoms of dementia.

Sixty-six per cent of retirement village staff survey respondents thought that the retirement village they work in is a suitable place for people with dementia (graph 6). Respondents who work in a village that is co-located with a residential aged care facility on site were more likely to think that the village they work in is suitable for people with dementia (78 per cent compared to 50 per cent for stand-alone village respondents). There were also differences in responses when analysed by whether respondents worked for a not-for-profit or for-profit operator. Seventy-two per cent of not-for-profit retirement village staff respondents thought that the village was suitable for people with dementia, compared to 58 per cent of for-profit respondents.

Graph 6: Retirement village staff:

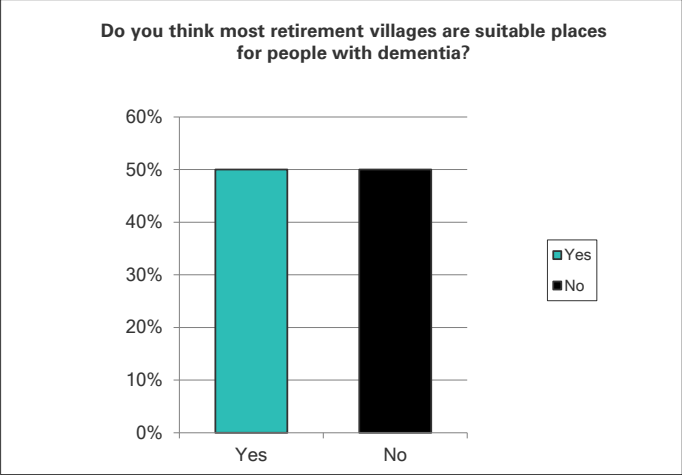


"As we have a multidisciplinary business we are fortunate to be able to support residents who require no assistance, residents who require mild assistance and residents who require high and low care daily assistance. Being able to work with our residents and transition them to the relevant building/care option is essential."
(Retirement village staff)

Community care survey respondents were divided on the question of whether most retirement villages are suitable places for people with dementia, with 50 per cent saying yes and 50 per cent saying no

(graph 7). Respondents based in metropolitan areas were less likely to agree that retirement villages are suitable places for people with dementia.

Graph 7: Community care staff:



Analysis of responses to subsequent questions indicated a number of reasons why community care staff do or do not think retirement villages are suitable for people with dementia. The ranked responses given to whether retirement villages are, or are not, suitable for people with dementia were as follows:

<i>Retirement villages are suitable for people with dementia because:</i>	<i>Retirement villages are not suitable for people with dementia because</i>
1. There is a supportive community	1. The design and layout of villages isn't appropriate for people with dementia
2. People with dementia included in the community	2. Residents with dementia are socially isolated
3. There is good access to support services	3. There is limited access to services
4. Staff understand dementia	4. The design and layout of units aren't suitable for people with dementia
5. The design and layout of village and units are appropriate for people with dementia	5. Staff don't understand dementia

Benefits of retirement village living for people with dementia

Staff survey respondents and people with dementia and carers who participated in interviews reported many benefits of retirement village living. These included:

- Village maintenance relieves people with dementia of onerous responsibilities of a large house and garden
- Villages have higher levels of peace and

security than the wider community

- Neighbours, community and staff can be supportive, especially for carers of people with dementia
- Attentive village staff and community can provide monitoring and a caring presence compared to what is available living in the broader community;
- Villages with organised social activities are conducive to maintaining greater social engagement.

Challenges of retirement village living for people with dementia

Participants in the group consultations and survey respondents identified the challenges of retirement village living for people with dementia and carers including:

- Families that have limited contact with their relative or they are in denial of their relative’s condition and fail to make appropriate arrangements for support services and/or expect more than the village offers or can provide
- Village operators/sales agents can fail to screen and match applicants in respect to the appropriate conditions and level of services available at their village;
- The layouts of retirement villages can be complex and confusing for people with dementia
- Few villages are gated communities and are not secure for people with dementia
- Government-funded community care services can have long waiting lists and private fee-for-service arrangements are dependent upon the resident’s income
- There is the potential for conflict, especially if symptoms of dementia negatively impact on other residents.

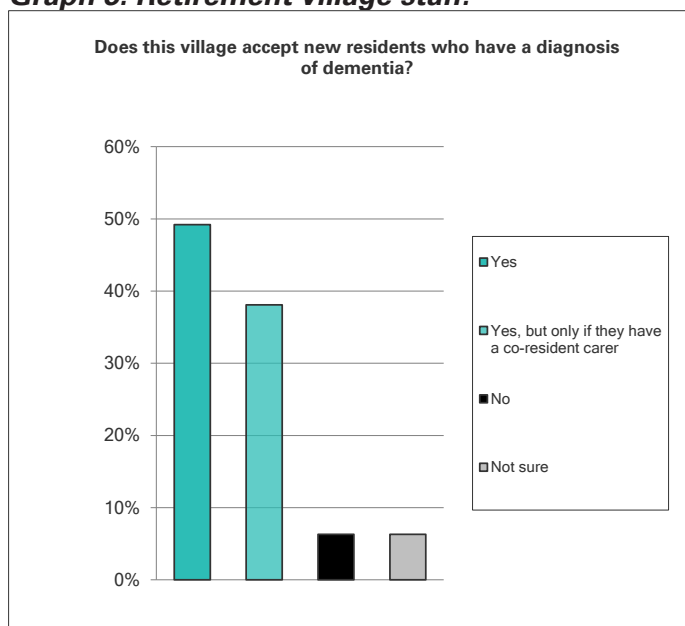
Challenges and opportunities for retirement village operators

Most retirement village operators appear to have little or no policy directives/guidelines to inform staff, residents and their families, and future residents about how, and to what extent, the village will support residents with dementia. There is wide variability in the adaptation of retirement villages to the needs of their residents, ranging from being dementia inclusive to dementia exclusive. Village policies and managerial imperatives often shape the experiences and opportunities for people with dementia.

During the group consultations participants reported that some villages screen out potential residents who have a diagnosis of dementia, especially if they live alone. This was confirmed in the survey responses, with almost 40 per cent of respondents reporting that the village they work for only accepts new residents with dementia if they have a co-resident carer (graph 8).

Under existing conditions in retirement villages it is probably wise, and preferable, that those who cannot offer sufficient support for a single person with dementia screen such potential residents out to prevent disappointment and an expensive premature exit from the village. However, with the changing clientele demographic, more retirement villages are going to need to offer a broader range of support services to appeal to that client-base and accommodate the Government's ageing in place policy. Residents will want confidence of support and tenure until/if a move to a RACF is required. These developments will need to be addressed by operators across the spectrum, both not-for-profit and for-profit operators. While not every retirement village operator may want to, they will need to be able to respond a growing proportion of residents with dementia. In addition, transparent processes for how progressing dementia is accommodated within the village will be needed.

Graph 8: Retirement village staff:



Some operators do not have a comprehensive medical assessment process in place and are therefore not identifying dementia during the sales process. The sales staff of some operators identify if village life might not be appropriate for a potential resident, perhaps referring them for an assessment

to determine if they can live independently. Screening procedures of applicants need to include families, in order to ensure that families have an appropriate understanding of their relative's capacities, what level of support is required and that their expectations of what support the retirement village can provide are realistic.

"It doesn't matter how bad people are because once they've got you in, it's going to cost you a lot of money to get out. And they don't care. And we've had people come into our village and they've only lasted a few weeks and it's been horrific and the families have realised they've put them in the wrong place. And the operator gets all the fees you have to pay to get out of the village. And fortunately, in some good villages, there is an assessment to make sure that you can live independently, but that is not the majority. Most of them couldn't care less if you can manage or not." (Retirement village resident)

In the RVRA consultations, resident interviews and qualitative survey data, distinct differences arose in perceptions of for-profit and not-for-profit operators, with the former seen as more likely to avoid the subject of persons with dementia and less likely to provide additional support services.

"This village is good for people with dementia because of the attitude the people I suppose, and it's a not-for-profit organisation, whereas a lot of the others are in it for the all the money they can make and they don't care... [this operator] is exceptionally good." (Retirement village resident, whose wife has dementia and now lives in RACF on site)

Some of the more innovative operators have developed more supportive health and welfare strategies for residents who develop dementia. Some who are co-located with a RACF can provide effective transition to residential care when necessary. The question arose during the research as to whether retirement villages that are co-located with RACFs are better equipped to manage dementia within the village and the transition to residential care? Early indications based on the analysis of the findings of this research suggest that they are, however there is a need for further research.

Although the retirement village industry has indicated that it has a role to play in supporting Australians as they age, how are they planning to respond to the needs of residents with dementia? The historical

legacy of retirement villages as independent living presents a challenge for operators. At their inception, villages were not envisaged as places that would support people with progressive conditions, such as dementia. Therefore, operating models, built environments, staffing levels and skillsets in most retirement villages were not designed to meet the support requirements of residents with dementia. There are additional costs associated with implementing universal design principles to a whole village to make it appropriate for people with dementia. For people who pride themselves in their success in achieving a stylish retirement lifestyle, there is also a certain stigma associated with sharing a village with people with dementia.

This research has revealed that retirement village practices are highly variable. There are some that have a dementia policy, provide sufficient services for ageing in place for people with dementia, and are co-located with an RACF. However, others have few of the services required to maintain a satisfactory lifestyle for residents with dementia, and only a portion of those will make that clear to potential buyers. With the projected increase in numbers of older Australians moving to retirement villages, there is a serious need for the development of operational policy and preparation of a more systematic provision of support services for all retirement village residents, especially for residents with dementia.

"Most retirement villages in our area appear to put financial management as their priority. Residents with dementia are sometimes seen as providing difficulties to other residents and thereby making the village less desirable." (Community care staff)



CONCLUSIONS:

DEMENTIA-FRIENDLY RETIREMENT VILLAGES?

As the prevalence continues to rise, dementia is increasingly a health and social issue that retirement village operators are required to address. However, as demonstrated in this research, there is a tension between this new context and the historical legacy of retirement villages established for independent older people with limited support needs.

People living with dementia have the right to age in place in their own home whether they reside in a general neighbourhood or a retirement village setting. Legally, operators do not have any responsibility to support residents with dementia yet some feel they have a moral obligation to do so. Some operators have a greater sense of duty of care and support their residents than do others, regardless of their physical or cognitive condition.

The ageing baby boomer demographic, the forecast increased number of people developing dementia, the government's ageing in place policy and the community preference for ageing in place are all presenting new challenges for the retirement village sector. Until recently, many retirement villages were designed to offer a 'carefree lifestyle package' with the expectation that residents who developed debilitating illnesses would move to a residential facility that offered an appropriate level of care. There are still those who advertise in this format and avoid the less photogenic aspects of ageing.

However, consumer demand is increasingly placing pressure on the retirement village sector to guarantee a wider range of quality care services that will enable residents to remain in their own home for as long as possible. This study has initiated and clarified the points of the discussion that must take place, both within the retirement village sector, regarding new designs and standards of accommodation, and for the relevant agencies that need to consider to what degree intervention is required to set standards of care, disclosure of services and contract conditions.

As their condition deteriorates, a person with dementia is more vulnerable to confusion. Therefore, to accommodate ageing in place for a growing number of residents with dementia,

villages need to simplify layout where possible and improve signage and security. Village operators, staff and the village community in general all require education to work and live with people with dementia.

This project has identified areas of need for further research on a range of issues with regard to retirement village residents with dementia. These include quality of life indicators, social isolation, community inclusion, and residents' perceptions and expectations of operators.

Based on the findings of this research, Alzheimer's Australia NSW advocates that retirement village operators decide whether or not they will provide dementia-friendly villages. Dementia-friendly communities are defined as "a city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives"^{xli}. This concept can certainly be applied to retirement village settings.

If an operator decides that they do not want to provide dementia-friendly villages, then they must be transparent about this in the marketing and promotion of the village and in the sale of units. It is important not to set up an expectation that a village is a suitable environment for people with dementia if that expectation cannot or will not be met. It then follows that such villages would not accept new residents who have a diagnosis of dementia, and that they would have a clear exit or transition policy for existing residents who develop dementia and require support which can be provided in a residential aged care facility.

If an operator does decide to become a provider of dementia-friendly retirement villages then they need to adjust their business and operating model accordingly. Dementia-friendly retirement villages require an operator to orient their business to an accommodation and care development, in line with service integrated housing models. It also requires

consideration of how dementia fits into this broader organisational strategy. Important elements include partnerships, new business models, staff training, dementia-friendly design, and dementia awareness initiatives for residents.

Operating within a dementia-friendly framework will require innovative, high-quality support and collaboration between retirement village operators, managers and staff, community service providers and a range of support agencies. Some retirement village operators are currently successfully supporting residents with dementia. It is not necessarily about Government policy and funding contexts; it is about operator motivations, priorities, interests and skills. Appropriate village design, policies and structures and well-educated and motivated village managers and staff are not too difficult to achieve, however they do need to be made priorities. A forthcoming research-to-practice guide (to be published in late 2015) will provide guidance to operators who wish to create retirement villages that are supportive and inclusive of residents with dementia.

RECOMMENDATIONS

Based on the findings of this research, Alzheimer's Australia NSW makes the following recommendations:

Australian Government:

1. Allocate funds from the Department of Social Services' *Dementia and Aged Services Grant* to promote dementia awareness, risk reduction messages and healthy ageing in retirement villages.
2. Provide dedicated funding for developing dementia education programs specifically for retirement village operators and staff.
3. Provide pilot funding for capital grants to retirement villages to incorporate dementia-friendly/universal housing design principles and environments in new retirement villages.
4. Issue instruction that the *MyAgedCare* website provide information which clearly delineates the difference between residential aged care and retirement villages to avoid terminology confusion for prospective residents and families.
5. Department of Social Services prioritise allocations of home care packages which provide service integrated housing in retirement villages for people with dementia.

State/Territory Governments:

6. Incorporate reduced developer contributions in State/Territory planning policies for retirement villages that support people with dementia and/or developments that co-locate retirement villages and residential aged care facilities that incorporate dementia-friendly design and environments.
7. When the relevant legislation is next reviewed in each State/Territory ensure that greater clarity and transparency for consumers is achieved.

Retirement Village Industry Peaks:

8. Provide guidance to operators to improve transparency in communication between operators and residents and families.
9. Include dementia education in training delivered to retirement village managers with content development funded by Recommendation 2.
10. Encourage retirement village operators to develop housing that achieves the highest level in universal housing design.
11. Promote the *World Health Organisation (WHO) Age-friendly guidelines* to encourage wider community interaction with retirement villages.
12. Implement a communications strategy to reframe public perceptions and expectations of retirement villages, particularly in relation to their capacity to provide ongoing, high level care and dementia-specific support.

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