

Living Well in an Aged Care Home



Sarah Russell
October 2017



Research Matters
researching issues of health and illness

Living Well in an Aged Care Home

Research report

October 2017

Correspondence
Research Matters
Sarah Russell PhD, BA (Hons)
Principal Researcher
PO Box 1235
Fitzroy North VIC 3070
Email: sarahrussell@comcen.com.au
Website: www.research-matters.com.au

Design and desktop publishing: Kate Jeong, Minuteman Thornbury Design
Front cover photo: Joan Russell at Victoria By The Park
Back cover and page 2 cartoons: Simon Kneebone

© Research Matters. All rights reserved.
ISBN 978-0-646-97844-4

Russell S (2017) "Living Well in an Aged Care Home" Research Matters: Melbourne

Acknowledgements

Firstly, my deepest thanks to all the contributors to this report who so generously shared their insights about the aged care homes they visit. My thanks also to colleagues Judi Kiraly, Stephen Norris, Colin Penter and Kathleen Brasher for their feedback on early drafts of this report. I also appreciate assistance with access to data from the Australian Institute of Health and Welfare. A grant from the Thomas More Foundation financially supported desktop publishing the Living Well in an Aged Care Home report. Its support is greatly appreciated.

Executive Summary

Australians are living longer than at any time in our history. The Intergenerational Report predicts that 40,000 people will celebrate their 100th birthday in 2055 (Commonwealth of Australia, 2015). If history is any guide, around 50 per cent of these centenarians will live in an aged care home.

Aged care homes are places where our most frail and vulnerable older people live. How do we ensure the highest possible standards of care in aged care homes? Some claim a consumer driven and market based residential aged care system will provide 'world class' care; others claim we need effective regulation, government intervention and increased transparency to prevent neglect in aged care homes.

In recent years, there have been numerous government inquiries into aged care homes. Until recently, none of these inquiries included 'standards of care' in their terms of reference. When stories about inadequate personal care, neglect, abuse and negligence are reported in the media, the aged care industry dismisses these stories as 'one-offs'. But are they?

This research project provides evidence about standards of care in aged care homes around Australia. The primary aim was to identify factors that contribute to elderly people 'living well' in an aged care home. The 'living well' concept is based on the World Health Organisation's Active Ageing framework that emphasises six areas of life: social, physical, economic, civic, cultural and spiritual life (World Health Organisation, 2002).

In her essay *Dear life: on caring for the elderly*, Hitchcock (2015, p9) claims: "Supporting independence and wellbeing in old age remains a low priority". She believes ageism is rife in aged care homes, claiming staff, relatives and residents accept ageism. She also believes false assumptions are made about what residents are capable of doing and what they would like to do.

In this study, one hundred and seventy four (174) relatives and visitors from around Australia described what was good about the aged care home(s) they visited. They also described what was not good. By sharing positive and negative views about aged care homes, and suggestions about how residents can have the best possible quality of life, relatives provide a rich source of experiences to inform policy and standards of clinical care.

The report presents a view of aged care homes from the perspective of relatives. Although relatives are not the 'consumer/customer' per se, they are legitimate 'users' of the aged care system. Relatives' views are expressed directly and are unmediated (i.e. they have not been translated into professional language). Although relatives'

perceptions of an aged care home may be seen through the lens of emotions, perhaps grief and sometimes guilt, their views remain valid.

The most reliable indication that an aged care home is providing high quality care is a resident's demeanour. Relatives are reassured when residents are happy, well groomed, pleased to see staff members and call the aged care home their "home".

The research found that aged care homes with high numbers of well-trained, empathetic staff invariably provide high quality care. The physical environment matters less than the personal care. Residents' wellbeing depends on staff having time to deliver genuine person-centred care, irrespective of whether there is a chandelier in the lounge room.

Most of the 2,670 aged care homes in Australia operate under federal legislation. Relevant legislation includes Aged Care Act 1997; Quality of Care Principles 2014 made under the Act; and User Rights Principles 2014 made under the Act. According to the Aged Care Act 1997, aged care homes must "maintain an adequate number of appropriately skilled staff to ensure that the care needs of care recipients are met". Relatives are concerned about the lack of clarity in the federal legislation.

Staff in aged care homes are often hard working, dedicated people doing a very difficult job for not much pay or professional kudos. However, relatives are concerned that personal care attendants (PCAs) provide most of the 'hands on care' in aged care homes rather than registered nurses. They are particularly concerned about PCAs administering medication.

The training of PCAs is variable. Some PCAs gain their qualification to work in an aged care home after completing a Certificate 3 at a reputable training organisation while others complete less rigorous training (e.g. a five-week online course). According to the 2013 audit of registered training organisations, 90 per cent of aged-care courses did not comply with training standards under the Australian Qualifications Framework (Australian Skills Quality Authority, 2013).

Relatives describe residents with health conditions such as dementia, chronic pain, urinary incontinence, heart conditions, diabetes and depression. They claim the management of these complex conditions requires the skill of experienced registered nurses, supported by doctors and allied health providers such as physiotherapists and psychologists. Relatives claim registered nurses are sufficiently trained to manage older people with complex health conditions; PCAs are not.

This study provides evidence that some aged care homes employ an “inadequate number of appropriately skilled staff”. Data indicates some registered nurses are responsible for more than 100 residents; in one example, one registered nurse was responsible for 190 residents. This was described as unsafe.

Relatives also describe low number of PCAs working in some aged care homes. When an aged care home employs a low number of PCAs, there may not be time for staff to walk residents to the toilet or even help them out of bed. Relatives describe feeding, showering and dressing residents because staff are too busy.

Relatives provide examples of hospital admissions they believe were preventable. They blame low staffing levels and the absence of registered nurses for these “*unnecessary hospital admissions*”. Relatives also complain when residents’ incontinence pads are not changed regularly, when bruises or tears appear on skin, and when pressure sores are not treated appropriately, in one case turning gangrenous.

Relatives also complain when residents are chemically restrained. Some relatives suggest anti-psychotic and anxiolytic medication, prescribed by medical practitioners to be taken “prn” (i.e. as needed), are sometimes administered because the aged care home does not employ enough staff to provide diversional activities, particularly in late afternoon when residents with dementia are more likely to experience confusion and agitation (i.e. “sundowners”).

Relatives claim aged care providers have a responsibility to ensure residents have an opportunity to be actively engaged in meaningful, enjoyable activities. It is not acceptable that residents spend their day sitting sedated in front of a TV.

Aged care homes that prioritise activities/engagement employ a high number of trained activity staff – diversional and occupational therapists, social workers and psychologists. Qualified staff provide an extensive range of activities that are not only fun but also meaningful. These activities encourage residents to socialise with each other while providing mental stimulation and/or physical activity, including activities outside in sunlight.

Some aged care homes do not prioritise activities. Rather than employ qualified staff who are able to provide activities for residents with a range of capabilities and interests, they rely on PCAs and volunteers. PCAs and volunteers have neither the training nor expertise to tailor activities to meet an individual resident’s needs. Relatives claim that some activities infantilise residents.

For many residents, meals are the highlight of their day. Some aged care homes provide delicious and nutritious meals catering for individual dietary requirements and residents’ likes and dislikes. Other aged care homes spend less than \$10 per day on meals – these meals not only lack nutritional value, they also are sometimes inedible.

Aged care homes that employ a high number of staff at mealtimes are able to feed residents who require assistance with meals slowly and responsibly. When an aged care

home is short staffed, residents are fed their meals too quickly. This puts residents at risk of choking.

A significant problem for many residents is dehydration. Clearly, it is one thing to serve residents morning and afternoon tea, it is another to ensure that these drinks are actually consumed. One idea is to invite volunteers from the local community to have morning or afternoon tea with residents. This may help to ensure residents drink more. It may also help aged care homes to be connected to people in the local community.

Relatives describe the importance of aged care homes being connected to the local community. However, some providers are building aged care homes on the fringes of cities. The Aged Care Financing Authority (2016), for example, recommends “availability of greenfield sites for the construction of new aged care homes” (p26). Residents living in aged care homes that are built on undeveloped sites on the fringes of cities are isolated from family, friends and the local community.

Many new aged care homes are large with more than 100 residents. A for-profit provider in Brisbane, for example, proposes to build an aged care home for 255 residents in a nine-storey tower (McCosker, 2017). It is not only for-profit providers who are building large aged care homes. Both private and not-for-profit aged care providers are undertaking mergers and acquisitions to achieve economies of scale.

Despite the trend for large multi-storey aged care homes, relatives believe residents receive more holistic care in small aged care homes. Relatives claim small aged care homes often have regular staff who know all the residents well. Relatives also prefer aged care homes to be on a single level because of the absence of stairs/lifts.

The Aged Care Roadmap describes the aged care system transitioning towards a consumer-driven market (Aged Care Sector Committee, 2016). However, the so-called ‘consumers’ living in an aged care home are often vulnerable elderly people, many with dementia. Relatives question how an elderly person with dementia can possibly “*drive*” the residential aged care system without family support. Some claim that both residents and relatives are the “consumers”. Others refer to residents and relatives as “*users of the system*”.

The Aged Care Sector Committee recommends further aged care reforms. According to The Aged Care Roadmap: “Providers are seeking a *lighter touch approach to regulation* (my italics) to allow innovation in how they deliver services” (Aged Care Sector Committee, 2016, p2). Relatives, on the other hand, recommend “*much, much stronger regulation*”. They describe corporate values “*detracting from what should always be a community approach to care*”. They discuss the ethics of some aged care providers (both for-profit and not-for-profit) making large profits.

Relatives recommend improving the accreditation of aged care homes. They are concerned that the current accreditation system relies heavily on paperwork rather

than standards of care. They also claim some aged care homes may know in advance that a 'spot check' has been scheduled. Relatives describe some aged care homes passing accreditation despite poor standards of care.

The publication of this research coincides with a series of media stories alleging incidents of poor standards of care in Oakden (South Australia), Tricare (Queensland), Opal Raymond Terrace Gardens (NSW) and Opal Lakeview (Victoria). The Quality Agency had accredited all four aged care homes. Oakden Older Persons Mental Health Service, for example, had passed three accreditations during the past nine years, despite relatives' ongoing allegations of poor standards of care. Oakden received a perfect score (i.e. passing 44/44 standards) at all three accreditations.

Relatives described the current complaints system as ineffectual. They describe complaints escalating because managers of some aged care homes do not respond appropriately. Relatives appreciate managers who respond quickly and honestly to complaints – irrespective of whether complaints are from a resident or a relative – and welcome a genuine apology. Relatives are also pleased when managers work collaboratively with families and encourage feedback.

In this report, the term 'aged care home' is primarily used though some relatives also use 'aged care facility' or 'nursing home'. Brasher (2016) claims the term 'aged care facility' dehumanises aged care.

Facilities are built to perform functions in the most efficient manner. In contrast, a home is a welcoming place, where friends and family drop in for a cuppa or a chat. (Brasher, 2016)

Report overview

This report is unsettling to read in parts, but that is its value and significance. In a system where policy and practice is dominated by perspectives of government, bureaucrats, providers and professional groups, it is unique to read the views and experiences of people who are at the coalface.

The report begins with some background information about the aged care system including statistics about who operates and who lives in aged care homes. It also provides some information about the aged care reforms, the Aged Care Funding Instrument, the workforce, accreditation and government inquiries.

The next section describes the research method, including its strengths and limitations. A limitation of the study is that participants volunteered themselves for the research. Self-selected samples may be biased toward people with strong opinions. Relatives who are dissatisfied with the standards of care in the aged care home they visit are more likely to complete an anonymous survey than those who are satisfied.

The research findings are divided into four main sections. Firstly, factors that contribute to older people living well in an aged care home. This section concludes

with a summary of factors that reassure relatives that residents are safe in an aged care home.

Secondly, factors that hinder residents' wellness in an aged care home. Relatives' main grievance concerns staffing. Without a sufficient number of well-trained staff, relatives are concerned about residents' safety. Relatives describe poor standards of care, inappropriate activities, inadequate services and low quality meals. They also discuss the ethics of some aged care providers making large profits.

Thirdly, relatives make suggestions about how standards of care in aged care homes could be improved. Unlike the 'pie in the sky' suggestions that consumers commonly make for all health services, relatives made some practical suggestions about how the current standards of care could be improved.

The final section includes suggestions for systemic change within the residential aged care system. Relatives call for greater transparency and accountability. They believe increased government intervention is required to ensure all residents live well and safely in an aged care home.

Table of Contents

Executive Summary	i
Report overview.....	iii
Introduction	1
Background	3
Statistics.....	3
Aged Care Reforms.....	3
Aged Care Funding Instrument.....	4
Aged care workforce.....	5
Regulation of aged care homes.....	6
Government inquiries.....	6
‘World Class’ aged care homes.....	6
Research Method	7
Recruitment.....	7
Data collection.....	7
Sample.....	7
Data analysis.....	7
Strengths and limitations of the research.....	7
Findings	8
Factors that contribute to older people living well in an aged care home	8
Finding a suitable aged care home.....	8
Home.....	8
Staff.....	9
Environment.....	11
Services.....	11
Activities.....	12
Safety.....	13
Factors that hinder residents’ wellbeing in an aged care home	16
Moving into an aged care home.....	16
Institutional care.....	16
Financial costs.....	17
Standards of care.....	18
Environment.....	27
Services.....	29

Activities.....	31
Safety.....	32
Suggestions for improving aged care homes.....	34
Increased resources.....	34
Finding an aged care home.....	34
A home.....	34
A workplace.....	34
Location.....	35
Consumer participation.....	35
Staff.....	35
Person-centred care.....	37
Privacy.....	38
Managing risk.....	38
Working with families.....	38
Communication.....	38
Routines.....	39
Environment.....	39
Services.....	40
Laundry.....	40
Activities.....	41
Systemic change within the residential aged care sector.....	43
Moving into an aged care home.....	43
Current model.....	43
Transparency and accountability.....	45
Accreditation.....	45
Government intervention.....	45
Conclusion.....	48
References.....	50
Appendix 1: Recruitment flyer.....	52
Appendix 2: A personal story of living well in an aged care home.....	53

Introduction

Over the past twelve months, several stories have been reported in the media about inadequate personal care, neglect, abuse and negligence in an aged care home. We hear much less about elderly people who live well in an aged care home.

When residents move into an aged care home, they and their families are aware this is the final stage of their life. Relatives want residents to be happy and engaged and treated with respect and kindness. They also want residents to be as independent as possible and have opportunities to form friendships with other residents and staff.

The primary aim of this research project was to identify factors that contribute to elderly people's wellbeing in an aged care home. Relatives and other visitors were asked to describe what was good about the aged care home they visit, and what was not good. If they could change one thing about the aged care home they visit, what would it be?

Relatives identified staff as the most important factor that contributes to residents' wellbeing. Competent, friendly and empathetic staff – managers, registered and enrolled nurses, personal care attendants (PCAs), as well as kitchen, reception and activities staff – were considered more important than a nicely appointed aged care home.

When an aged care home's primary focus is residents' wellbeing, the aged care home is staffed appropriately so residents receive the quality of care they deserve – and for which they and the government pay. Although there are no mandated staff-resident ratios or skill prerequisites, research findings demonstrate aged care homes with high numbers of well-trained staff provide high standards of care.

In many aged care homes, PCAs provide most of the direct care. Residents' wellbeing depends on PCAs having enough time to deliver genuine person-centred care. The more PCAs on duty, the more likely residents will receive person-centred care that meets their needs. When there is an insufficient number of PCAs on duty, the care is not only task-oriented but also rushed and often thoughtless.

Although many PCAs treat residents with respect and kindness, their training is variable. A review found training programs were too short and provided insufficient time to enable the proper development of all of the competency and skills required to work in an aged care home (Australian Skills Quality Authority, 2013). In some aged care homes, PCAs receive extra on-the-job training. Although this extra training is beneficial, relatives claim the management of complex medical conditions requires registered nurses.

There are many different views about ideal staffing models and levels in an aged care home. Recent petitions

such as “Safe staffing in aged care” and “Mandate aged care staff/resident ratios” call for staff-to-resident ratios. These petitions have more than 63,000 and 59,000 supporters respectively. Others claim ratios are a “blunt instrument”. According to the Productivity Commission (2011):

An across-the-board staffing ratio is a fairly ‘blunt’ instrument for ensuring quality care because of the heterogeneous and ever changing care needs of aged care recipients — in the Commission's view it is unlikely to be an efficient way to improve the quality of care. (p206)

Two recent government inquiries¹ recommend commissioning an independent evaluation of research on optimal staffing models and levels in aged care homes. Given the dearth of rigorous research on optimal staffing models and levels in aged care homes in Australia, this evaluation will need to include international research.

According to relatives, residents have a better quality of life and improved health outcomes when registered and enrolled nurses are on duty in an aged care home. Registered and enrolled nurses have expertise in administering medication, ensuring residents are receiving adequate nutrition and hydration, managing dementia and other challenging behaviours, and supporting residents in their final weeks of life.

Over the past 25 years, numerous research studies have shown a strong positive relationship between registered nurses and standards of care in an aged care home (Harrington et al., 2016). Literature reviews (both systematic and non-systematic) have documented more than 150 staffing studies undertaken in United States, Canada, United Kingdom, Germany, Norway, and Sweden (e.g. Dellefield et al., 2015; Backhaus et al., 2014; Castle, 2008; Bostick et al. 2006). Hongsoo et al. (2011), for example, demonstrated that the presence of registered nurses is a predictor of standards of care. In addition, Horn et al. (2005) found having registered nurses on duty in an aged care home resulted in fewer pressure ulcers, urinary tract infections and admissions to hospital. Preventing unnecessary admissions to hospital is not only in the best interest of residents but also the public purse.

For residents to live well in an aged care home, they need access to meaningful, enjoyable social activities that promote both mental stimulation and exercise. When an aged care home employs a sufficient number of qualified therapists (diversional therapists, occupational

1 The Senate's 'Future of Australia's aged care sector workforce' inquiry and Australian Law Reform Commission's 'Protecting the Rights of Older Australians from Abuse'

therapists, social workers), activities can be tailored to the capability and interests of residents. Also, when a high number of activity staff are employed, activities can be offered during afternoons/evenings and during weekends.

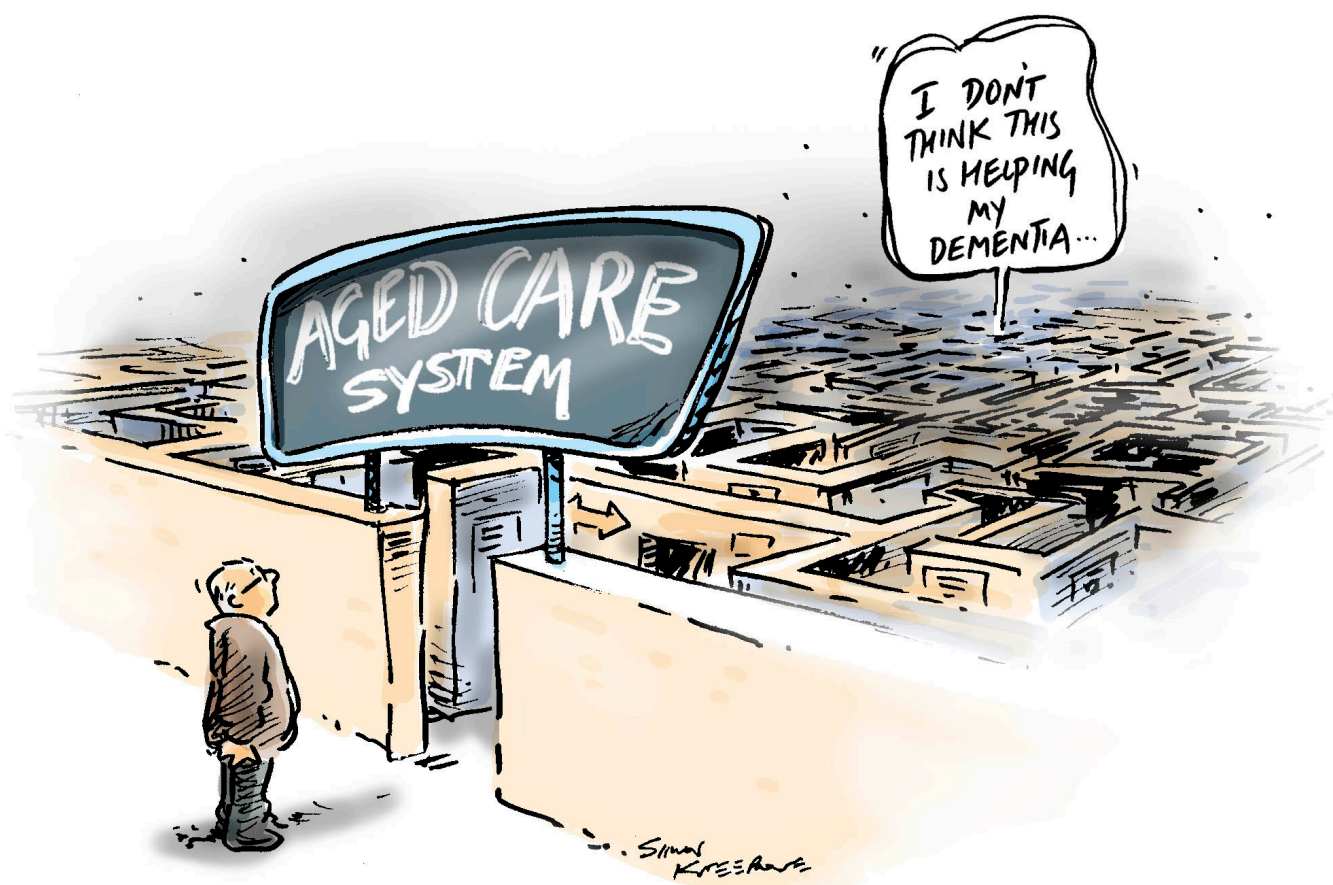
For many residents, meals are the highlight of their day. Relatives spoke positively about meals prepared by a trained cook in an aged care home's kitchen. Some cooks provide a nutritious, varied menu, cater for individual dietary requirements, are mindful of residents' likes/dislikes and serve appropriate portion sizes. Residents like meals to be served at the correct temperature, irrespective of whether they eat in the communal dining room or their private room. Relatives feel reassured when they know residents who require assistance with meals are fed slowly and responsibly.

Relatives value good relationships with management. Managers who are visible in the aged care home are able to get to know residents and their families and provide supervision to the direct care staff. Relatives appreciate management encouraging staff to work collaboratively with them. They also value managers being open to feedback and responding quickly to complaints. Relatives also noted the importance of a genuine apology.

The most reliable indication that a resident is living well in an aged care home is a resident's demeanour. Relatives felt reassured when residents were happy, well groomed, pleased to see staff members and called the aged care home their "home".

The living well concept used in this research is based on the World Health Organisation Active Ageing framework that emphasises six areas of life: social, physical, economic, civic, cultural and spiritual life (World Health Organisation, 2002). The Productivity Commission's Caring for Older Australians (2011) commends the wellness approach.

The Living Well in an Aged Care Home research project provides evidence about 'quality and safety' in aged care homes around Australia. This evidence is required to properly evaluate aged care homes. It is also required to inform policy and clinical care.



Background

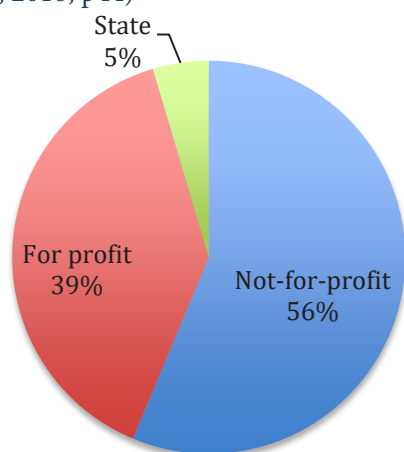
Statistics

- 6.4 per cent of Australians over the age of 65 live in an aged care home.
- On 30 June 2016, 175,989 people were living permanently in an aged care home.
- The average age (on entry) was 82.0 for men, 84.5 for women.
- The average length of time in an aged care home was 34.7 months.
- 50 per cent or more of residents in an aged care home have been diagnosed with dementia.
- On June 30, 2016, there were 2,669 aged care homes in Australia.

(Department of Health, 2016)

Not-for-profit organisations are the main providers of residential aged care (Figure 1). However, the recent Aged Care Approval Rounds (ACAR)² allocated 63 per cent of new aged care places to for-profit providers. This may suggest a shift towards for-profit sector ownership of aged care homes. In addition, some local councils have sold their aged care assets to the private sector.

Figure 1: Ownership of the aged care homes (Department of Health, 2016, p44)



There is a growing trend for both for-profit and not-for-profit aged care homes to be large. According to the Australian Institute of Health and Welfare, the proportion of aged care homes with more than 60 places increased from 56% to 72% of facilities between 2007 and 2014³. Both private and not-for-profit aged care providers are undertaking mergers and acquisitions to achieve 'economies of scale'.

Aged Care Reforms

The main providers of residential aged care used to be religious, community-based and charitable organisations. After the reforms in the Aged Care Act 1997, there was an increase in private investment. Private equity firms, new foreign investors, and superannuation and property real estate investment trusts entered the residential aged care market. Macquarie Bank, AMP Capital, Japara and BUPA, for example, acquired thousands of beds across Australia. According to Ansell (2014), these large investors were attracted to the aged care sector, in part, by "its cottage nature and the potential to introduce scale efficiencies" (p3).

The Aged Care Financing Authority (2015) estimates the residential aged care sector requires an investment "in the order of \$33 billion" over the next decade (p119). To encourage increased private investment in aged care homes, the Productivity Commission Inquiry Report Caring for Older Australians (2011) recommended fundamental reform of the aged care system. These reforms are reflected in the bipartisan Aged Care (Living Longer Living Better) Act 2013. According to the Department of Health Ageing and Aged Care website, the government's vision is "Australia's aged care system will encourage aged care businesses to invest and grow"⁴.

In 2015, the Victorian government introduced the Safe Patient Care Act. This Act prescribes ratios of registered nurses for the 30 or so state owned aged care homes. On the morning shift, one registered nurse is required for every seven residents; in the afternoon, one registered nurse for every eight residents; and on the night shift, one registered nurse for every 15 residents.

In contrast to the Victoria legislation, there is no federal legislative requirement for aged care homes in Australia to have staff-to-resident ratios or skill prerequisites. In the Aged Care Act 1997, the Quality of Care Principles 2014 state: "The service provider manages human resources to ensure that *adequate numbers of appropriately skilled and trained staff/volunteers* (my italics) are available for the safe delivery of care and services to service users" (Section 1.7).

Determining what is "an adequate number" and what qualifications determine "appropriately skilled and trained" is at the discretion of the provider and overseen by the Quality Agency. There is no legislative requirement that a registered nurse be on duty in an aged care home at all times. There are several aged care homes around Australia, in both rural and urban areas, that have a registered nurse 'on call' but not 'on site' during the afternoon and night shifts.

² The 2016-2017 aged care approval rounds (ACAR) created 9911 new aged care places.

³ <http://www.aihw.gov.au/aged-care/residential-and-home-care-2013-14/services-and-places/>

⁴ <https://agedcare.health.gov.au/ageing-and-aged-care-aged-care-reform/why-is-aged-care-changing>

Aged care homes formerly known as ‘high care’ homes were required to have a registered nurse on duty at all times. This requirement was made inoperable after the Commonwealth removed the distinction between high and low care. Removing the distinction between high care and low care homes supported ‘ageing in place’ – residents could transition from low to high care without needing to move into a new aged care home.

Aged care homes formerly known as ‘high care’ homes generally had more staff than low care homes because residents had higher care needs. Removing the distinction enabled aged care home previously classified as low care to accommodate residents with high care needs, though there was no legal requirement for staffing levels to increase. They were required, like all other aged care homes, to have an “adequate (my italics) numbers of appropriately skilled and trained staff/volunteers”.

In 2017, a bill to reinstate the requirement to have a registered nurse on duty at all times in NSW aged care homes passed the NSW Upper House unanimously but not the Lower House. Members of Parliament who opposed the ‘RN 24/7’ bill expressed concern that the requirement to have a registered nurse on duty at all times would have a negative impact on the viability of aged care homes, particularly those in rural areas.

Aged Care Funding Instrument

The Aged Care Funding Instrument (ACFI) classifies residents depending on their care needs. ACFI focuses on three different areas of care – activities of daily living, cognition and behaviour, and complex health care. There are 12 questions about assessed care needs, each with four ratings (‘high’, ‘medium’, ‘low’, and ‘nil’).

ACFI appraisals have been used since 2008. Between 2008 and 2014, an overall care need (high or low care) was recorded. According to Australian Institute of Health and Welfare website⁵, the proportion of high care classifications increased during that period. In 2009-2010, 71 per cent of people in permanent care had an ACFI classification for high care. At 30 June 2014, 83 per cent of people in permanent care had an ACFI classification for high care.

An overall care need level (high or low care) is no longer recorded. Instead, care need ratings in each of the three ACFI domains (activities of daily living, cognition and behaviour, and complex health care) are recorded.

The changes in care need ratings between 2009 and 2016 are illustrated in Figures 2, 3 and 4. These graphs were downloaded from the Australian Institute of Health and Welfare GEN Aged Care Data website⁶. They show an increase in high care needs in each domain since 2009. The most significant increase has been in the complex health care domain.

Figure 2: Care need ratings of people in permanent residential care for Activities of daily living, 30 June 2009–2016

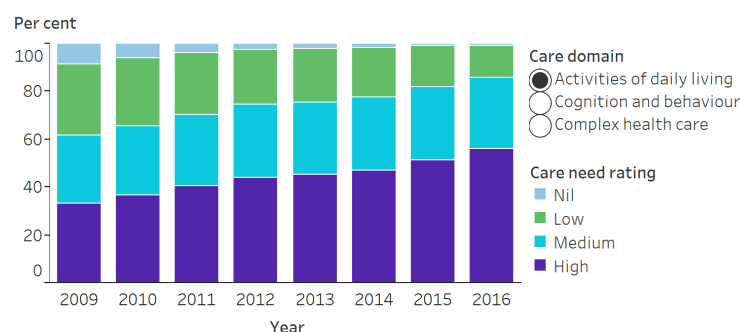


Figure 3: Care need ratings of people in permanent residential care for Cognition and behaviour, 30 June 2009–2016

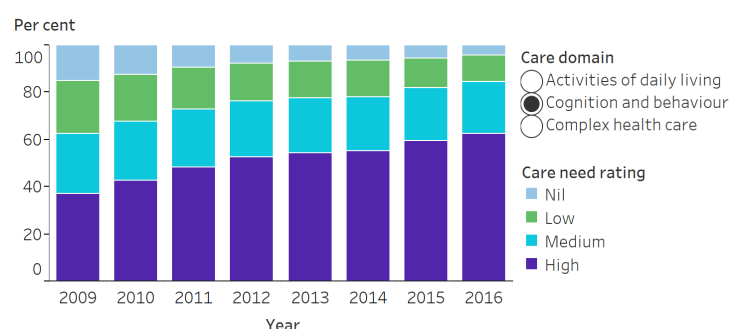
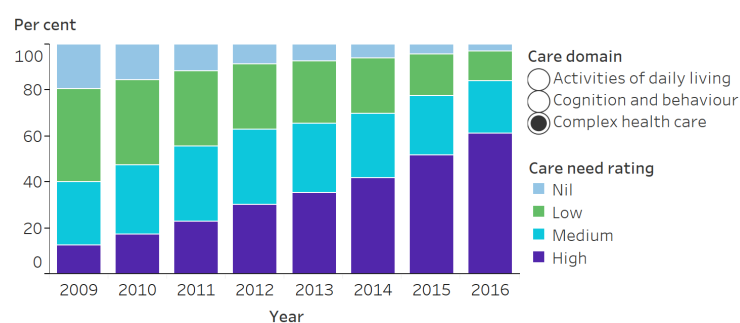


Figure 4: Care need ratings of people in permanent residential care for Complex health care, 30 June 2009–2016



An aged care home receives higher federal government subsidies for residents with high care needs. Higher funding relates to individual needs and drivers of costs. The Specified Care and Services Schedule outlines what is to be provided to all residents and to those with high care/complex health needs. The Schedule forms part of the Aged Care Act.

ACFI is criticised because providers do their own assessments for government subsidies. To ensure residents are correctly funded for their care needs and to protect public expenditure, the Department of Health conducted 15,763 reviews of ACFI claims in 2015–16. Of these reviews 2,500 (15.9 per cent) resulted in reductions in funding and 120 (0.8 per cent) resulted in increased funding. (Department of Health, 2016).

5 <http://www.aihw.gov.au/aged-care/residential-and-home-care-2013-14/care-needs/>

6 <https://www.gen-agedcaredata.gov.au/Topics/Care-needs-in-aged-care/Explore-care-needs-in-aged-care>

ACFI is also criticised because it is based on a 'terminal decline model' rather than 'restorative care'. Providers receive higher government subsidies when residents' health declines, not when it improves. There is no financial incentive for providers to focus on residents' wellness by providing services such as strength training or lifestyle programs that would improve residents' quality of life.

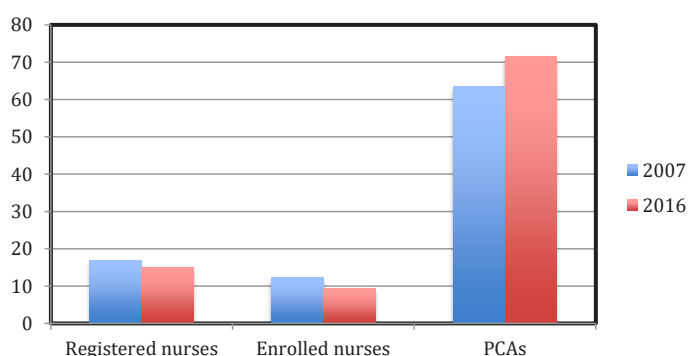
When the higher funding is used to provide extra care (e.g. registered nurse, physiotherapist), residents whose needs increase can be managed well at the aged care home. However, when this higher funding is not spent on extra care, residents may have unnecessary transfers to hospital when their health deteriorates. Once again, there is no financial incentive for providers to provide extra care that may prevent a resident being transferred to the Emergency Department because the state government, not the provider, funds these unnecessary trips to hospital.

Aged care workforce

During the past decade there has been a shift in the composition of the residential aged care workforce. There has been a decrease in registered and enrolled nurses and an increase in PCAs.

In 2007, registered nurses accounted for 16.8 per cent of the aged care workforce, enrolled nurses 12.2 per cent and PCAs 63.6 per cent (Martin and King, 2008). According to the 2016 National Aged Care Workforce Census and Survey, registered nurses now account for 14.9 per cent of the aged care workforce, enrolled nurses 9.3 per cent and personal care attendants (PCAs) 71.5 per cent (Mavromaras et al. 2017).

Figure 5: Comparison of ratios of registered nurse, enrolled nurses and PCAs in 2007 and 2016



The staffing profile of aged care homes today does not reflect the increase in high care needs of residents (as described in the previous section on ACFI). If it did, there would have been an increase in the number of registered nurses to manage the increased level of care needs. Instead, the number of registered nurses has decreased while the number of less-skilled personal-care attendants has risen.

Staffing costs are the main outgoings for operating an aged care home. A grade 5 registered nurse costs approximately twice as much as a PCA. Costs also increase on afternoon, evening and weekend shifts because penalty rates apply.

There is a significant difference in training between registered nurses and PCAs. Registered nurses complete a three-year bachelor degree at university and enrolled nurses complete an 18-month diploma. Both are registered with the Nursing and Midwifery Board of Australia and must meet registration standards in order to practise.

PCAs have a Certificate 3 in Aged Care. The training of PCAs is variable: some PCAs gained their qualification to work in an aged care home after completing a Certificate 3 at reputable training organisations while others completed less rigorous training (e.g. a five-week course). Some PCAs undertake additional credential training (e.g. Medication Management course).

According to the 2013 audit of registered training organisations, 90 per cent of aged-care courses did not comply with training standards under the Australian Qualifications Framework (Australian Skills Quality Authority, 2013). No registration body oversees PCAs.

Registered and enrolled nurses are trained to assess, monitor and manage complex medical conditions. PCAs on the other hand are responsible for residents' personal hygiene, such as showering and toileting. They also provide assistance with meals and mobility.

When PCAs observe changes in a resident's behaviour or health, they should report these changes to a registered nurse. When a registered nurse is on duty, changes in health status can be managed well (e.g. GP and family contacted). However, when no registered nurse is on duty in the aged care home, residents may not receive timely treatment when their condition changes. This may result in a resident experiencing significant distress or pain, a preventable transfer to hospital or, in some cases, death.

During the past decade (i.e. the same period that there has been a shift in the composition of the residential aged care workforce), the incidence of premature and potentially preventable deaths of residents in aged care homes has increased (Ibrahim et al. 2017). Ibrahim et al. (2017) found the most frequent causes of death were falls (82%), choking (8%) and suicide (4%). Whether there is a connection between the increase in premature deaths and changes in workforce composition that have occurred during the same time frame is debateable.

Russell (2017), for example, claims residents may:

- Fall over because there is lack of staff to supervise residents when they walk (e.g. walk to the toilet);
- Choke because staff do not have time to feed residents slowly and responsibly or because residents with a poor swallowing reflex (e.g. after a stroke) are given inappropriate food;
- Become disengaged, depressed and potentially suicidal due to a lack of meaningful activities being provided in an aged care home.

However, Dr Stephen Judd, chief executive of HammondCare, claimed: “All life is about risk; we have to encourage people to enjoy life, not just keep themselves hermetically sealed in a life of boredom. Rather than trying to eliminate risks, we must manage risks intelligently.” (Colyer, 2017)

Regulation of aged care homes

According to the Department of Health, “Commonwealth legislation establishes processes for the regulation of care delivered to all aged care residents and to ensure providers deliver appropriate care that meets expected standards. These include processes dealing with aged care accreditation, monitoring, review, investigation and complaints”⁷.

In 2017, a review of Commonwealth aged care regulatory processes was announced in response to the failures in the quality of care delivered at the Oakden Older Persons Mental Health Service in South Australia. The review will examine why regulatory processes did not adequately identify the systemic and longstanding failures of care at Oakden. The aim of the review is to improve Commonwealth regulatory processes so that people in residential aged care facilities are safe, well cared for and have a good quality of life. The reporting date is 18 February 2018.

The accreditation process is designed to monitor the standards of care in all aged care homes, including whether adequate numbers of skilled staff are employed. The current accreditation standards and outcomes include phrases such as “adequate nourishment and hydration”, “effective continence management”, “optimum levels of mobility” and “an adequate number of suitably qualified staff”.

The current accreditation standards are vague. For example, what is “effective continence management”? Is it regularly helping a resident to go to the toilet? Or is it ensuring incontinence pads are changed regularly? If it is the latter, how often should an incontinence pad be changed to ensure continence management is “effective”?

In 2005, a Senate committee held an inquiry into the aged care sector. Their report *Quality and equity in aged care* was critical of the accreditation standards of aged care facilities, finding them too generalised to effectively measure care outcomes. The committee acknowledged that a rigorous evaluation of a health service requires measurable outcomes. Part of Recommendation 14 stated: “that the Commonwealth, in consultation with industry stakeholders and consumers, review the Accreditation Standards to define in more precise terms each of the Expected Outcomes”.

If the federal government had acted upon this recommendation, Australia may have a rigorous and robust accreditation system with standards and outcomes that provide the degree of precision necessary to perform an accurate measurement. However, like many other government inquiries, recommendation number 14 of the *Quality and equity in aged care* Senate Inquiry was not acted upon.

Government inquiries

The publication of this report coincides with numerous reviews and a federal government inquiry. The government has reassured the public that these reviews/inquiries will be undertaken transparently and include genuine consumer consultation with both residents and relatives.

During the past decade, there have been numerous government inquiries, reviews and consultations into aged care. These have resulted in countless recommendations to improve aged care homes and minimise the risk of elder abuse. Although economic reforms have been translated into action, only a few recommendations to improve delivery of care have been actioned.

The current government inquiry⁸ is one of few inquiries/reviews to include ‘standards of care’ in the terms of reference. Although ‘standards of care’ was not included in the terms of reference of the recent *Future of Australia’s aged care sector workforce* inquiry, the inquiry received 73 submissions from staff and relatives who indicated they are extremely concerned about standards of care in aged care homes (Commonwealth of Australia, 2017).

The Aged Care Legislated Review was tabled in parliament on 14 September 2017. The Review looked at the impact and effectiveness of the Living Longer Living Better aged care reforms. Although quality of care is an important indicator of the effectiveness of the reforms, ‘quality and safety’ were outside the scope of this Review. It was surprising therefore that this review concluded: “there is no evidence to suggest that there has been a decline in the quality of care since the Living Longer Living Better reforms” (Department of Health, 2017, p 187).

‘World Class’ aged care homes

It is often claimed that Australia’s residential aged care system is “amongst the best in the world” (e.g. Underwood, 2016). It is not clear, however, what criteria is used to make these claims. It is also not possible to test these claims without data.

There are many examples of innovation in residential aged care homes overseas. A Dutch aged care home, for example, established a program providing free rent to university students in exchange for 30 hours a month of their time “acting as neighbours” with aged residents (Harris, 2016). As part of their agreement, students also spend time teaching residents new skills – such as how to email, use social media and Skype.

In addition, the United Kingdom undertook an experiment of introducing four-year-olds to an old people’s home (Stewart and Johnson, 2017). The results showed marked improvements in the residents’ physical ability and mood.

A systematic, comparative evaluation of Australia’s aged care homes with those in other countries, such as The Netherlands and United Kingdom, requires the development of an evaluation framework with measurable outcomes. The obstacle to undertaking such a systematic analysis is the lack of measurable outcomes in aged care homes in Australia.

7 <https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes>

8 Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised.

Research Method

Recruitment

A community engagement method was used to recruit people who visit an aged care home. Opinion pieces in newspapers, television appearances and radio interviews encouraged people to visit the Aged Care Matters' website. The recruitment flyer was published on the Aged Care Matters website (Appendix 1). Flyers were also circulated at aged care homes and via email. A snowball technique was also used (i.e. participants told other 'potential participants' about the project).

Data collection

Data was collected via a survey uploaded to Survey Monkey on 28 July 2013. The survey was disabled on 31 March 2017.

Participants were invited to complete an online questionnaire. The questionnaire contained 12 open-ended questions. Participants were also invited to make additional comments.

Although the survey was anonymous, several participants provided their name and email address on the survey. Some participants provided additional information about the aged care home they visited via email. This additional data has been included.

Table 1: Questionnaire

1. What do you like about the aged care facility (or facilities) that you visit?
2. What don't you like about the facility (or facilities) that you visit?
3. If you could change ONE thing to improve services in aged care facilities, what would you change?
4. What do you like about the physical environment (e.g. rooms, lounge, dining room, outside area)?
5. How could the environment be improved?
6. What do you like about the personal care (including the medical and nursing care)?
7. How could the personal care be improved?
8. What do you like about the services (e.g. meals, laundry, hairdressing)?
9. How could the services be improved?
10. What do you like about the activities?
11. How could the activities be improved?
12. What things reassure you that residents are safe in the aged care facility?

Sample

The sample contained 174 participants.

Although 185 people completed the questionnaire, 11 respondents were excluded: 9 because they were employees in an aged care home (8 registered nurses; 1 PCA); 2 visited an aged care home in a professional capacity (1 GP, 1 pastoral carer).

Data analysis

The data contained 70,000 words. Data were critically analysed using thematic analysis. This method of analysis is a qualitative research method that is used to generate common themes. The aim was to produce themes that were solidly grounded in the data.

Strengths and limitations of the research

One of the strengths of this research is that it explored non-professional perspectives of aged care homes. A further strength of the research is that the researcher does not work in the aged care sector or for a government agency. This allows for analysis of the data without any conflicts of interest.

The researcher, Dr Sarah Russell, is the Director of Aged Care Matters. Aged Care Matters promotes dialogue between residents, relatives, staff, providers and government. Aged Care Matters does not receive funding from any source. Sarah's personal experiences visiting her mother in an aged care home – what was good about the aged care home and what was not good – is provided in Appendix 2.

A further strength of this research is the survey was anonymous. An anonymous survey enables participants to be 'frank and fearless'. Research shows a disinclination for people to be critical of health services in face-to-face interviews because of not wanting to jeopardise their treatment/care.

A limitation of the study is that participants volunteered themselves for the research. Self-selected samples may be biased toward people with strong opinions. Anonymous surveys result in higher reporting of dissatisfaction than identifiable face-to-face methods. Relatives who are dissatisfied with the standards of care in the aged care home they visit are more likely to complete an anonymous survey than those who are satisfied.

Findings

In this section, all text in italics is a direct quote from a participant. In longer quotes, a number identifies the specific participant. An effort has been made to ensure that all participants have a voice, and that no individual participant dominates the discussion.

A sample size of 174 is large for a qualitative study and allows some confidence that a wide range of views is represented. However, the results of the research are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

As is customary in reporting qualitative data, terms such as “most”, “the majority”, “more than 50%” etc. are not used. Rather than quantify the responses, the intention is to present in-depth insights. To indicate a small number of participants the descriptor “some” is used to indicate less than five participants and “several” to indicate between five and twenty participants. When more than twenty participants share a specific insight, a general descriptor “relatives” is used.

Factors that contribute to older people living well in an aged care home

Finding a suitable aged care home

Several relatives described aged care homes as “*greatly improved with more options available*”. These relatives remembered aged care homes as “*dull and depressing*” and “*smelling of urine*”.

The aged care home I visit is welcoming, friendly, clean, comfortable, secure and safe. Staff are skilled and supportive of residents, family members and each other. Strong ongoing staff training policy. Excellent activity programs for residents. It is a very well run organisation, excellent management structure, good facilities and caring staff. (Participant 150)

Local community

Relatives described the importance of older people remaining in their local community so they could remain connected to family, friends and familiar local health professionals.

Close to family and friends so the resident does not lose contact with people she is used to have visiting her... This helps to ensure lots of familiar faces and also the families of each resident look out for each other. (Participant 49)

Nonetheless, some relatives chose an aged care home in a new suburb. Although remaining in a familiar community and being close to family was considered to be an important factor when choosing an aged care home, the most important consideration was the standards of care.

Although the aged care home may be in a new community, it was considered important for residents to be involved in the local community (e.g. parks, coffee shops) and for people/groups in local community to regularly visit the aged care home.

Local school kids come in weekly. Residents are encouraged to be involved in community groups and activities and there is a regularly updated newsletter produced by residents that includes this information. (Participant 155)

Home

Relatives felt a sense of relief when residents were “*well and happy*”. They were pleased when residents called the aged care home their “*home*”.

Aged care facilities vary greatly but the culture and staff are a fundamental thing to create a homely and safe environment. Nothing can replace home but the aged care facility that my father is in has also become his home. My mother visits every day and engages with the staff and activities. (Participant 153)

Some relatives described residents receiving more attention living in an aged care home than they did in their own home with family support.

Residents have a measure of security that they don't have when living alone, no matter how frequently family can visit. Medication needs are supervised. Personal care is supervised. (Participant 156)

In some cases, health and wellbeing improved after an elderly person moved into an aged care home. Relatives attributed this to personal care, company, engagement and having a routine. They described a “*sense of community*” in which residents formed genuine friendships with each other and with members of staff.

Personal care staff are such an important part of the residents' life... because they are right there each day in their lives. I see how fond Mum is of the ones that demonstrate appreciation of the resident as an individual, an equal and take the time to form an individual friendship. I also appreciate and enjoy it when staff make an effort to connect with Mum's family and friends - it shows an understanding

that they now play an important part in the social relationships that exist for the resident. (Participant 128)

Relatives described residents having a sense of ownership of “their home” when they were given opportunities to contribute to management decisions. For example, both residents and relatives felt empowered when decisions and suggestions at residents’ meetings were taken seriously. They were also pleased when both feedback and complaints were acted upon. Some aged care homes kept formal minutes of residents’ meeting with actionable items.

Many residents are still completely able to make all their own decisions and participate in decisions within the care home. (Participant 109)

Ageing in place

Aged care homes that offered ‘ageing in place’ accommodate residents with a range of different needs. Several relatives described ageing in place as working “brilliantly”. Most importantly, when older people needed a higher level of care, they did not need to be moved. They remained in the same environment with familiar staff.

The facility allowed them to be together offering high care and low care (separate rooms). Very important transition I think. The staff (both management and carers) were very nice, caring, personal and flexible. The level of nursing care for Dad was impressive. They cared, were kind... Dad was trapped in a paralysed body, unable to eat by himself, unable to read, barely able to speak. Mum on the other hand was still very able and we were encouraged to make her quarters as homely as she would like. Management were very flexible with the rules for her, respecting her need for independence and dignity, but still giving her a level of care that she never realised she could have had living independently in her home. If anything I think she actually found a new sense of freedom, no longer having to be a housewife. (Participant 128)

Ageing in place provided relatives with the reassurance that familiar staff would care for them and their families when their loved one was dying.

I know that, unless there are extenuating circumstances, my relative will die in that facility rather than a hospital, and this process will be conducted with expert care in both a social and medical sense. My relative will therefore die ‘at home’, hopefully surrounded by those who love her, and not in some horrible clinical setting like a hospital. (Participant 154)

Staff

Managers, registered nurses, personal care attendants (PCAs), as well as kitchen, cleaning, reception and activities staff all play a crucial role in ensuring older people live well in an aged care home. Relatives appreciated staff who

were competent, courteous, caring and friendly and who respected residents.

When an aged care home employed a high number of well-trained staff, relatives felt confident that residents would receive high standards of care. Relatives also noted the importance of continuity of care. Regular staff noticed changes in residents’ behaviour/health status, and intervened early.

They care about residents, they enjoy them, they actually get to know them and therefore they know or recognise when something is ‘out of character’ for someone or they are beginning to get sick. (Participant 154)

Some residents and their families formed a “real connection” with regular staff. The regular staff invested time to understand residents – their interests, quirks, strengths etc. – and also to get to know their families.

Residents know the regular staff and become very attached to them. My mum hugs them every time she sees them. The staff are very caring. (Participant 24)

Relatives commented about how specific staff – managers, clinical care managers, registered and enrolled nurses, PCAs, receptionists, cleaners, kitchen and activity staff – helped residents to live well in an aged care home.

Managers

Managers were described as the foundation of an aged care home. A well-run aged care home had managers who were collaborative, good communicators, empathetic and visible. Although managers need to spend a significant amount of their time in their office, relatives were reassured when they saw managers “on the floor” supervising staff. They also appreciated managers who collaborated with residents’ families.

The calm manner of the manager and her down to earth approach is great. She is open to suggestions and acts on concerns. She appears to genuinely love the industry and loves making a difference. She takes the time to talk to everyone and her staff. (Participant 132)

Managers are responsible for staff morale. Relatives described morale as a factor that contributed to the standards of care in an aged care home. When staff morale was high, standards of care were generally high (and visa versa). A manager who created a happy workplace – in which staff are encouraged to use their initiative – invariably created a happy home for residents.

Clinical care manager

A competent clinical care manager knew each resident’s medical history. They met regularly with relatives and responded respectfully to any concerns. They developed care plans collaboratively with residents, their family and medical practitioner, and updated care plans each year.

The care manager meets regularly with me to discuss my mother's wellbeing and any concerns regarding her health both mental and physical. (Participant 176)

Registered and enrolled nurses

Registered nurses are trained to assess, monitor and manage complex medical conditions. Relatives described “feeling lucky” when registered and enrolled nurses were on duty.

I like that registered and enrolled nurses staff the facility that I visit daily. I have had previous experience in a facility that had mainly PCAs. The difference in care regimes is worlds apart. PCAs do not have the skills to recognise and manage the comorbidities that exist in frail older people and those living with dementia. They cannot report accurately to registered nurses because in most case they have no idea what they are seeing. No medical knowledge leads to people suffering needlessly. (Participant 10)

Relatives were reassured when registered nurses were responsive to suggestions from residents and family members. Some relatives described registered nurses working collaboratively with both residents and their families.

From what I've seen, registered nurses are responsive to care requests of residents and relatives. They take clinical concerns seriously rather than make you think that you don't know what you're talking about. They welcome feedback. They don't try to prevent relatives from "interfering" which I've heard about in other facilities. (Participant 127)

Personal care attendants (PCAs)

The best aged care homes had a high number of competent and caring PCAs working alongside registered and enrolled nurses. Relatives described PCAs working extremely hard for not much pay.

Relatives valued PCAs with compassion, empathy, gentleness and kindness. They also appreciated PCAs who were thoughtful, friendly and treated residents respectfully.

Most of the PCAs are compassionate people who genuinely care for my mother and provide her with love, and work extremely hard under difficult conditions. (Participant 34)

PCAs who were both well trained and experienced created a level of trust that residents would receive high standards of care.

With only the very occasional exemption, the carers are very considerate and well trained. Each of them has formed a bond with my mother so that she feels comfortable in their care. She trusts that they are there to take care of her needs. (Participant 176)

In addition to helping residents with their activities of daily living (toileting, showering, dressing) some PCAs made an extra effort to engage residents in things that interested the resident (e.g. sport, old movies, current affairs).

The staff are fabulous and treat him like he is their father... Dad loves discussing his footy tips with some of the staff. (Participant 68)

Receptionist

Relatives appreciated being met at the entrance of the aged care home by a friendly receptionist. Receptionists who found time to chat with residents and their families, and show an interest in their lives, were highly valued.

Receptionists were generally employed only during normal work hours. During that time they monitored the front door to ensure that residents did not inadvertently leave the aged care home.

Kitchen staff

Kitchen staff were not only responsible for preparing and serving meals, but also for creating a pleasant, cheerful and relaxed environment in the dining room. Relatives described kitchen staff as friendly, kind and considerate.

It was important for kitchen staff to know residents' food preferences, serve them food they liked to eat that was appropriate for their culture and/or religion and to give them the correct size portions. Relatives appreciated kitchen staff knowing the residents' name when they served them their meals.

The home has its own chef. He is great and the meals are nutritious and delicious. The chef has taken the time to learn residents' likes and dislikes. The kitchen team are all friendly. They know all the residents' names. (Participant 25)

Activity staff

Residents enjoyed a higher quality of life when they were engaged in meaningful activities. Some aged care homes employed qualified diversional or occupational therapists who had experience working with people who had a range of physical and mental abilities.

Relatives described activities for mental stimulation (e.g. quiz), emotional wellbeing (e.g. oral histories) and physical strength (e.g. exercise class). However, not all residents had the mental or physical capacity to engage in these activities. A skilled therapist would find activities that were suitable. In addition, not all residents wanted to participate. A skilled therapist would encourage participation, but also respect a resident's decision not to participate.

Activity staff were fun, friendly, imaginative, patient and enthusiastic. They work really, really hard to find interesting things for all the residents. (Participant 84)

Environment

According to relatives, the physical environment of many modern aged care homes was as close to a home-like environment as possible. The distinctive smell of urine that was associated with older aged care homes was absent.

Design of aged care home

Relatives described some aged care homes as being well designed – spacious and visually attractive with a homely ambience and lots of natural light. Some aged care homes resembled a hotel.

When you walk in it has a good 'feel' about it - clean, well maintained and comfortable. There are private areas as well as communal spaces for residents. Areas (inside and outside) can be zoned/closed off to allow separation between residents. Dogs are welcome visitors. It is secure and safe (dementia unit) without looking like a prison. (Participant 150)

Relatives described smaller aged care homes as “more homely”. They also preferred aged care homes that were built on a single level. They claimed the absence of stairs/lifts made the aged care home safer.

The accessibility: it's all on one level - no stairs or lifts. The environment is wheelchair and mobility friendly, light, airy, spacious, clean. (Participant 155)

Residents' rooms

Relatives described residents' rooms as comfortable and homelike, particularly those that contained furniture from home and decorated with personal items. Importantly, bathrooms were well designed for wheelchairs and walkers and had non-slip floors.

My mother's room is delightful. It faces north with a lovely window out onto a garden with a large camellia that she loves. The room is nicely furnished, not hospital like at all. (Participant 144)

As the room is decorated by our personal things, it is a lovely space that we all enjoy visiting...I like the fact that the room also has a kitchenette and small living room. Great for the grandkids to visit in private. (Participant 147)

Lounge rooms

Relatives described lounge rooms in some aged care homes as spacious with comfortable places to sit and talk. Relatives liked the openness of the communal spaces, particularly those with natural light. They were suitable spaces for concerts and pop up stalls (e.g. clothes stalls).

Big rooms, floor to ceiling windows, plenty of natural light, a view onto the garden and public area park where people walk their dogs. Clean and tidy public areas, all facing outside gardens. (Participant 28)

Some aged care homes provided rooms for family gatherings.

There are a number of general lounge areas that are great for family gatherings if you want the option to celebrate an event [at the aged care home] instead of taking the resident out. (Participant 5)

Dining room

The dining room in some aged care homes was a welcoming space that provided residents with an opportunity for social interaction with other residents. Having a named place at the dining table assisted the social interaction – so residents could be addressed by their name.

Dining rooms with named place mats for each resident - it helps them remember each other's name and also to confirm they are at the right table. Helps family members visiting one resident to get to know the others in the dining room and be able to address them by name in a friendly manner. The residents respond well to being addressed by their own names even if they don't know who is speaking to them. (Participant 49)

Garden

Access to outside areas gave residents the opportunity to enjoy the garden on their own and have access to “fresh air”. Some aged care homes grow seasonal flowers/vegetables and have chickens.

There are multiple outside garden areas to access, some secure that are great for residents with dementia. They are well maintained and have seasonal plantings. (Participant 5)

Animals

Relatives appreciated being encouraged to bring their dog to visit residents.

They welcome our family dog in all areas of the nursing home and residents love being with her. (Participant 140)

Some aged care home had their own animals on site - including cats, dogs, fish and birds. Relatives felt animals made the aged care home feel more like home, particularly for residents who had always had a family pet.

Services

Some aged care homes encouraged residents and relatives to provide feedback and make suggestions about ways to improve services (e.g. surveys, suggestion box). Relatives appreciated management wanting their ideas for improving the quality of services, particularly when the gesture was genuine (i.e. not a token gesture).

The services are of high quality. Regular surveys of relatives regarding quality of meals, laundry etc. Unit Manager and staff continually exploring ways to improve services. (Participant 150)

Hairdressing

A private contractor often provided on-site hairdressing services. Relatives described this service as excellent. Hairdressers were caring, patient, empathetic and accommodating. Most importantly, they were not rushed. Spending time being pampered by a hairdresser was good for residents' self esteem.

The hairdresser is the only person working in the aged care home that is not rushing. She is able to spend more time with residents than other staff. She often chats and laughs with residents. (Participant 112)

Meals

Meals were often the highlight of a resident's day. Relatives spoke positively about meals prepared by a trained cook in the aged care home's kitchen. It was important that meals were served at the right temperature, irrespective of whether residents ate in the communal dining room or their own room. Some cooks provided a nutritious and varied menu, catered for individual dietary requirements (and remembered residents likes/dislikes) and served appropriate portion sizes.

Lunch was often the main meal of the day. In some aged care homes, relatives ate in the dining room with residents.

Meals are generally nutritious with the main meal in the middle of the day and a choice of two main courses and two desserts. There is a range for breakfast with a hot option each day. The evening meal always has a soup first which is a good way to get a serve of vegetable in to most people then a choice of two lighter options. (Participant 2)

Relatives described the best thing about meals in an aged care home was the fact that residents did not have to cook them. Some however were delighted that residents were able to cook snacks because it was a meaningful activity.

Residents are encouraged to cook light snacks/scones and the kitchen is made available at certain times for this purpose. Supervision is on hand only if needed for safety purposes, otherwise residents are autonomous. (Participant 155)

At some aged care homes, the bus outing may occasionally include a meal at the local Chinese/Italian/Indian restaurant or local pub. Aware that not all residents are able to go on these outings, some aged care homes also arranged take-away fish and chips, pizza or MacDonald's meals for residents who may be interested.

Activities

Encourage participation

An aged care home that prioritised activities provided both group and individual activities. The challenge was sometimes motivating residents to participate in these activities. In some aged care homes, activity staff went

from room to room to encourage participation. Family and friends were also encouraged to attend activities.

The centre regularly organises activities and outings which, even though my mother may not wish to take part in, at least she has a choice and is encouraged to participate when possible. (Participant 176)

Participation also involved aged care homes having equipment (e.g. wheelchairs) so that residents who spent most of the time in their room could attend group activities (e.g. concerts).

Range of activities

Some aged care homes provided an extensive range of activities that were not only fun but also meaningful. These activities encouraged residents to socialise with each other while providing mental stimulation and/or physical activity.

They are extensive and varied. High priority given to activities recognising that they are important for residents everyday active engagement and enjoyment but also their role in maintaining residents' self esteem, dignity and sense of purpose. Daily 'work' roles are encouraged - setting dining room tables, folding washing, cutting up vegetables for soup, watering the garden. Activities are well planned with great variety - include in-house morning and afternoon sessions, arts- and sensory based, walks around the neighbourhood and regular small bus trips (e.g.: for lunch at local RSL, trips to the beach for fish & chips, visits to music events and other sites of interest. Annual 7 day holiday at Phillip Island is a fantastic time for residents supported by staff and relatives and financially supported by the Aged Care Facility. (Participant 150)

Some relatives described the activities' program as having "something for everyone". This was challenging given residents' range of capabilities and interests. The most common activities provided were:

- Exercise class
- Bus trips
- Special days
- Concerts

Exercise classes

Residents were encouraged to attend exercise classes. These classes not only had health benefits but also were fun.

The exercise classes seem to be popular and are tailored to those with limited mobility. I've noticed the health benefits of these in my grandmother (despite the fact that she was really reluctant to take part in them when she first moved there). (Participant 127)

Bus trips

Residents looked forward to the bus trips, particularly when the bus drove them to new places and included an activity (e.g. shopping, lunch, concert, movie or play). Relatives commented on the amount of effort and skill required to get some older people, particularly those with high needs, onto the bus.

Special days

Some aged care homes marked special days during the year (e.g. Mothers/Fathers Day, AFL Grand Final, Melbourne Cup) with decorations and activities.

The many special events that bring residents together for cheerful celebrations, with appropriate thematic decorations around the building, the most recent being Mother's Day 'high tea' - a no-fuss friendly, happy occasion. (Participant 83)

Some aged care homes also celebrated residents' birthdays with a cake and a 'Happy Birthday' sing-a-long. A relative described being "amazed and gratified" at the celebration the aged care home arranged for her mother's 100th birthday. The manager gave her mother a large bunch of flowers and arranged an afternoon tea in which everyone (both residents and visitors) received "dainty Petite Fours served on non-institutional china".

Concerts

Aged care homes that provided a range of entertainment (musicians, dancers, magicians) were praised for acknowledging the diversity of interests among residents (i.e. not all residents liked old time songs). It was considered important to source entertainers from the local community. A local school choir, for example, created connections with the local community.

Safety

At the very least, residents should be safe in an aged care home. Several relatives described the need to trust that residents were safe.

I have to trust the facility will care appropriately. I do not trust the spoken word or written policy, it is the actions and care that speaks. (Participant 102)

A range of factors reassured relatives that residents were safe. These factors included:

- Size of aged care home
- Residents' demeanour
- Regular visitors
- Staff on duty
- Staff attitudes
- Correct administration of medication
- Regular toileting
- Prompt response to call bells
- Availability of safety equipment
- Communication

- Accountability
- Lack of hazards
- Privacy
- Hygiene
- Fire plan
- Security of belongings.
- Secure front door

Size of aged care home

Relatives claimed small aged care homes felt safe because staff knew all the residents well.

There certainly seems to be a sense that the staff know everything about the residents. The staff follow up on what's going on in the residents lives, get to know their family. (Participant 136)

It was important for staff to regularly visit residents who were bed/room bound. Relatives felt this was more likely to occur in small aged care homes than large aged care homes, particularly those with a high staff-to-resident ratio.

I'm reassured that my mum is safe as there is a constant stream of people in and out of her room during the day so she's kept busy and occupied when family can't get to visit. (Participant 147)

Residents' demeanour

The most reliable indication that a resident is safe in an aged care home is a resident's demeanour. Relatives felt reassured when residents were happy and said they wanted to be there. They also noticed when residents smiled when they saw a particular staff member.

Seeing that my Dad was happy in his interactions with staff reassured me that he was well cared for even when I was not visiting. (Participant 128)

It was also important that residents wore clean clothes, had brushed and tidy hair, and no bruises or skin tears.

Regular visitors

Some relatives visited regularly and kept their eye on standards of care in the aged care home. At some aged care homes, relatives formed an informal group and worked together.

We compare information on what is happening at the facility and take it up as a group issue when required. When residents had no heating recently, we all complained and kept each other updated as to what was happening with our respective family members. (Participant 49)

Some relatives who were not able to visit regularly chose to employ a private carer to provide one-on-one companionship.

Having external companionship for my relative...I pay for this service and it provides comfort to know that my loved one will at least have some consistent

special and peaceful time with a human who is caring. The companion has also alerted me when changes are seen or there are concerns regarding my loved ones wellbeing. (Participant 22)

Staff on duty

Relatives were reassured that residents were safe when a high number of regular, qualified staff were on duty. Registered nurses in particular provided relatives with a sense of safety.

I feel Mum and Dad are safe when there is consistency in staff who have got know my parents care needs and are attentive to these needs. (Participant 6)

Frequent attention of well-trained staff who can anticipate problems before they occur - physical, psychological and emotional care. (Participant 129)

Having staff who were both visible and approachable was important, including in the lounge room where residents may need assistance urgently to go to the toilet.

Relatives were also reassured when an aged care home had a low turnover of staff. Low staff attrition suggested the aged care home was an enjoyable place to work.

There is little staff turnover with many having worked at the facility for 10 or more years. When 'agency' staff need to be employed on some shifts they stand out because they don't have (cannot have) the established relationship with residents that the permanent staff develop. There is also a strong organisational 'culture' that is reinforced through ongoing staff training sessions... Regular staff training sessions strengthen the 'care-culture' of the place - important for maintaining quality of activities and general care.

Staff attitudes

Relatives judged staff by how they spoke to residents. Staff who introduced themselves and referred to residents by their name indicated respect for older people.

The staff mostly use respectful language - people's names rather than 'sweetie' and 'dearie' etc. that is condescending to old people. (Participant 154)

Correct administration of medication

Relatives relied on staff administering medication safely. They expected registered and enrolled nurses to administer medication, not PCAs. This was particularly important when specific medication (e.g. analgesia) was prescribed as “pro re nata” (Latin for “as required”). A registered nurse was trained to assess whether a resident required the specific medication, and what dose to administer. For example, a medical practitioner may order “1-5mg morphine prn”. It required expertise to undertake a pain assessment, particularly with residents who were non-communicative.

It was important that staff not only gave medication at the correct dose and correct time but also had the skills/time to ensure that residents actually took the medication. Relatives expected staff to take the time to make sure residents had swallowed their medication.

Assistance with toileting

Some relatives initiated a ‘toileting schedule’. Assisting residents to the toilet regularly ensured that residents did not feel a “sense of urgency”. When residents felt a sense of urgency, it was likely they would walk to the toilet unsupervised, placing them at risk of falling over. It also put residents at risk of soiling themselves.

The staff that took the time to help my relative to the toilet without hurrying. It was done regularly and in a relaxed fashion. (Participant 92)

Prompt response to call bells

Relatives expected emergency call bells to be accessible, functioning and promptly answered. The response time depended, in part, on the number of staff on duty. The more staff on duty the more reassured relatives felt that, in the case of an emergency, staff would be available promptly.

Availability of safety equipment

Safety equipment prevented accidents in the aged care home. Relatives expected aged care homes to provide safety equipment (e.g. pressure mats, lifting machines and air mattresses). They also expected staff to have the skills to recognise when residents needed to utilise safety equipment, and to arrange for this equipment to be provided.

Relatives noted that an adequate number of staff needed to be available to use certain equipment safely – for example, two people were required to use the lifting machine safely. When a physiotherapist assessed a resident as needing the lifting machine, it was important for PCAs to follow the physiotherapist’s instructions.

Communication

Relative felt safe when there was direct, honest and clear communication between staff, residents and relatives. They appreciated staff who kept them informed and took their concerns seriously.

The philosophy and policy of the place is open and clear - and it is enacted rather than just lip service. Most importantly, I feel that if ever I had concerns about my relative or something that happened that was not OK, I could actually talk to the manager and be heard with great respect, rather than some 'defence of staff' attitude coming into place. (Participant 154)

Good communication involved staff communicating with each other (e.g. informative handovers). It also involved staff informing relatives promptly when residents' health status changed. When residents had an accident (e.g. a fall) or there was a medication error, relatives appreciated being given honest information about how the accident/error occurred. They also appreciated staff providing information about measures taken to prevent a re-occurrence.

I like the fact that staff talk to the families and residents openly and appear honest and transparent in their dealings with you. If a resident has a fall, or a medication mistake, they need to be open about that and be prepared to show they will change things to avoid it happening again. (Participant 173)

Accountability

Managers who took responsibility for the care of residents were valued. Relatives liked seeing managers supervising staff – it gave relatives some reassurance that residents were receiving a high standard of care.

Relatives also felt reassured by an effective complaints process. Managers who were able to provide clear and honest explanations and, when necessary a genuine apology, prevented complaints from escalating to the Aged Care Complaints Scheme.

Lack of hazards

Relatives were reassured when aged care homes were well designed. A well-designed aged care home had the capacity to prevent accidents by minimising the risk of residents falling over. Relatives mentioned corridors without obstacles to trip on, non-slip surfaces in bathrooms, handrails in corridors, and gates at the top of stairs.

Privacy

Relatives observed that residents felt safe when staff respected their privacy. They appreciated staff who knocked before entering their room and those who asked permission before touching residents when assisting them with personal care.

Hygiene

Relatives expected an aged care home to be kept clean, particularly bathrooms. They also expected residents to maintain a basic level of hygiene. For example, they expected residents' hands to be washed after using the toilet, faces wiped clean after meals, teeth/dentures to be cleaned regularly etc.

Fire plan

Relatives expected an aged care home to have an effective fire plan. Regular fire drills reassured them about the aged care home's safety procedures.

Recent fire at facility handled well by staff. Timely responses, families notified. (Participant 144)

Security of belongings

In some aged care homes, residents were able to lock the door of their room and only senior staff had access to a master key. This reassured residents that their belongings were safe when they were not in their room. Other aged care homes provided a locked drawer in which residents kept their valuable items.

My relative's privacy and belongings were secure. She had a lockable drawer and her key was respected absolutely. (Participant 105)

Secure front door

Although relatives wanted aged care homes to have a secure entry/exit, they did not want residents to feel like prisoners. They welcomed the opportunity for residents to be free to come and go, but also expected the aged care home to have a system in place to know of their presence/absence (e.g. sign in/out book). They expected the front door entrance to be constantly staffed during the day and locked at night.

Relatives were reassured when residents could not leave the aged care home without anyone noticing. The methods used included a device on the front door that required people leaving to insert an exit code, the receptionist monitoring the front door and certain residents being fitted with an alarm that sounded when they were close to the front door.

An effective method to ensure residents did not accidentally walk out of aged care home was staff walking relatives/visitors to the front door. Not only was this considered a polite gesture but also ensured a resident did not follow visitors out the door.

Engagement with local community

Relatives liked people from the local community regularly visiting the aged care home (e.g. community visitors⁹, entertainers). They considered aged care homes that were connected to the local community as safer spaces than aged care homes that were isolated. Relatives liked locals taking an interest in the wellbeing of residents.

A relative described the aged care home they visited having a coffee shop that was used by both residents and members of the public.

The facility has a coffee shop that is open to the public. So access from the street is freely available and it makes the facility more open and less institutional. But there is the risk that openness poses. There have been no adverse incidents of which I am aware. (Participant 125)

9 The Community Visitors Scheme (CVS) uses volunteers to make regular visits to residents in aged care homes.

Factors that hinder residents' wellbeing in an aged care home

Moving into an aged care home

Unable to find an aged care home

It was difficult for many relatives to find a suitable aged care home, particularly when an aged care home was required urgently (e.g. after an elderly person had a fall or an acute illness). Relatives often did not know how to determine whether the aged care home was suitable. They did not know what criteria to use.

I was given a glossy brochure and a tour of the facility. I didn't even know what questions to ask. (Participant 33)

Several relatives described being “fooled” by the physical appearance of an aged care home. They assumed because the aged care home looked lovely, residents would receive high standards of care.

The outside appearance and the physical environment all seem adequate because first impressions matter... But there was not enough skilled staff. Also not enough unskilled staff to take residents to the toilet. (Participant 66)

Relatives claimed some aged care homes misrepresented the services they provided. They described the system as lacking transparency.

The lack of transparency in the system and the way providers can just change what they provide without any come back of residents and their families paying for this service. (Participant 28)

Some relatives were so distressed by the low standards of care in some aged care homes that they advised older people not to move into an aged care home unless it was “absolutely necessary”.

Do everything possible to keep your old one out of a home for as long as possible. (Participant 42)

Several relatives, particularly those in rural areas, had difficulty finding a local aged care home with a vacancy. They were put on a “wait list”, but often waited so long that they had to settle for an aged care home simply because it had a room available – even if it was not local.

My mother needed to be in an aged care facility several years before we secured a spot for her. There simply just was not a spot for her anywhere even though she had been assessed by ACAT as needing one. My mother was also assessed as needing a level 4 homecare package, but there were no level 4 packages available. We had her name down at three different

aged care facilities in our area and had to keep ringing, they did not chase us up at all even though her name was down as Urgent! We had to settle on an aged care facility that was not in our local area as we became desperate, as we could no longer cope with her needs and declining condition. This meant that we could not attend to her needs and care as often as we would have liked. The roads were often closed due to snow so we could not visit her. (Participant 30)

Ageing in place

Aged care homes that offered ‘ageing in place’ accommodated residents with a range of different needs, ranging from low to high care. Some relatives were distressed seeing residents with high care needs living side-by-side with other residents with low care needs.

It is unfortunate that in the nursing home there are people who need full nursing care and no longer can carry out any activity on their own. I know it is hard for my father and for us when we visit to see this and be surrounded by this as a constant reminder of how some people become so disabled. My father needs support with showering and dressing and mobility but his confusion is relatively minor. He is very much aware of his surroundings and it can be very distressing for him. I know there is a distinction between high and low level care but there is still those people who need high level care but who have full cognitive capacity and sharing their living quarters with confused and completed incapacitated people is extremely depressing. (Participant 153)

Relatives appreciated the need for staff to prioritise residents with high care needs. However, residents with low care needs should receive some care, certainly more care than some low care residents currently received.

People who are considered more able than other residents don't seem to have ready access to a carer who can help with minor things (e.g. hair and coordination of clothes for people with low vision). (Participant 29)

Institutional care

Although aged care homes were advertised as “home-like”, relatives described some aged care homes as “institution-like”.

In reality, aged care facilities are not home-like. They are dehumanising. (Participant 41)

Factors that contributed to an aged care home resembling an institution included:

- Loss of autonomy
- Impersonal
- Rigid mealtimes
- Fixed seating in dining room (with no flexibility)
- Residents' lack of personal control over:
 - Space
 - Noise
 - Diet

There was concern that the loss of autonomy in an aged care home led to residents becoming passive.

I think in the end it's the loss of autonomy and meaningful activity that occurs when people enter aged care. You give over a lot and this makes residents very passive both mentally and physically. This is especially the case when a person enters for a physical condition but is still very alert mentally. (Participant 98)

Relatives brought items from home to make the aged care home more personal. However, without co-operation from staff, these personal items were not used.

I supplied an iPod shuffle with all of my mother's favourite music on it with headphones...Not once did she have it on when I arrived to see her. I also supplied a cd player for her room with her favourite music. This was rarely on when I arrived. (Participant 30)

Relatives also described aged care homes with a “one-size fits all approach”. With a low number of staff, it was not possible to tailor care to each resident's different cognitive and physical abilities, sexuality and culture/religion.

There is often one-size fits all approach where residents' individuality is not supported fully due to understaffing. (Participant 16)

Relatives suggested different reasons for residents becoming bored. For example, an insufficient number of staff to engage residents in activities may cause some residents to become bored. However, irrespective of the number of staff, some residents do not want to be involved in activities.

Many Nursing Home residents are bored, quickly become institutionalised and lose interest in life. (Participant 164)

Places to die

Rather than places where elderly people thrive, some aged care homes were described as “sad institutions where people go to die”.

Some facilities felt like a place you would go to die, rather than a place where you could happily live the rest of your life. (Participant 30)

I feel that some people go into aged care facilities and literally die a bit each day - there doesn't seem to be many people flourishing in the environment - just forgotten people. (Participant 51)

Relatives reported heart-breaking end of life stories – most commonly stories about residents being left alone for extended periods, often in pain, because the aged care home did not provide extra staff to accommodate the extra work load when a resident was dying.

[My relative] fell critically ill and passed away, about 4 weeks later. This was a terrible period and the care she received was simply not up to the task, particularly on weekends and after 3pm. She was isolated in her room, stuck in bed, unable to ever work out how to use the call bell and unable to get staff attention by calling out. She was in pain and disoriented but was not a dementia patient - she needed intensive rehabilitative care. Once she felt stronger, she was not closely monitored. I found her standing in a full nappy, alone, in her bathroom trying to go to the toilet but distressed and calling out for help because she couldn't get the nappy off. There were no care staff in the wing to hear her. (Participant 105)

Some relatives felt a lack of compassion after a resident died. They were shocked when they were given a short time to move residents' belongings out of the aged care home. They described the manager as being “in a hurry to get the next paying customer booked in”.

When residents die, you have to get their room cleared within 3 days, I understand the urgency, but surely a week would be a more decent amount of time. (Participant 39)

Inflexible systems

Like other institutions, some aged care homes had inflexible systems. Some rules and regulations were described as “ridiculous”. For example, residents in some aged care homes were unable to continue with their own GPs and pharmacists. This was disruptive, particularly for residents who had developed trusting relationships over many years with their local health care professionals.

Overly rule based, too many notices up, too officious, too precious. Treat the resident like they are owned and can't go out. (Participant 173)

Financial costs

The cost of moving into an aged care home was described as “astronomical”, with some older people being “ripped off”. Some relatives described this as financial elder abuse.

The cost to get into such facilities is too much. Even after selling the family home, many people cannot afford to purchase aged care accommodation. (Participant 75)

Relatives questioned whether aged care homes were value for money, particularly when residents were charged additional fees.

It is very expensive...I feel that my elderly mother is being over charged. There is a fee for everything she does which makes her uncomfortable in asking for things to be done. (Participant 149)

Some relatives questioned the relationship between providers and governments.

Most of all I do not like the fact that both State and Commonwealth governments collude with providers to take as much money as they possibly can and provide as little as they can get away with. As these are little old people, they can get away with quite a lot. (Participant 81)

Profit motive

Relatives suggested that the primary motive of some aged care providers was to make a profit. They objected to profits being put above the wellbeing and welfare of elderly people.

I know most of these aged care facilities are businesses and they run them as such. But they are dealing with human beings and their families who love them and are constantly concerned for them. I was recently encouraged to move my family member into the dementia section – but this wasn't for her wellbeing. It was so they had a vacant room. They could see that they could make a profit on her current room (a double one with a large bond). (Participant 44)

Relatives described corporate values “detracting from what should always be a community approach to care”. They claimed some companies made record profits by reducing expenditure in aged care homes: they not only cut the number of staff but also provided “cheap consumables”.

I hate it that Aged Care has become privatised for the benefit of owners/shareholders, while residents have cordial given to them with their evening meal - that is cheap home brand cordial and tastes dreadful. There are cheap teabags and coffee, cheap consumables everywhere. Even though there may be expensive looking furniture and fittings in open areas that visitors walk through, residents rarely use them. (Participant 42)

Providers made huge profits last year and hold billions in bonds which they are free to spend and invest as they see fit. This, when the industry is massively publicly funded. This when there are no mandated staff ratios and providers spend less than \$10 per person per day on food. Critically, this situation will get even worse as standards are watered down and the consumer is expected to pay even more. Consumers will not tolerate paying for care and services they do not receive. (Participant 20)

Some providers in both the for-profit and not-for-profit sector were focused on expanding their business (i.e. building/acquiring more aged care homes). Relatives objected to these providers spending a large proportion of their profits on new investments rather than investing in the aged care homes that they currently owned and operated.

Even though they are a 'not for profit' organisation they are making healthy profits and obviously not putting the money into caring and improving life for the residents. They obviously believe in growth by acquisition, but do not choose to use the profits by increasing staff numbers and actually caring for the residents. I understand that to them it is all about the bottom line and not about their residents, and that they will not do anything about staffing levels until government legislation is changed. Absolutely appalling! (Participant 4)

Relatives also expressed concerns about overseas ownership of aged care homes. They questioned the government's probity processes.

Too many places are run for profit only and by too many overseas owners who have very lower standards than here and get away with it. (Participant 70)

According to a relative, the Aged Care Funding Authority reports providers are making large profits.

The government's own reporting authority, the Aged Care Funding Authority, reports that the providers are making a motza. The figures are likely to be wildly underestimated, as all through the Report there are notes saying 'this is an estimate, as not all the providers delivered this information' or 'this is an estimate as providers not obligated to supply this information' etc. Government and the industry are trying to create a financial crisis in aged care that simply does not exist, for the purpose of acquiring the value of your home and assets. (Participant 81, email)

Standards of care

Relatives reported low standards of care in some aged care homes. They reported residents' needs being unmet – when incontinence pads were not changed regularly, when bruises appeared or skin tears, and when pressure sores were not treated appropriately, in one case turning gangrenous. Relatives also reported residents suffering from malnutrition and/or dehydration and being chemically restrained. In some cases, the low standards of care were described as “neglect”.

These places are being paid (quite well) to “care” for the elderly. That does not mean just shove food into them, hoist them to the toilet and then put them to bed to make staff's workload easier...It means being kind, engaging them, showing some respect. (Participant 15)

Specific concerns

Relatives' specific concerns about standards of care included:

- Continence management
- Hydration
- Hygiene
- Medication errors
- Care plans not followed
- Dementia care
- Physiotherapy
- Dental care
- Podiatry

Continence management

Relatives expected residents who needed assistance with toileting to be taken to the toilet regularly. At the very least, they did not expect residents to be left in soiled incontinence pads for hours.

In my case I am particularly aggravated by what seems to be a lack of attention to wet beds and continence issues. I have been promised pad reviews but not getting feedback. (Participant 2)

Hydration

Relatives were concerned that some residents did not drink enough. Relatives noticed that staff offered residents drinks (e.g. morning and afternoon tea) but did not check that residents drank them. Relatives also noted the serious consequences of dehydration, including organ failure and death.

Staff ratios need to be higher to address hydration. Many residents need to be encouraged to drink. A PCA would give Mum a full cup of tea and then later take away a full cup of tea. No one seemed to notice that Mum had eaten the biscuit but not drunk any of the tea. (Participant 33)

Hygiene

Relatives were upset when they saw residents looking dirty. They were also upset when simple daily tasks, like checking hearing aids, combing hair, brushing teeth/dentures, shaving and clipping nails were not done. In some aged care homes, relatives routinely did these tasks because staff did not have the time to do them.

Some days he hadn't been shaved for up to a few days. I shave him but my husband (son in law) doesn't like to do it. The staff are sometimes too busy to make sure things have been done, like teeth cleaned and clothes clean. (Participant 68)

Medication errors

Relatives suggested some medication errors occurred because staff responsible for administering the medication

did not have sufficient knowledge of the effects and side effects of the medication they administered. For example, PCAs may not be aware they should take a resident's pulse before administering digoxin (a medication that many residents take). The lack of knowledge about the effects of digoxin (i.e. slows the heart rate) was potentially dangerous.

Often residents even in high care are not seen daily by a registered nurse. Medication is now administered by trained personal care attendants who are unable to recognise clinical deterioration in residents. (Participant 33)

Given the risk of medication errors, some relatives monitored the administration of medication.

I regularly have to monitor and review that medication chart is being followed correctly. Specific instructions for drops after cataract operations were not followed requiring emergency visit back to eye specialist. Tablets being left on the 'table' not in any medicine cup and without checking resident has actually taken them. I again took this issue up recently with the Manager...It is the nurse's responsibility to ensure Mum takes her medication. (Participant 49)

There was also concern that GPs prescribed antidepressants without first addressing the underlying causes of a residents' diminished mental health. One relative suggested residents might be depressed because of inadequacies within the aged care home.

Mum's immediate neighbour was continually calling out "help, help" day and night. The staff ignored her and all Mum could do was turn up the TV very loudly to drown her out. It was suggested Mum might be a bit depressed and maybe "medication" would help. (Participant 128)

Care plans not followed

Relatives who developed a care plan with the clinical care manager described feeling initially reassured. However, soon afterwards they noted that the instructions in the care plan (e.g. toileting plan) were ignored. Some relatives questioned whether PCAs read care plans. In cases in which a PCA's English was poor, relatives questioned whether the PCA had the capacity to understand what was written in the care plans.

I developed a care plan with the Clinical Care Coordinator. It included taking Mum to the toilet before morning tea, lunch, afternoon tea and dinner – irrespective of whether she felt she "needed to go". This also provided an opportunity for Mum to have a walk with supervision. Mum's incontinence pad was often saturated when I visited. So clearly they did not follow the care plan. I sometimes wondered whether some staff who spoke very poor English could read the care plan. (Participant 33)

Dementia care

Given at least 50 per cent of residents in aged care homes have a diagnosis of dementia (Australian Institute of Health and Welfare, 2017), it is reasonable for relatives to expect staff to have training in dementia care. However, relatives were concerned some staff had not received dementia care training. They described staff not knowing some basic techniques in caring for people with dementia.

Staff are too busy and don't necessarily have specialist dementia care training. I have seen staff push and grab residents and talk to them as though they are children... The nursing coordinator told me that they deal with things as they happen, so they don't really divert behaviour until it happens - in other words, it's not anticipatory and they don't manage triggers. I think that's quite neglectful (Participant 111)

Physiotherapy

Relatives were concerned when physiotherapy was not considered a priority, particularly after residents had surgery (e.g. a hip replacement). In some aged care homes, the physiotherapist treated 30 residents a day. In addition, physiotherapists were often on duty only on weekdays and when physiotherapists went on leave, they were not replaced with a locum.

There was no physio expertise on duty outside weekdays. My relative was returned on a Saturday as a mobile patient after her hip replacement but was confined to bed by the nursing home. They had no physio available until Monday. So a woman with severe scoliosis and the beginnings of pressure points was left lying on her back in bed for 2 days. I had to ask staff to address a wound dressing that kept coming off her elbow, causing her great pain, and relieve the pressure on her heels. She was left with food and water on the hospital-style tray table but she couldn't move around in bed to reach them. She needed lots of encouragement but staff made fleeting, brusque visits and she was utterly forlorn when I left the room. I got private intensive physio for my relative and she bounced back. It struck me then that the aged care home had formed a view that my relative was simply a palliative care patient. Old, frail and on track to quickly pass away. With proper rehab, care and company, she amazed everyone, more than once. (Participant 105)

Relatives were shocked by the lack of access to physiotherapists. One relative suggested ageism was the reason residents did not receive rehabilitation.

My relative wasn't offered physiotherapy after a small stroke - I felt this was age discrimination and the inadequate staffing of the care facility to either provide it or identify her need and ensure she had the option... why would someone not be offered physio after a stroke? (Participant 93)

Dental care

Aged care homes do not provide dental care. Relatives must arrange a mobile dentist to attend the aged care home. Alternatively, they must take residents to a dental surgery. Given the difficulties and expense involved in accessing a dentist, some residents had ill-fitting dentures that prevented them from eating a normal meal. Their meals were pureed because they could not access a dentist.

Podiatry

Without regular podiatry, some residents developed sore feet. This discouraged them from walking. When older people stopped walking regularly, they often became permanently immobile.

Over the first couple of years of his confinement in aged care, he was almost never attended by the podiatrist. The provider only engaged a podiatrist every six weeks. The podiatrist could not do 74 pairs of feet in a day, so it would be 12 weeks in between treatments. What happened? Father stopped wearing shoes, because they hurt. After he stopped wearing shoes, he stopped walking. Now his mobility is pretty limited, so even though the podiatrist attends more regularly these days, my father no longer walks anywhere, except to the bathroom and back. (Participant 81)

Reasons for low standards of care: (1) Staffing issues

Relatives attributed the low standards of care to the following staffing issues:

- A lack of registered nurses
- Low ratio of PCAs-to-residents
- Poor training of PCAs
- Lack of supervision
- High turnover of staff
- Unsuitable staff
- Task oriented care

Lack of registered nurses

The main complaint about registered nurses was there were not enough of them on duty. Several relatives gave examples of one registered nurse being responsible for over 100 residents. In one case, one registered nurse was responsible for over 190 residents. This was described as “*extremely unsafe*”. It was also unsafe when an aged care home had no registered nurses on duty.

Relatives noticed an increased number of residents with high care needs living in aged care homes that were previously classified as ‘low care’. Relatives claim some of these aged care homes did not provide a high standard of care because they did not increase the number of registered nurses when they increased the intake of residents with high care needs.

The problem is that since the low care-high care distinction was removed the facility is taking in more high care residents but not providing them with quality care. (Participant 108)

Relatives described residents suffering unnecessarily from medical conditions such as undiagnosed urinary tract infections, unrecognised hyper- and hypo-tension, untreated pain and poor pressure care.

Residents receive poor pressure care because of lack of registered nurses... My mother developed a deep leg ulcer due to poor pressure care. (Participant 139)

Relatives also described preventable trips to hospital as disruptive for residents and their families. They were also described as a “waste of tax payers money”. For example, a resident with a preventable heel ulcer spent over a week in hospital under the care of a vascular surgeon.

Low PCA-to-resident ratios

The low ratio of PCAs-to-residents in some aged care homes led PCAs to hurry whilst undertaking their caring duties. Relatives described PCAs rushing when they showered and dressed residents and assisted them to the toilet. Staff also made unnecessary mistakes when they were in a hurry (e.g. throwing glasses and hearing aids out in the laundry).

7 minutes to wake them up, strip them off, put them in a shower, make their bed, dress them and get them to the breakfast table. And that's for everybody... How can you give good care with such a ridiculous time restraint? (Participant 31)

Although PCAs should encourage residents to do as much as possible for themselves, it was often quicker and easier for PCAs to do tasks for residents.

So demeaning to have nurse pull down lower clothing/remove all clothing to enable resident to toilet/shower. This is OK if patient is dependent, but most people can still do things for their selves and may only need minimal support/prompting. Value the person: they've been able to wash their face independently since the age of 5. (Participant 41)

In some aged care homes, PCAs were simply too busy to do their jobs thoughtfully. This led residents to have a decreased quality of life.

Staff are so hard pressed for time that they don't have any time to genuinely engage with the residents. Staff are so busy trying to get through the basics of what they need to do, the residents are treated as a number - not listened to, not considered. Every day residents are left propped in a chair or in wheelchairs locked into a table - usually asking to go to the toilet but are told to wait (and soil themselves) as staff deal with other issues or have their lunch. Often no one has thought to put on some appropriate music

or a movie or have someone provide some form of light entertainment...instead, they are left in a room staring at the wall (sometimes with a CD on repeat that goes on and on and staff don't seem to notice or care. (Participant 15)

A shortage of PCAs resulted in call bells taking too long to be answered. In some cases, residents had no choice but to walk unsupervised to the toilet.

My relative woke wanting to go to the toilet. She needed help to get out of bed. Nobody came quickly when she buzzed so she tried herself. Her frame had been left without the brakes on. She grabbed it and it moved away from her and down she went. And lost her independence ever after. She is now wheelchair bound. (Participant 42)

Relatives described the low ratio of PCA-to-resident in some aged care homes as unsafe. They attributed preventable accidents (e.g. falls) to not enough staff being on duty. Relatives also described PCAs forgetting to administer medication because they were too busy.

I don't like the fact that staff ratio is not enough for staff to give quality care. Not enough kind interaction with residents. Staff always rushing to do basic care. I have come across a resident watching her TV with no picture. It had been offline and needed tuning since the day before. Nobody noticed and the resident hadn't complained so nothing was done... You can ask the nurse for your relative to have a particular treatment (e.g. eye hygiene) – the nurse may direct the carer to do that daily, but it is not done because the carer is too busy and forgets. (Participant 42)

Relatives noted excessively low staffing levels during times providers were required to pay penalty rates (e.g. afternoon and night shifts and during weekends). They described some aged care homes being staffed only by PCAs overnight (i.e. no registered nurse on duty).

There was distressingly inadequate nursing staffing levels after 3pm and on weekends. This became a real health and welfare issue for my relative. (Participant 105)

Relatives were concerned that aged care homes were often understaffed in the afternoons - when residents were more likely to be restless and experience a condition known as 'sundowners'. Medical practitioners prescribe benzodiazepine and anti-psychotic medication as “pro re nata” (to be given as needed). Relatives suggested this medication might be “needed” because there was not enough staff on duty to manage difficult behaviours.

Residents are medicated, often to point of no knowing, or being fully aware, of what is going on around them. This seems to be a cost saving measure. (Participant 76)

Relatives suggested residents spent too long in bed due to the low ratio of PCAs-to-residents. They were concerned residents were put to bed soon after dinner to suit staff, not residents.

Relatives also complained about the lack of PCAs working in the lounge room where many residents spend most of the day. Relatives noticed residents walking around unnoticed and unsupervised. They were particularly concerned about the lack of assistance when residents needed to go to the toilet.

Many residents sitting in lounge room but no staff members are in lounge. Makes it unsafe when a resident wants to go to the toilet. Or gets up by themselves and walks around unsupervised. (Participant 159)

Another concern was the lack of ability of managers to increase staff numbers (both PCAs and registered nurses) when residents were sick. Relatives noted that rosters did not change when residents required additional care (e.g. when residents were dying and required palliative care).

Management does not seem to be able to quickly respond to the need for increasing/decreasing staff numbers, particularly when resident intakes are changing, which frequently is the case. (Participant 12)

The situation becomes life threatening when my mother is sick because the facility does not have the staff to provide the additional care she needs at these times. (Participant 32)

Relatives often found it difficult to find a staff member. As a result, family members were forced to provide the necessary care. This can be very challenging for family members who feel overwhelmed by the high care needs of their relative.

Poor training of PCAs

Relatives described PCAs as poorly trained and “not very knowledgeable”. They were particularly concerned that PCAs were not trained to notice signs and symptoms of illness.

Registered nurses have been replaced with unregistered staff. The resident I visit is a diabetic. He told a staff member that he was having a "hypo" (i.e. he needed some glucose). The staff member asked him: "What is a hypo?" (Participant 94)

My husband recently passed. I have concerns because medical conditions were missed – dehydration over-looked in one case, resulting in a broken arm and unnecessary suffering and discomfort. His behavioural change was put down to dementia when it was in fact caused by a urinary tract infection that went on for some time until he was sent to hospital. A resident with dementia cannot be 'blamed' and change in behaviour must be investigated. I regret I

was not more assertive as assumptions were made, especially by junior staff. They need more and better-trained staff who can treat residents as individuals. (Participant 130)

Without adequate training, PCAs may not notice basic things that need to be done (e.g. cutting toenails, ensuring residents' dentures are in place). These small things made a big difference to a resident's quality of life.

Carers have to notice. They have to notice that a resident needs their toenails cut. Providers rely on the fact that the frail aged person 'did not ask' for a service. If you just ask, they say, of course it will be provided - you did not ask. But the frail aged don't ask. They must notice. My father lost his denture. I was away that week. No one noticed. For a week, no one noticed. By the time I returned, my father had stopped eating. (Then they claim he is in mental decline!) When we located the denture (under the bed) he cheered up, started eating, and is in better health... Another time I went away for five days to find that my father - who only watches television and reads the newspaper - could not find his remote control. For five days he sat in his room with no television, and no one noticed...I could supply dozens of examples (Participant 81)

Relatives were concerned that they, not PCAs, often noticed changes in a resident's health status. Relatives felt they needed to “keep an eye” on residents' medical issues. Relatives who worked full time worried that PCAs might not recognise changes in a resident's physical and emotional wellbeing. Relatives were also worried about the safety of those residents who don't have regular visitors.

Carers fail to notice when health issues arise and thus do not alert the RN. By the time the RN has noticed (usually because I have notified them) the resident's condition has unnecessarily deteriorated. By the time the doctor arrives, the resident is sick and distressed, and by the time a prescription has been written and supplied, the resident is at risk. My father is not paying \$1000 a week for me to be responsible for raising the alarm. (Participant 20)

I don't know what happens to residents who don't have family members that are both aware of medications and times for them or who visit regularly enough to pick up something is wrong well ahead of staff (e.g. UTIs). I can notice when Mum is 'out of sorts' much quicker than the staff. (Participant 49)

Lack of supervision

In some aged care homes, PCAs were not adequately supervised. Managers who spent most of the time in their office were unable to provide direct supervision to PCAs. Relatives also explained that registered nurses were too busy with their own work to supervise PCAs.

High turnover of staff

Relatives described a high turnover of all staff, including managers. They suggested chronic understaffing and the demanding workload in some aged care homes led staff to “burn out”.

The registered nurses I talk to don't want to work in aged care anymore because of how distressing and difficult it has become. (Participant 33)

Numerous changes in staff resulted in a lack of continuity of care. Residents had to familiarise themselves to new staff, and new staff had to get to know residents and relatives. Relatives complained about having to give the same instructions to each new staff member about residents' needs, likes and dislikes.

Staff changes so rapidly. So no-one gets to understand the residents' needs/moods and any special requirements. They all have to try to get up to speed in a rapid time which overall must cost not only time but reduce care. (Participant 49)

Agency staff also disrupted continuity of care. Agency staff did not know the idiosyncrasies of the resident and could not possibly provide the same level of interaction because they don't know the residents.

Too many staff are agency staff. They use that as an excuse to say they don't know what's been happening with your loved one, or are not able to give up-to-date information. (Participant 5)

Unsuitable staff

Relatives described the low pay rates and demanding work in an aged care home as “attracting many low skilled workers some with limited language skills”. They were particularly concerned about a new Centrelink program¹⁰ that encouraged people on unemployment benefits to undertake aged care training. They worried this program might result in people working in aged care homes who were unsuitable. Several relatives described working in aged care as “not just a job”.

Aged care has become a dumping ground for people who can't get jobs anywhere else. (Participant 10)

Task-oriented care

With a low number of well-trained PCAs on duty, it was not possible to provide person-centred care. Instead, personal care was often task-oriented.

For most staff, personal care is dictated by a task 'roster'. There is nothing 'personal'. (Participant 22)

Relatives noted that some aged care homes operated with less staff during the afternoon and evening shifts. They described residents as less likely to receive person-centred care after “penalty rates kick in”.

Person centred and rights based (on paper)... After 3pm, staff is reduced, shift changes and full time staff tend to knock off at that time - so the person centred approach seems to wane when penalty rates kick in. (Participant 111)

Some relatives wanted female PCAs to provide personal care for female residents and male PCAs to provide personal care for male residents. Elderly women were often not comfortable when a male carer showered her and helped her to the toilet. Also, older men may prefer male carers to help with personal hygiene and toileting.

My mother in law begged and begged at 94 years old that she did not want a man that could hardly speak English wash her. It frightened her so much she screamed (Participant 60)

Reasons for low standards of care: (2) Non-staffing issues

In addition to staffing issues, relatives suggested other reasons for poor standards of care in some aged care homes. These included:

- Current legislation
- Aged Care Funding Instrument
- Inadequate oversight by Quality Agency
- Lack of power of Complaints Commissioner
- Size of aged care home
- Cost cutting
- Poor management
- Incompetent medical care
- Task oriented care
- Ineffective communication
 - Between staff
 - With relatives
 - With residents
- Unwillingness to work with families
- Low proficiency in English
- Lack of cultural awareness

Current legislation

According to the federal Aged Care Act 1997, aged care homes must “maintain an adequate number of appropriately skilled staff to ensure that the care needs of care recipients are met”. There is no federal legislative requirement for aged care homes to employ a registered nurse on site 24 hours per day. Even those aged care homes that have mostly high care residents are not required by law to employ a registered nurse on each shift.

Relatives described many instances when there was not a registered nurse on duty.

The ratio of registered nurses to residents is criminally negligent and results in residents being neglected and at worse dying because of the lack of trained staff on-site who know what to do in an emergency. Registered nurses are almost non-existent overnight. (Participant 32)

10 For example, the ‘Get Into’ pilot program (Edwards, 2017).

There is also no federal legislative requirement for aged care homes to have mandated staff-to-resident ratios. The staffing numbers and mix is at the discretion of the provider and overseen by the Quality Agency.

The fact that there is no legal minimum requirement for staff to resident ratio in Australia allows care providers to side step the reality that high care residents require a higher staff to resident ratio. They don't employ enough carers because of the cost. (Participant 13)

Although the Quality Agency oversees standards of care in all aged care homes, relatives claim aged care providers were not sufficiently held to account when residents suffered an injury.

Under existing legislation management are not accountable, and therefore take no responsibility for the problems and injuries to residents that occur on a daily basis in residential aged care facilities. They know they can't be held accountable and therefore take no responsibility. (Participant 32)

A relative compared the low fines given to unscrupulous providers of aged care homes with high fines to those who delivered “shoddy” courses in private colleges.

Aged Care Funding Instrument (ACFI)

Relatives described some aged care homes using ACFI to claim maximum government subsidies for delivering high care but not providing the services that high care residents required (e.g. physiotherapists).

I do not like the way they claim every ACFI dollar they possibly can, and then fail to provide, or fail to provide consistently, the services for which they are claiming. (Participant 81)

Relatives suggested that rorting was common and claimed this was the “inevitable consequence” of governments funding the private sector to deliver a public good. They described aged care homes getting maximum government subsidies for each resident even though not all residents in the aged care home had high care needs. A relative described a provider incorrectly claiming her father had Parkinson’s disease.

I have documentary evidence that my father's aged care provider was defrauding the Commonwealth by claiming my father has Parkinson's disease, and related health deficits, for which the provider claimed subsidy under ACFI. My father does not have Parkinson's disease. (Participant 81, email)

Inadequate oversight by Quality Agency

The Quality Agency is responsible for the accreditation of aged care homes. Relatives were concerned that an aged care home was able to pass accreditation with a perfect score, despite residents receiving poor standards of care.

I didn't like that the facility passed its 44 requirements as part of the audit even after I had presented evidence to the auditors that they had breached many of the regulations. (Participant 1)

Relatives described the current accreditation process as primarily paperwork. They were concerned that accreditation did not focus on problems such as inadequate numbers of registered nurses and insufficiently trained staff.

Accreditation in its current form is a farce. It does not mean anything. Families cannot be assured of good care because a place has passed its accreditation. That is wrong. (Participant 10)

Relatives described aged care homes as employing extra staff for accreditation. Some also claimed the aged care home knew in advance that a ‘spot check’ had been scheduled because on the day of the spot check more staff than usual were on duty.

My comments relate only to [an aged care home unit] – which is principally high care. I spent around 5/6 hours in that Unit virtually every day for well over 3 years until my Wife passed away. During the last ‘spot inspection’ that I witnessed I made a point of approaching and speaking directly to the QA lady who reviewed unit as part of the so-called ‘spot inspection’. My initial comment to her was along the lines “I thought spot checks happened without any prior notice”. Her response was along the lines: “Yes, spot checks are undertaken without any prior notice”. My response was then: “I do not believe that. Two ladies from head office spent a large part of yesterday examining every corner of this Unit! That could not have been a random coincidence”. The QA lady tried to extricate herself from that comment so I concluded the discussion by stating: “As the ex head auditor of a major Australian company, I do not believe you”. There was no point in taking the discussion further. A short while later the Unit 1 EN advised me that the QA lady I had spoken to had previously worked at the aged care home. All circumstantial, but I bet a jury in a court of law would have an easy time making a clear-cut decision...Every audit should happen without any prior notice whatsoever if it is truly an audit. Further, aged care homes are active 7 x 24 hours operations and QA visits (spot or full audits) should also include night times and weekends. That would really set the cats amongst the pigeons - reduced/casual staff on duty etc. (Participant 104, email)

Aged Care Complaints Scheme

Some relatives who made a complaint to the Aged Care Complaints Scheme about substandard care in an aged care home were dissatisfied with the process. They described it as ineffectual because the Complaints Commissioner had

no power to take action, took too long to investigate and did not appear to be accountable to any government body. Some residents felt aggrieved by the process.

I have a list of scores of things I don't like and are substandard in these facilities. But when I made complaints, nothing happened to address long-standing, life threatening situations. (Participant 32)

Size of the aged care home

Despite efficiencies of scale in large aged care homes, relatives believed standards of care were lower in large aged care homes because staff were unable to get to know the large number of residents.

My dad's home has over 100 residents who are mostly high care. It is too big. Staff don't know residents. How can you provide a high standard of care for someone you don't know? (Participant 175)

Cost-cutting

Relatives described aged care homes as “cutting costs” to maximise profits. They described reduced staffing levels, fewer activities (e.g. bus trips) and limited access to safety equipment (e.g. air mattresses). In some cases, relatives claimed cutting costs led to neglect.

I look around and get a sense of cost cutting - we are paying the highest amounts for this care and the idea that costs are cut or that my mother doesn't have things (like an outing) rubs against the grain. (Participant 111)

Relatives described having to be “constantly vigilant” to ensure residents received access to basics such as toilet paper and fresh drinking water. Relatives noticed that water jugs were often unchanged for several days.

That is why we relatives must be constantly vigilant that our relatives receive the basic minimum - like there is toilet paper provided, for example, or that there is fresh water available. (Participant 81)

Poor management

Relatives described “a lack of engagement” in some aged care homes between management and residents/relatives. In some cases, managers did not know residents' or relatives' names.

Relatives were particularly disappointed by the manner in which some managers responded to complaints and feedback. Rather than accept feedback as constructive – as an opportunity to improve standards of care – some managers became defensive. Relatives were also mindful about the possibility of negative repercussions when making a complaint – they were concerned their complaint may cause their parent, spouse, sibling or friend (i.e. the resident) to be punished.

Facility Manager and executive management treat family members as nuisances rather than accepting that their efforts provide useful assistance. They also

treat complaints with contempt, providing trite/demeaning responses. (Participant 82)

Relatives described managers as “risk averse” – making “nonsensical decisions” just in case residents had an accident.

They don't let my Nan eat normal food as she once choked. The speech therapy lady said she could but management said “No” just in case. She hates it and won't eat. She has lost so much weight. (Participant 86)

Incompetent medical care

Some GPs provided sub-optimal medical care in aged care homes. Relatives described GPs billing Medicare for extremely short consultations with residents. Some GPs billed Medicare for a consultation after reviewing a resident's medication chart but not actually seeing the resident. Relatives were appalled at those GPs who made “obscene profits from residents”.

The GP visiting once a week at 6am to attend to 30+ residents, and said GP never actually seeing or examining the residents, but collecting his fee nonetheless. (Participant 79)

Some GPs did not respect residents' privacy. They examined residents in public (e.g. lounge room) and gave results using a loud voice that could easily be overheard by other residents and visitors.

The doctors who attend the facility often hold a chair side consultation with residents in the public lounge area. This can include telling residents the result of their urine test and other personal information... I think that it is totally unsatisfactory. The GP blows into the facility, usually does not give the resident the opportunity of being seen privately in their room, and remains standing for the brief conversation. Comments, questions and results can be overheard by other residents and visitors in the lounge area. (Participant 29)

Relatives also expressed concern about residents' polypharmacy, particularly GPs who prescribed many different medications without considering their interactions.

My mother was doped up on every medication going. When she had side effects, they simply added another medication to counteract the reaction. Consequently she had to be rushed to hospital emergency. (Participant 79)

Ineffective communication

Poor communication is a significant problem in some aged care homes. Poor communication included staff's communication with both residents and relatives. It also included staff's communication with each other.

With relatives

Relatives expected staff to communicate with them about issues that have an impact on residents. It was particularly important for staff to follow up with family members after medical and/or nursing issues have been raised. Some relatives described having to chase staff for information.

Lack of communication with me, my mother's primary advocate, with regards to all aspects of her care. I have just lodged a complaint with the Aged Care Complaints Commissioner about this and other matters. I often find out about issues after they occur, by the carers (usually as a result of me probing them. They are not supposed to talk to me but no one else does). (Participant 34)

Relatives were disappointed when staff did not talk with them when they visited the aged care home.

Staff don't make much effort to engage families when we visit. They don't get to know us or introduce themselves. (Participant 111)

With residents

Relatives were upset when staff did not show respect towards residents, particularly when they assumed all residents were deaf and talked very loudly. They also did not like staff talking to residents as though they were young children.

The way the staff talk to the residents. They often talk to them as though they are young children and they don't treat them with dignity as befits their age and status. In many cases these people have been high functioning members of society and they play ridiculous games with them...Show some respect. Ask them what they would like to be called. It is often humiliating for these people to be addressed by their first name by very young people. Some of them still want to be called Mr and Mrs. (Participant 66)

Relatives described staff not taking enough time to listen and understand residents. In some cases, staff lied to residents.

The fact that some staff do not take time to listen to residents and will sometimes dismiss some residents as being difficult or demanding rather than acknowledging they have life experiences and often know what they are talking about and are making reasonable requests. (Participant 164)

Some staff lie to patients to keep them quiet (e.g. "You saw the doctor yesterday. You just can't remember.") (Participant 29)

Between staff

Relatives described "poor communications systems" in some aged care homes (e.g. poor handovers between shifts). Residents also expected PCAs to be able to give them medical updates, particularly when there was no registered nurse on duty.

Lack of communication between doctors and PCAs. PCAs often don't know when the doctor last visited and what the outcomes of the visit were. (Participant 157)

Proficiency in English

In some aged care homes, many staff and residents do not speak English as their first language. This sometimes made communication difficult.

There is a great range of cultures and nationalities among staff and residents. Communication can be difficult when one doesn't understand the other's accent. (Participant 2)

Residents from a non-English speaking background had specific difficulties communicating with staff who were not competent at speaking English.

Hard for some residents as they revert to native tongue when in nursing homes. They find staff from other cultures difficult to understand. (Participant 114)

Staff who were not competent at speaking English, such as staff on 457 visas, had difficulty communicating with residents. This poor communication sometimes led to poor standards of care.

There is a language problem with care staff, who are often from another country and have quite strong accents. This is especially a barrier for residents who have not grown up hearing such a variety of accents, so it can be quite a problem for them to understand what is said to them. It also deters residents from asking for what they need (e.g. toileting or pain relief etc.) Instead the resident will 'just let it go' and wear the pain. I don't think our facility is alone in this. This is a serious problem when it comes to dignity for those who still have normal cognitive ability as it impacts negatively on their mental as well as physical well-being. (Participant 5)

Residents with impaired hearing found it difficult to understand some staff, particularly those with a strong accent.

My mother has very bad hearing so she has difficulty understanding what staff say to her. This is compounded, to various degrees, when Australian/English is not the first language of the staff concerned. This applies to many of the staff at mum's place. Added to this is the uncaring attitude of some of the staff. (Participant 125)

Lack of cultural awareness

Relatives were disappointed when an aged care home was unable to cater for different cultures, particularly those aged care homes that explicitly stated they catered for a specific culture.

We placed my mother in a facility that purportedly catered for her cultural requirements – Italian. What we found after a few weeks on my mother entering the facility was that this was minimal. The food was appalling and mostly not Italian. (Participant 32)

Not working with families

Relatives were disappointed when staff did not work collaboratively with families. They described some staff as hostile to relatives, particularly when relatives made suggestions about a resident's personal care.

Whenever I make a suggestion I feel that staff are immediately on the defensive. They tend to hover watching if I lift the bedclothes or try to look at charts. (Participant 85)

Some relatives formed informal support networks with other relatives, though management sometimes opposed such initiatives.

The latest residents representative is also a daughter of a mother in care and she was told off for reaching out to families "her job was to represent residents not families". (Participant 2)

Some aged care homes had resident representatives. Having resident representatives did not however guarantee that management would listen to their suggestions.

Many meetings have been held between resident representatives and management over the past few years but nothing has changed. (Participant 15)

Relatives described feeling unwelcome at residents' meetings. They also noted the timing of these meetings was inconvenient for those who worked 9am to 5pm.

Resident meetings are held at 2pm on a weekday that few of us can attend, if we were even welcome. (Participant 2)

Advocacy

Once a resident had moved into an aged care home, some relatives described feeling powerless. Relatives described the aged care system as being controlled by government and providers rather than staff, residents and relatives.

I am alarmed by the lack of control both staff, residents and residents' families have over the aged care system. (Participant 28)

Relatives observed that residents were some of the most vulnerable people in our community. They believed residents deserved better than what they were currently getting. Relatives felt there was a need for ongoing and sometimes "aggressive advocacy" to ensure residents received minimal standards of care.

My mother was clean but only after vigorous and at times aggressive advocacy from me to ensure that she was bathed everyday, her clothes changed on a daily basis and she wasn't to be left sitting in a wet

and soiled nappy for over four hours on a daily basis. The neglect is horrific and should not be tolerated by any one. The facilities treat residents as second-class citizens because of their age. (Participant 32)

Questions were raised about residents who did not have a relative who advocated on their behalf. Who monitored the standards of care for these residents?

I was my mother's advocate and had to fight all the way to get her the assistance that she needed and deserved. My mother sadly passed 6 weeks ago. I had to insist on adequate pain relief in her final days... One of my biggest concerns now is for people who have dementia who do not have an advocate. They would simply just fall through the cracks and die. The aged care system and the hoops you have to jump through to get access to it is hard enough for an able bodied/minded person to navigate, let alone someone suffering from dementia. A dementia sufferer would not have a chance. (Participant 30)

Several relatives used advocacy services provided by Older Persons Advocacy Network to try to resolve problems with management of an aged care home.

Constant problems have arisen necessitating contact with the Aged Care Complaints Scheme and Elder Rights Advocacy. Management have continued to "push-back". (Participant 104)

Environment

Facilities in aged care homes

Several relatives described old aged care homes with poor facilities. Despite relatives not liking the physical environment, they described staff in these old aged care homes providing high standards of personal care.

I don't like anything much about the physical environment. It is old, two bed wards and no air conditioning but the care is outstanding...The personal care in the current facility is timely at a time we have requested. It is professional and done with dignity and respect unlike the previous facility in which our mother was scalded (2nd degree burns) while being bathed by PCAs. The nursing care is professional delivered in a caring and compassionate way unlike the previous facility. (Participant 10)

My mother's facility is quite small - a large converted 2 story heritage house - so doesn't have much outdoor space at all, and only one large room which is used for dining as well as activities plus a small 'reading room'... Local GP visits regularly, RN on duty at all times, friendly caring staff...I have no complaints with the personal care. (Participant 121)

Relatives believed providers of modern aged care homes prioritised appearance rather than standards of care for residents. They described "fancy" facilities that have grand

pianos and chandeliers but no warmth. They believe some providers do not understand what is important to elderly people. They suggested if providers put the same effort into standards of care as they put into the physical environment, they would receive fewer complaints.

The aged care home is more about appearances than the reality of proper staffing and duty of care. To a casual visitor the interior and external appearance is quite good. If only the level of care matched that appearance! (Participant 104)

Relatives described many aged care homes as having wonderful facilities. However, without enough staff, many facilities in the aged care home, such as entertainment rooms, courtyards and BBQ areas, were rarely used. Rather than being full of life, relatives described some areas of the aged care home as mostly empty. Even the lounge room in some aged care homes was under utilised because no staff member was allocated to work there.

The aged care home has exceptional environments. They can't be faulted on that side of things... Complete with their own hairdressing room. They have been provided with most comforts that could be desired. Simply not enough personnel to ensure it is all put to use on a regular basis. It is no good having a spa bath if staff don't have time to put patients in it and supervise them while they relax for ten minutes. Or a sensory room to relax in but again staff not having enough hours in the day to allow all patients the time needed to appreciate the facility. Outdoor BBQs are great but rarely used. (Participant 87)

Furniture

Some modern furniture used in aged care homes looked impressive but was unsuitable for older people. For example, relatives described couches that were too low for residents with mobility problems.

Furniture is not designed for residents with mobility problems (e.g. couches not a suitable height). (Participant 178)

The chairs they spend most of their time in don't have side support for their heads. As they spend most of their time dozing (because there is no reason to stay awake), their heads fall forwards and this can't be good for their posture or their necks. (Participant 141)

The layout of the furniture in the lounge room was important for residents' social activity. Having chairs lined up in front of the TV or around the perimeter of the lounge room did not encourage social interaction between residents.

Sitting area is large and rectangular and has 20-30 chairs in a large rectangle around the perimeter. Residents can only chat with the person sitting on either side of them. It is not a very good environment for socialising or quiet conversations. (Participant 2)

Residents' rooms

Some aged care homes did not allow residents to personalise their rooms with their own furniture. Some bedrooms were so small they did not fit a double bed. As a result, couples could not sleep together. In addition, the bathrooms in some aged care homes did not accommodate mobility devices.

The bedrooms and bathrooms should be larger to accommodate couples. Currently couples must be separate as rooms only fit a single bed. Bathrooms also need to accommodate mobility devices. The bathroom is too small for walkers. (Participant 127)

Dining room

Some aged care homes had large dining rooms. These were described as "cafeteria-like". Some dining chairs were unsuitable for elderly people (i.e. no arms). In addition, some dining tables were unattractively set for meals with dirty crockery and inappropriate cutlery.

Lift

Multi-storey aged care homes had lifts. Several relatives were concerned about the number of times the lift was out of order.

There is no access to the first and second floor except via a lift. When lift breaks down (which it did quite often), people who can't walk must stay where they are until it's fixed. On several occasions, the lift broke down in the evening and those residents who were on the ground floor could not go to their rooms to have a rest and sleep. Can you imagine 80 or 90 year old people not being able to get to their room? I was also surprised that a large building with about 60 residents had only one lift. (Participant 19)

Corridors

Relatives described cluttered corridors that sometime smelt of urine.

Often there was "medical" apparatus and large laundry bins marked "soiled/contaminated waste" sitting in the corridors and thoroughfares. I think the elderly are well enough aware of their reality but don't particularly need to see constant reminders in their immediate environment. (Participant 128)

Courtyard

Although courtyards looked attractive, they were often "inaccessible" (e.g. doors heavy/locked). Most importantly, staff were too busy to take residents outside. Relatives were concerned that residents did not get regular fresh air and sunlight.

Pets

Some aged care homes did not allow pets inside.

Services

Hairdressing

Although the hairdressing services were mostly described as excellent, the residents' hair-dos lasted a short time. PCAs often washed out the hair-do the following day.

The hairdressing is quite good - it is just what the caring staff do with the hair afterwards. (Participant 44)

Meals

Relatives expressed alarm that the meals in some aged care homes were inedible, including in some expensive aged care homes. The complaints about meals included:

- Time of meals
- Food preparation
- Quality of food (e.g. nutritional value)
- Lack of assistance with meals

Time of meals

Meals were restricted to set meal times. In some aged care homes, residents had no access to additional food in-between the regimented meal times.

Relatives complained that dinner was so early that some residents thought it was afternoon tea. They suggested the timing of meals was designed to accommodate staff not residents.

Very early eating times - dinner is at 5pm. Particularly during daylight savings it is light for hours and my grandmother takes issue with this and I think therefore eats less as she thinks it's afternoon tea. It's clear this is done so that food is prepared and cleaned up during business hours rather than when meal times should actually take place. (127)

Residents also complained that residents were brought into the dining room too early – sometimes an hour before dinner. Relatives claimed this was to suit staff and was not in the best interests of residents.

Food preparation

Some aged care homes spend less than \$10 on meals per resident per day. In addition, rather than prepare meals on-site, some aged care homes used a catering service. This created some problems, particularly for residents with food allergies.

Meals are bussed in from ARV. The food in aged care is a disgrace. You cannot even find out what menu options ARV offers unless you are a provider. There is a lot of secrecy in aged care. (Participant 20)

Some relatives complained that residents were not allowed to participate in food preparation. Although residents had spent most of their adult lives preparing food for their families, they were told that food preparation put residents at risk of injury. Even a simple activity like peeling potatoes was not allowed in some aged care homes because residents (many of whom have peeled potatoes all their adult lives) were at risk of cutting themselves.

Quality of food

Relatives described the food in some aged care homes as inadequate, bland, horrible, poorly presented, repetitive, dull and served at an inappropriate temperature. Although the importance of older people having a nutritious, well balanced diet is widely acknowledged, some aged care homes saved money by using processed food and cheap ingredients.

Budget pressures affecting the quality of meals: ingredients that are quick to prepare, often processed, rather than the best fresh seasonal produce. (Participant 83)

Relatives were particularly concerned about the nutritional value of the food that was served at some aged care homes. Relatives described residents often being served meals such as meat pies, deep-fried patties and chicken nuggets. Sugary desserts were also common. Given the incidence of diabetes, heart disease and cancer in older people, relatives were angry at the high levels of sugar and salt in the meals served in some aged care homes.

The lack of nutritional quality food. This is pretty much the only thing the elderly look forward to. They are bitterly disappointed when dished out food that is not fit for animals. I believe that prisoners are treated better than our elderly. Food is not hard. Then why is it a common denominator in most if not all the facilities? (Participant 27)

Meals often did not meet residents' dietary requirements. A relative described ham sandwiches regularly being served to a Jewish resident. Relatives were also concerned that there were few multicultural options.

Residents who once enjoyed eating complained that the food in the aged care home was often inedible.

My mother used to enjoy a wide variety of cuisines prior to being admitted to the facility. She complained for a long time of the food being bland. I think that she's now used to the food, but as she doesn't have a great deal of interests, it would be good if she looked forward to meals rather than just endured them. This seems to be a point of complaint from many of the families of residents. (Participant 176)

Relatives complained that hot meals were often served cold, particularly for those residents who ate meals in their room or who needed assistance with eating their meals.

The delivery of meals was scheduled during a change of staff. Those who needed feeding had to wait for a staff member. By the time they were fed their meal, it was cold. (Participant 14)

Assistance with meals

Relatives were concerned there was an insufficient number of staff to assist residents to eat their meals.

Meal times can be chaotic and distressing for those who can't feed themselves. There is an insufficient

number of staff. There is not enough to help everyone who needs to be helped. Meal times can be depressing. (Participant 156)

Staff were also too busy to notice whether residents finished their meal. Sometimes staff did not notice when residents were not eating their meals nor question why this was the case.

If a resident with dementia stops eating, assess what types of food will attract him/ her, make it easier to eat. This shouldn't be left to the family to fight for these changes. (Participant 140)

It was also difficult for some older people (e.g. those with arthritis in their hands) to access some meals, such as those wrapped in plastic. Without assistance, these meals were often left untouched. Relatives were alarmed that staff took away the tray without noticing the unwrapped food remained on the tray.

Leaving a meal tray with packaged food that is difficult for old hands to open. No one seems to notice when the food is not eaten. (Participant 79)

A relative described some residents being overlooked at meal times. There was also concern about residents not drinking enough.

If you can't speak up and make yourself heard and understood you will be overlooked, rarely offered ice cream after dinner despite it being on the menu, often don't get offered toast/bread with soup. I have asked for water to be offered first with meals but some days she doesn't even get juice. Morning and afternoon tea is supposed to come around on a trolley but I have been there on more than one morning or afternoon and nothing comes... If you are not mobile you can't help yourself to the fruit bowl or drinks. (Participant 2)

Some residents did not receive assistance to clean their face, hands and clothes after they had finished their meals.

Faces and hands are not washed after meals to remove crusts. You often see food on their clothes. (Participant 101)

Laundry

Relatives described the laundry facilities in some aged care homes as “disgraceful”. The complaints included:

- Lack of quality control
- Laundry fees
- Lost clothes
- Ruined clothes
- Unironed clothes

Lack of quality control

Relatives were concerned about the lack of quality control in the laundry. They described not enough staff working in the laundry to ensure a high standard. Several relatives took residents' clothes home to be washed and ironed.

Laundry is a disgrace with items not bring folded or dried correctly and frequently lost. Laundry staff are reduced over weekends and after hours because of penalty rates. Hence on Mondays there is minimal underwear available. (Participant 99)

Laundry fees

Some relatives described paying extra laundry fees even though they took residents' laundry home to wash. A relative was charged \$120 to have her father's clothes labelled. A relative questioned whether aged care homes were allowed to charge these “extra fees”.

Lost clothes

Residents' clothes were frequently lost despite clothes being labelled with their name. These clothes were sometimes never found. Although residents may not notice being dressed in someone else's clothes, relatives were upset when they saw another resident wearing their mother or father's clothes.

Laundry gets lost. All clothes need to be labelled (school camp style) but still things go missing and you end up with the clothes of other residents in the mix which my grandparents wouldn't notice on their own and the staff don't seem to - it's my mum who goes through and checks from time to time and wanders the hall looking for the rightful owner of the items she finds. (Participant 127)

Some relatives were suspicious about the missing clothes. They claimed only new clothes went missing. They were angry that management took no responsibility for missing clothes, and refused to investigate whether a staff member may have taken them.

My mother's clothes went missing regularly which resulted in me taking her laundry home to wash so that I could keep track of her clothing. Management took no responsibility for this. I believe staff took the clothes (not residents who were bedridden). Other personal belongings also went missing. (Participant 32)

Ruined clothes

Relatives attributed the ruined clothes to industrial washing and tumble dry machines. Some relatives complained that bleach was used though management denied that bleach was ever used.

Unironed clothes

Relatives described residents looking “shabby” when clothes were not ironed. This impacted on residents' “dignity”.

Nothing is ironed so on some days the residents look a little shabby with crumples clothing... We are talking about the dignity of our loved ones. (Participant 34)

Equipment

Relatives described some aged care homes cutting back on the provision, quality and maintenance of equipment. The lack of maintenance of some equipment made it unusable. For example, wheelchairs with flat tyres and brakes that didn't work could not be used. In addition, some residents had equipment removed from their room without any consultation.

Crash mats were removed from all rooms recently with no consultation, and my mother's air mattress was removed without anyone notifying me; when I asked about this I was told it "was no longer necessary". No further explanation. (Participant 34)

Extra/Additional charges

Relatives were confused about the distinction between extra and additional charges. They were also angry about continuing to pay for services that residents no longer used.

Mum paid extra for WiFi when she used the computer to skype with her grandchildren. But as she got older, she was unable to use her computer. She paid the extra WiFi charge for over a year without using it once. Why should she continue to pay a monthly fee for something she didn't use? (Participant 33)

Activities

No activities

Without trained therapists and resources (e.g. buses, board games, jigsaw puzzles), aged care homes were not able to offer a meaningful, varied activities program. In some aged care homes, TV was the only entertainment offered. A lack of stimulation created boredom, depression and, in some cases, a desire to die.

There is presently no activities officer at all (the previous one was shared with another facility) and it has taken three years to get the (shared) use of a bus. Without an activities officer, the lounges and the movie room are not used. (Participant 81)

In some aged care homes, activities were only scheduled during the morning shift. Relatives were concerned when there were no formal activities in the afternoons and after dinner. They described afternoons and early evenings as a critical time for residents to be engaged in a meaningful activity to minimise the impact of 'sundowning'. Playing a DVD or CD on repeat, or having a sing-a-long, was not considered an engaging activity. In addition, relatives did not consider religious ceremonies as an "entertainment activity".

Without any activities, residents became inactive. In some cases, this inactivity contributed to residents becoming immobile. Relatives were disappointed that residents were not encouraged to participate in activities.

Residents are left to do nothing if they choose. This means their exercise can be very limited. I would

like a situation where residents are encouraged to participate in activities that motivate them and make them ambulant... Walking to the activities room to play bingo is exercise. (Participant 98)

Relatives also noted the absence of activities for residents who have poor vision or hearing.

Many of the activities planned are inaccessible for people with poor vision or hearing. (Participant 29)

Under-resourced

Relatives suggested some aged care homes advertised activities (e.g. bus trips) so they were "seen to provide something". However, some buses only accommodated a certain number of wheelchair bound residents. Relatives with mobility issues were often disappointed because they were unable to go on some bus trips. In addition, residents were disappointed when outings were cancelled due to staffing issues (i.e. no staff available to accompany them).

While the home advertised outings, these were limited and rare. The bus used could only take two wheelchairs so someone had to miss out. Also a staff member needed to accompany residents and there was usually no one available so the outing was cancelled at short notice. (Participant 94)

A well-run activity program depended on an aged care home employing enough suitably qualified activity staff. However, rather than employ trained therapists, some aged care homes used PCAs and volunteers to deliver activities. PCAs and volunteers often had minimal training in diversional therapies.

I wonder about the training of activity staff as often they 'promote' PCAs to these positions. Activities are a chaotic experience rather than structured. (Participant 6)

Unsuitable activities

Apart from passive activities (e.g. concerts), group activities were mostly unsuitable for high care residents. High care residents responded better to one-on-one activities. However, there was rarely enough staff on duty to tailor activities to meet an individual resident's needs.

Unfortunately activities are too generic due to lack of staffing and are unable to meet all residents' needs. (Participant 22)

Gendered

Most activities offered in an aged care home were oriented towards women. Relatives were disappointed that activities that might interest older men were rarely offered.

Childish

It upset relatives when residents were offered activities that were more suitable for children than adults (e.g. playing with balloons). Relatives were concerned that some staff infantilised residents, particularly residents with dementia.

My husband always found the activities in his 'high care' facility a little childish, even though he was suffering from dementia. Important to be treated like adults, no matter what. (Participant 130)

Meaningless

Relatives found many of the activities (e.g. bingo) unstimulating and meaningless.

Same old stuff... bingo... Bingo played once a year is sensational - for its novelty, but played repetitively, routinely is akin to neglect. (128)

Unlike older people who live at home who were busy with chores, most activities in an aged care home were diversional rather than meaningful. They were also passive. Relatives suggested a lack of active engagement in stimulating activities might contribute to residents' mental decline.

These are often 'games' or entertainment that is quite passive. I have another elderly relative who still lives at home and she is busy all day with chores in the house and garden etc. In an aged care facility there is no 'real' activity to do and it there is not necessarily any motivation for the resident to be involved. Aged care means you give up any management of your own life and I think this encourages residents to slow down and reduces their mental acuity. (Participant 98)

Safety

Relatives not present

Relatives were often worried about the safety of residents when they were not present at the aged care home.

We were sick with worry. What is happening when we are not there? Are the residents being supervised? Are their incontinence pads being changed regularly? (Participant 82)

Lack of staff

Relatives did not feel residents were safe when there was a low number of staff on duty (e.g. when they walked around the aged care home without finding any staff). The lack of visibility of staff made them worry about residents' safety.

Restless, calling-out residents get no response. The calling-out of some residents confined to rooms, combined with the complete absence of staff at about 7 in the evening, made the place seem spooky and desolate. (Participant 146)

When an aged care home did not have a registered nurse on site, PCAs were responsible for residents. PCAs did not have sufficient training to recognise when to call a doctor.

I am not assured. A resident recently tripped and fell, because there was a trip hazard no one did anything about. The old lady broke her nose. This was on the weekend, and carers assured her she merely had a

cut. She was not given anything, not even Panadol, until the RN arrived on Monday. (Participant 81)

The lack of staff resulted in residents spending far too much time in bed. This increased the risk of residents getting pressure sores, particularly when staff did not have the time (or skills) to provide proper pressure care.

Not enough staff, especially on weekends. My mother is sometimes not transferred to the "day room" until between 11am and 12 midday as there do not seem to be as many staff. This is after her having been put to bed at 4pm the previous day. I fear for her risk of pressure wounds now that the air mattress has been taken away. (Participant 34)

Residents' appearance

When relatives visited, they noted residents' appearance – their demeanour, cleanliness etc. When they saw residents walking around the aged care home with dirty clothes, they worried that residents were not safe.

I am scared often for the safety and wellbeing. The residents are allowed to walk around with soiled clothing and obvious smells of defecating on themselves. (Participant 118)

Response to call bell

Relatives were concerned when it took a long time for a staff member to respond to an emergency call bell. They worried what would happen if urgent attention was needed after a fall or heart attack.

It took 20 plus minutes for staff to arrive after a room buzzer was pressed (on at least 4 or more occasions)... Eventually I left the room to find a staff member and while walking towards reception, met a staff member slowly strolling toward the bedroom I had just left. I was asked if something was wrong! This, after the emergency buzzer had been activated multiple times, and more than 20 mins had passed since the last time it was activated. There was no concern that a resident may have fallen/ had a heart attack / was repeatedly buzzing as there could be a serious problem. When I responded by saying yes, the failure to respond. I was informed that the staff were busy as lunch was on. Most unprofessional and unsatisfactory. (Participant 143)

Residents walk out of aged care home

On some occasions, residents walked out of the aged care home without anyone noticing. Some relatives attributed this to providers not investing in a security system.

When the main gate is out of order then they can escape. It is continually being repaired and still it breaks down. Here is another case of not spending money! (Participant 131)

Valuables

Relatives described elderly people in aged care homes, particularly those with dementia, as vulnerable to being robbed.

I had my mum in transitional care in an aged care residence and she had all her rings stolen over a period of three weeks, every Wednesday night. When I reported the first one, I was told she must have flushed it down the toilet – that was something my mother would never had done. I tried to get the rings off my mum myself but couldn't remove them. When the next one disappeared, I was really upset as I knew they must have hurt my mum to get them off. Still nothing was done, no follow up whatsoever. I was told there was no point going to the police as the police wouldn't do anything. (Participant 39)

Suggestions for improving aged care homes

Relatives made some practical suggestions about how the current standards of care could be improved. Relatives claimed that aged care homes will need to improve before baby boomers begin to enter the sector.

They will need to change to accommodate us as we will find the activities and current food choices etc. unacceptable. (Participant 173)

Increased resources

Improving standards of care within aged care homes requires additional resources. Some relatives suggested the government should provide more resources to the residential aged care sector. Others did not want the government to provide another cent of taxpayers' money to aged care providers. Instead, they believed providers should make less profit (i.e. invest some of their profits into the aged care home).

The owners should spend some of their huge profit to enhance the final days of these poor individuals. The establishment is in desperate need of improvements... The caring staff do their best under the circumstances but they are over-stressed and over-worked. So how can they give each resident a fair go? (Participant 131)

Finding an aged care home

Relatives advised speaking with other relatives before signing a contract with an aged care home. They believed the best way to determine whether an aged care home was suitable was to hear the views of current residents and family members. Relatives also suggested visiting the aged care home on weekends – to see how many staff are on duty, particularly the number of registered nurses. Relatives believed staffing levels gave an indication of how well an aged care home was run.

Family members of anyone who needs high care residential accommodation should speak to family members of existing residents. It is too late once their family member enters. (Participant 82)

Website

Relatives suggested a website with reviews of aged care homes written by residents and relatives, such as Aged Care Report Card¹¹, might assist people to select a suitable aged care home.

Currently there's no way to know if a facility is any good other than to book yourself in there - and

then it's so hard to get out. I'd like to see a website where people could comment on their relatives' (or their own) facilities. There would be some 'unfair' comments, but they're evened out by honest feedback. (Participant 63)

A home

Relatives wanted aged care homes to remove the sense of institutionalisation by creating a home-like environment for residents. They suggested changing some of the terms used. Given an aged care home is neither a hospital nor a prison, those who live there should not be referred to as "patients" or "inmates". Some relatives suggested changing the term "aged care facility" to "aged care home"; others preferred to use the old term "nursing home".

It is still a bit institutionalised and has a hospital feel. We need to get away from this model and design nursing homes that are more like the name suggests - nursing 'homes'. (Participant 24)

To decrease the institutional feel of some aged care homes, relatives suggested aged care homes should be small. Some relatives suggested a maximum of 60 residents others suggested no more than 20 residents. They also need to be more cheerful, not glum like an institution.

Aged care facilities be smaller, not great barns with endless sterile corridors. (Participant 79)

To reduce the hospital-like feel, some relatives wanted staff to focus on personal rather than clinical interactions with residents. They suggested shifting the focus in aged care homes from medical management to emotional wellbeing and meaningful social interaction. In contrast, others suggested permanent medical staff should work in an aged care home.

Training and resident geriatricians /doctors should be interned into aged care. Easy access to doctors is important as by the time someone is in age end care 'high care' they need expertise for quality of life. (Participant 123)

A workplace

Although an aged care home is first and foremost the residents' home, relatives observed that it is also the staff's workplace. To be able to deliver high standards of care, relatives believed staff needed good working conditions. They needed to work in an environment where they were happy and encouraged to show initiative.

11 <https://www.agedcarereportcard.com.au/>

No one should work in a position of caring for others where the role is performed under stress – that is, the employee is overworked, the work environment is ill equipped, the facilities underfunded or the employee is doing the position as a last resort to get employment. (Participant 128)

Location

Rather than isolating older people by building aged care homes on the fringes of cities, aged care homes should be built within communities, close to hubs of human activities (i.e. near schools, shops and sports facilities). Local community groups should be encouraged to visit aged care homes and residents should be encouraged to be involved in the local community (e.g. RSL clubs). Elderly people should be encouraged to share their knowledge and be valued by the society that they have helped build.

I would move hell and high water to greatly increase human contact. I would make it routine to have groups of people (e.g. school choirs rehearsing, dancers rehearsing, dog trainers training, art classes doing portraits, etc.) coming in to all public areas in all kinds of facilities. (Participant 146)

One idea to encourage people in the local community and residents to spend time together is to have a public coffee shop or a community garden located within the aged care home. Another relative suggested inviting volunteers in the community to have morning or afternoon tea with residents. This would not only encourage social interaction but also help to ensure residents drank their morning and afternoon teas.

Another idea was to locate aged care homes and pre-schools close together. Co-located aged care home and pre-schools would provide an opportunity for residents to not only have exposure to young children (which many older people enjoy) but also for residents to assist/educate where possible.

Consumer participation

Relatives believed residents' quality of life in an aged care home would be improved if residents had more control over their lives. Most importantly, they need to be consulted on decisions in the aged care home that affected them (e.g. shower time, meal times, types of activities, bus trip itineraries etc.).

Aged care homes would also be improved by seeking residents' views about how their 'home' is run. It was suggested that this could be done both informally and formally (e.g. a Committee of Residents). In both cases, it was important that management listened to suggestions from residents, and responded respectfully.

Give residents a greater voice. I was very instrumental in getting residents to meetings with their families to voice their concerns. Prior to me getting there, staff used to run the meetings and no matters were raised or fixed. (Participant 1)

Aged care homes should be enabling residents to maintain a sense of independence and to remain engaged in meaningful activities. For example, relatives wanted residents to be able to continue to offer hospitality. Relatives suggested residents should be able to invite friends/family for dinner and to stay overnight.

It is very important for a resident to feel able to offer things to people they love, rather than being forced to give up all the pleasures and generosities of hospitality and independent personhood... The biggest improvement would be to provide for residents to have someone stay over with them, and share meals with them, perhaps even cook together, sometimes. (Participant 146)

Staff

Staff Numbers

The most frequently made suggestion for improving aged care homes was to employ more suitably qualified staff – not only registered/enrolled nurses and PCAs but also occupational therapists, physiotherapists, social workers, psychologists and kitchen staff. It was however acknowledged that employing more staff would increase costs for providers.

Relatives claimed there was a correlation between the number of staff on duty and residents' quality of life: the more well trained and empathetic staff on duty the higher residents' quality of life.

More staff across the board. Also need to ensure that there is a proper spread of qualifications across the staff – i.e. enough registered nurses, as well as PCAs. Staff don't all have to be registered nurses, but there should be enough registered to provide support and expertise. (Participant 89)

Having more direct care staff on duty on each shift would enable staff to spend more time with residents and not rush them with showering, toileting and eating. When these activities of daily living are not rushed, residents feel less anxious. More direct staff would also ensure call bells are responded to in a timely manner.

They need to have time to listen to residents and reassure them about what's happening rather than rushing them through a shower/dressing/meal times. (Participant 2)

More staff on duty during the afternoon shift would alleviate the problem of putting residents to bed immediately after dinner. It may also help reduce the need for medication to treat residents with "sundowners".

More staff with time to actively engaging with residents in the evening instead of the way they are put into bed the minute they have eaten dinner. (Participant 134)

Qualified staff

It was generally agreed that living well in an aged care home required staff who were well qualified and empathetic. Relatives suggested a higher ratio of registered nurses-to-residents should be employed in all aged care homes. This is important given the increasing percentage of ACFI care need ratings of residents for complex health care. Unlike PCAs, registered nurses are qualified to care for people with complex medical conditions and to work collaboratively with other health professionals (GP, physiotherapist, geriatrician).

Nursing staff with expertise in particular diseases suffered by residents and the capacity to provide real feedback to doctors to improve ongoing patient clinical care. (Participant 28)

To avoid medication errors, relatives believed only registered and enrolled nurses should be permitted to administer medication.

Permanent staff

Relatives claimed it was important for aged care homes to retain staff who are competent, approachable and cheerful. Permanent staff provided residents with continuity and familiarity.

Several relatives suggested residents be allocated a regular PCA. This would enable PCAs to get to know residents better – their likes and dislikes and their routines.

Mum needs to be somewhere with consistent staff who will get to know her. I like it if I feel my mum is known and her care needs are taken care of in the way she likes. (Participant 173)

It was also suggested that residents should have more control over who provides their care. Relatives wanted residents to be able to choose who provided care, and who did not.

My father feels affectionately toward some carers and less so toward others. This is natural for all of us to have preferences. I cannot see why he cannot have easier access toward one carer over another, provided the carer also is agreeable. (Participant 81)

Wages

Relatives believed staff remuneration should reflect the important job staff did in an aged care home. They believed registered nurses who work in aged care homes should have equal pay (and prestige) to registered nurses who work in hospitals. Some relatives suggested the lower pay rates for registered nurses in aged care homes were due to ageism.

Increased pay and conditions for staff would not only attract more people to work in aged care but also may improve standards of care. Relatives suggested that valuing staff more would encourage staff to value residents more.

I would stop the building of magnificent, tall structures and put the funds that are spent on luxury

trimmings into paying care workers better at all levels. (Participant 23)

Screening staff

In addition to the compulsory police checks for all staff, relatives recommended additional screening (e.g. personality tests) to identify those who were not suited to aged care work. They suggested additional screening may ensure elderly people living in an aged care home were not abused, neglected or exploited.

According to relatives, aged care work is “not just a job” and staff should not be in an aged care home “just for the money”. Relatives disagreed with programs that made “people on the dole” work in an aged care home.

Staff who obviously don't want to be there should not be made to work in aged care homes. (Participant 130)

In addition, relatives believed only staff who were able to speak, understand and read English should be employed in an aged care home.

Staff who do not speak clear and discernible English should not be employed especially in dementia units where behaviours quickly escalate because residents do not understand what they are being asked. (Participant 99)

Training

According to relatives, all staff should be better trained before they begin working in an aged care home.

Better structured training for all staff should be mandatory before being able to work in aged care. All staff including maintenance should do a dementia module before applying for a job. (Participant 126)

Relatives were most concerned about the current training of PCAs. PCAs should attend a properly accredited training program delivered by a public training organisation. They did not want “dodgy” private training organisations offering short aged care courses. Some relatives were particularly concerned about the recent introduction of online courses.

Relatives wanted PCAs to be taught the signs and symptoms of medical conditions that are common among older people.

Staff should be trained so that they are more aware of conditions of the aged and reasons for behaviour (e.g. a resident who goes “off” could have a urinary tract infection). They should also be aware of medical conditions pertinent to the aged such as signs of stroke or heart problems. (Participant 174)

Relatives did not want newly qualified PCAs to be responsible for residents with high care needs. The most vulnerable residents need to be cared for by experienced PCAs. In addition, all staff should receive ongoing professional development.

The more officious staff (sometimes the longer-serving people) could do with professional development reminding them to not sacrifice the 'care' part of their job for convenience or complacency. (Participant 84)

Some relatives thought better training and ongoing professional development might help staff to better understand sexuality and sexual diversity among residents. They also wanted training to focus on cultural issues.

There are issues of a joint misunderstandings of a 'cultural' nature between the older Caucasian residents and some carers. Training would assist here. (Participant 164)

Supervision

According to relatives, PCAs needed better supervision. However, they believed registered nurses were too busy to provide PCAs with the supervision required. Relatives suggested the roster nominated a senior staff member to work as a supervisor/duty manager on each shift. Their role would include ongoing training for PCAs and other staff. Some relatives also suggested PCAs would benefit from a mentoring program.

Engage an experienced staff member to walk around and watch. This person could check that hygiene has been attended to. They would notice if a resident is delirious as opposed to demented and would identify falls risks. Quality doesn't happen because there is a policy. It happens because a person is making sure it happens. (Participant 20)

Managers

Rather than spend the majority of their workday in their offices, relatives wanted managers to be more “hands on”. They believed managers being “on the floor” would help them to be more aware and responsible about the day-to-day care of residents.

The 'big wigs' from the top (managers) need to do a 'buddy' shift and work on the floor so they can see the workload that is required of the staff before they make decisions (e.g. to reduce staff numbers). (Participant 77)

Multidisciplinary staff

Relatives wanted multidisciplinary staff such as physiotherapists, social workers, psychologists, occupational therapists and podiatrists to attend aged care homes more frequently. They did not want the specialist staff to be students. They wanted them all to be fully qualified.

I think there needs to be a lot more social/emotional/grief counselling type support for people who are sad, lonely and know the only way out [of the aged care home] is death. (Participant 2)

Uniforms

There were different views about uniforms. Some relatives wanted staff to wear uniforms – so they knew who was who, and who was responsible for what. Others felt the lack of uniforms made the aged care home more home-like.

Person-centred care

According to relatives, personal care would be improved if all residents received person-centred care. However, relatives acknowledged diversity among elderly people in an aged care home made this difficult. Residents had a range of cognitive and physical abilities, different needs, interests, cultures, religions, socio-economic backgrounds, sexuality etc.

The variety of personalities and personal needs in aged care residences make it a very tough environment to meet each individual's requirements. (Participant 84)

Person-centred care required staff spending time with residents so they can “really know residents”. Relatives suggested staff listen to residents whilst they were assisting them with activities of daily living (showering, dressing etc.). Relatives would like staff to care about residents and their welfare. They would also like staff to always show residents respect.

Don't make jokes at the expense of the residents or poke fun at the residents. Respect at all times. (Participant 111)

The staff that remain aware that the elderly person receiving the care is still in the room. Staff should include them in any discussions taking place. (Participant 128)

Some staff need to be reminded not to speak to residents as if they are children. Staff also need to encourage residents to do as much for themselves as possible. Although it is quicker for staff to do things for residents, it is much better for residents' self esteem if they do things for themselves. Care would be better if staff allowed residents to set the pace.

Care plans

Relatives wanted individual care plans to be developed in partnership with residents, relatives and health professionals. They believed involving residents and relatives would enable staff to provide better person-centred care. They also thought it was important for care plans to be updated as residents' needs changed. Some relatives noted the importance of PCAs being able to read care plans and follow them.

Have care plans for the individual that are arranged with the family member and the resident and make sure they are followed. (Participant 108)

Privacy

Relatives believed residents needed more privacy. At the very least, they wanted staff to always knock before entering a private room.

Deaths and funerals

Although relatives were aware of privacy laws, residents and relatives would like to know when another resident was unwell or has died. When residents were sick (e.g. hospitalised) or died, relatives suggested managers seek permission from the next of kin so that friends in the aged care home could be informed. This would enable residents and their relatives to send flowers to friends and attend their funerals.

There apparently is an issue in disclosing if a resident is ill/ passed away. If this is a privacy issue, perhaps a register could be set up whereby permission is given to pass this onto others so they are not suddenly confronted with a situation (e.g. a resident has not been seen for a while, and weeks later finding they had passed away.) It would be nice to be able to pass on condolences prior to a funeral, or possibly attend, rather than a resident (and their relatives) with whom you establish relationships, to all suddenly disappear from the facility, generally without warning or prior notice. (Participant 143)

Managing risk

Relatives wanted residents to have as much independence as possible, even if this increased their risk of injury. They felt good communication between management and relatives should alleviate management's fear of litigation.

Respect resident wishes when they wish to do things for themselves even though there may be some "risk" involved (i.e. they allow people to take personal risks rather than infantilising them). My grandmother showers herself and it's important to her that she does this even though she is at risk of falling. (Participant 127)

Working with families

Relatives believed working collaboratively with families not only enabled staff to "get to know" residents but it made staff's work easier.

I would ask management to recognise that we, the immediate relatives, want to be a team with management and PCAs. I want to be consulted, respected and included. I wanted to know that everyone can be honest and provide the best possible care for my relative. (Participant 115)

Relatives suggested some type of orientation for families and a regular newsletter to keep relatives informed about any changes in the aged care home (e.g. new staff).

An orientation for families might have been helpful. Perhaps not something we had to attend but a booklet or an online doco of what the day was like for residents? I was familiar with many nursing homes as I had been a community nurse but my siblings and children were quite freaked out when they went there. It became Dad's home and the carers became quite close to him. When he died that was it. I only returned once after that - as I live quite a distance away. I would have liked to have had some contact or news - a card or a newsletter from time to time. (Participant 128)

Relatives wanted staff to communicate with them when new initiatives were trialled in the aged care home.

Our facility started a pilot pastoral care program which involves a chaplain type person coming once a week but there has been no report on the success or otherwise. (Participant 2)

Relatives suggested all "outside visitors" to an aged care home should have a police check. Some believed "outside visitors" included relatives (i.e. all relatives who visit an aged care home should have a police check).

Outside visitors also need to be screened and supervised so they cannot influence the patients. Most outside visitors have good intentions, but unfortunately the odd unscrupulous person slips through occasionally. (Participant 87)

Communication

Relatives noted that aged care homes required staff who could communicate with residents. Relatives believed some staff, such as some PCAs who did not speak English as their first language, should be required to undertake English training.

Carers to have better English understanding and speech so questions get answered correctly and the residents understand what is being told to them or asked of them. (Participant 49)

In some aged care homes, residents speak languages other than English. In these aged care homes, relatives wanted some staff to be employed who speak the relevant languages.

Employing staff who have relevant resident language skills (e.g. Italian) There are many Italian residents with dementia and no one on duty speaks Italian! (Participant 6)

Living will

Relatives wanted all aged care homes to document residents' end of life wishes in a living will. They wanted living wills to be updated when residents' health status changed. They also wanted staff at the aged care home to respect the wishes that had been documented in a living will.

All residents should have living wills in place. These living wills must be honoured and respected. (Participant 155)

Routines

Relatives suggested schedules in an aged care home were designed to suit staff more than residents. Although residents benefitted from routines in an aged care home, some residents did not like being woken up and put to bed so early. Relatives wanted residents to be consulted about the time they would like to be woken up, assisted to bed and showered. For example, some residents prefer a shower in the evening.

Relatives suggested a routine be established to remind residents to drink. They were concerned that some residents do not drink enough.

I have already raised with management the need to offer residents morning and afternoon tea at set times so they can be reminded to have a drink and asked for water to be offered first with meals. (Participant 2)

Environment

Relatives wanted aged care homes to “replicate the home environment” so residents could do more things that reminded them of home (e.g. hanging out washing, sweeping paths etc.).

Smaller and more intimate lounge room areas and dining areas to replicate the home environment. More backyard gardens to wander in safely to get exercise and sunlight and do activities like veggie gardening and pegging up washing or sweeping a path. Just things people do at home normally. (Participant 24)

Relatives suggested providers consult with “a well-educated age care professional to assist in creating an appropriate environment”. In addition, aged care homes should comply with disability legislation.

Doorways and entrances and exits need to be electronic so that wheelchairs can be pushed through them without injury to residents and family members. In other words the facilities need to be compliant with current disability legislation. Currently many are not. (Participant 32)

Communal areas

Relatives believed the lounge room should be a welcoming space. In addition, they wanted a PCA to be allocated to the lounge room to assist residents when required.

The common living area is not always monitored so residents that are not mobile have to wait when needing assistance... I would make it a mandatory requirement to ensure there is always at least one carer present in the common area when there are residents present. (Participant 67)

Relatives suggested communal areas should be designed to both encourage spontaneous engagement between residents and also better accommodate visitors.

There need sufficient areas for family and visitors to meet with residents that are private and large enough to accommodate such gatherings. (Participant 32)

In addition to a large communal lounge room, relatives suggested some smaller spaces for reading and crafts.

Little areas for those who can, to get away perhaps reading nooks, knitting nooks with materials provided. (Participant 7)

A relative had an idea for combatting the distinctive smell that remained in some aged care homes.

Work out a way to deal with the distinctive and distasteful 'smell' of most facilities. Air conditioning just seems to move it around. Some sort of filtration system maybe. (Participant 49)

Bath

Relatives suggested aged care homes install a bath so that residents who enjoyed baths could have a bath from time to time.

Outdoors

Relatives wanted outdoor areas to be designed for active use – so residents could enjoy fresh air and sunlight. They suggested activities such as afternoon tea in courtyard and vegetable gardening). To enable residents to enjoy spending time outdoors, the outside areas needed to be accessible (e.g. doors unlocked, handrails, outside alarm). Relatives noted staff would need to supervise residents when they were outside. This would involve employing additional staff.

More established gardens, shaded verandas so residents can go outside everyday weather permitting. But you would need to have sufficient staff to be able to take residents outside - this does not exist. (Participant 32)

Rooms

To ensure residents were safe in their room, some relatives suggested they be allowed to install video surveillance. The change.org petition ‘Stop Elderly Abuse In Aged Care ... Support Video Surveillance Cameras In Residents Rooms’ has over 43,000 supporters. Some relatives, however, were concerned that video surveillance impacted on residents’ privacy.

Cleaning

Some aged care homes required a higher standard of cleaning. Relatives also suggested a warning sign was used to alert people when chemicals were sprayed in rooms.

I need to ask for rooms to be cleaned properly - by that I mean if there is a mess from toileting and carpets are steam cleaned, cleaners just do spots and leave what lies underneath bed / chairs etc. The dining area could be cleaner too. Again, this comes back to a level of caring. (Participant 15)

Services

Meals

A relative suggested Jamie Oliver should do an exposé on nursing home food like he did of lunch at US schools. Another mentioned Bond University's project in which they filmed the reactions of people who were not residents of an aged care home eating a typical aged care meal¹².

Choice

Relatives suggested staff should consult residents about their food preferences. At the very least, residents should be given a choice.

Give residents some choice in food would be great. I appreciate this is tough where numbers are high but if they could choose in advance, surely this could be managed. (Participant 15)

More staff

Relatives claimed more staff were needed at meal times – to ensure those residents who needed assistance were fed slowly and responsibly. In addition, a relative wanted staff to notice if a resident was eating alone in the dining room and for staff to ask whether the resident would like to move to another table.

Nutrition

Residents' wellbeing depended on nutritious and delicious meals. A relative suggested cooks in aged care homes should be encouraged to attend the Maggie Beer Foundation workshops.

Relatives believed meals needed to include more fresh food (salads and fruit) and fewer fatty stodgy desserts. Morning and afternoon tea should also be more nutritious (e.g. fruit) rather than cake and a sweet biscuit.

Flexibility

Relatives did not want access to food to be restricted to meal times. They also wanted some flexibility in the way meals were served.

People should be able to eat at any time really, at least some snacks should be available so you can grab a bowl of cereal if you like, or some fruit. A smorgasbord breakfast would be good so you can get up late or early. Brekky in bed would be nice if you want it. Dinner on your lap in front of the telly is nice sometimes too. Meals for visitors would be good. (Participant 173)

Preparation

A relative observed that some residents might enjoy helping staff in the kitchen.

These people, should they choose, should be able to participate in food preparation. Given them a goal. They have retired, and deserve a rest, but they're not dead. (Participant 31)

Variety

Relatives wanted kitchen staff to give more thought to “menu planning”. Rather than provide repetitive meals, they wanted residents to have variety. They also wanted meals that catered for different cultural and religious preferences.

The food needs to be varied, healthy and interesting and above all yummy. (Participant 119)

Have a better catering service - after all we are a multi ethnic society with different food needs. (Participant 43)

Kiosk

Relatives thought all aged care homes should have a kiosk or coffee shop on-site.

A coffee shop where friends or family could take the resident to buy tea/coffee and cake, or even a light meal, would be great and allow residents more independence when receiving visitors. A small shop or kiosk that sold chocolates, lollies, biscuits, cards, small gifts etc. would be a welcome addition. (Participant 29)

Laundry

Relatives claimed more care needed to be taken with residents' clothes. Aged care homes should supply facilities for washing fragile articles of clothing (e.g. woollen clothes) and offer a regular dry cleaning service (e.g. once per month). Some relatives were prepared to pay extra money for a better quality laundry service.

Laundry to include hand washing and ironing even if extra cost required (Participant 98)

12 <https://www.youtube.com/watch?v=7p7S7caNPXA&t=101s>

Activities

Relatives believed aged care providers had a moral responsibility to ensure residents' wellness and quality of life. Relatives claimed aged care homes must therefore provide opportunities for residents to be actively engaged in meaningful and enjoyable activities. Relatives found it unacceptable when residents spent their time just sitting around in front of a TV.

Relatives made many suggestions about how to improve activities that are offered to residents in aged care homes. These suggestions include:

- Increased resources
- Consumer consultation
- Types of activities
 - Inclusive
 - Meaningful
- Involving local communities
 - Volunteers

Increased resources

Relatives suggested making it compulsory for aged care homes to employ qualified staff (diversional or occupational therapists) rather than rely on PCAs and volunteers to provide activities.

Make it compulsory to engage a trained occupational therapist to lead the residents in valuable interesting activity within and without the facility - reading to school kids, teaching kids to knit, crochet etc.; holding debates and competitions to keep residents active and involved with their fellow residents and the younger folk in the community. (Participant 156)

Qualified staff

Relatives observed that many residents required encouragement to participate in activities. They noted that diversional and occupational therapists were trained to engage/motivate residents with diverse abilities and interests.

By asking more residents to actually join in. This could mean going to individual rooms and reminding residents that activities are taking place. My stepfather has Alzheimer's and would love to join in activities, but forgets when they are on, and so misses out on taking part. (Participant 39)

Relatives wanted inclusive activities that were tailored to residents' needs, interests and abilities. Although more women than men live in aged care homes, activities need to be provided that are suitable for older men. Relatives observed that male residents may not want to attend sewing and knitting groups. In addition, professional people should be employed to provide entertainment, educational programs (e.g. stimulating speakers) and art/craft. Aged care homes should not rely only on volunteers.

Relatives wanted activities to be offered during afternoons, evenings and weekends. This would require

employing more staff. They believed it was particularly important for residents to have something to do after dinner rather than just watch TV in their rooms. They suggested activities such as 'armchair travel' and activities that encouraged residents to reminisce (oral histories, digital diaries).

Relatives suggested activity staff supported residents to organise their own groups and activities. Residents with similar interests could form groups such as book, movie, gardening, sewing and knitting groups. Residents could also play card and board games together and do jigsaw puzzles.

Equipment

Relatives claimed aged care homes should provide/maintain equipment (e.g. bus, wheelchairs) so that all residents had an opportunity to attend activities.

Many residents can't get to these activities, as they are bed bound. They must provide sufficient lifting machines, auto beds and wheelchairs to get people to attend activities. (Participant 70)

Consumer consultation

Relatives suggested consulting residents to determine what activities they wanted. They also believed activity staff who took the time to get to know individual residents' interests would ensure activities were suitable for them.

Residents surveyed about what they want - different people need different things - some might be happy with card games others might need something else - choice is important. (Participant 93)

Involving local communities

Relatives wanted aged care homes to be actively involved in their local community. This included performers (e.g. singers, dancers, magicians, school choirs) visiting the aged care home. It also included residents sharing their skills with people in the community.

A relative suggested staff identify residents' skills/expertise and whether they would like to teach people in the local community (e.g. teach refugees English). Another relative suggested aged care homes open a cafe that both residents and public could access. This would help to connect residents with people in the local community and vice versa.

Be more open and engaged with the public e.g. having a public cafe that residents and the public have access (there should be a way to manage resident security). (Participant 98)

Volunteers

Relatives believed volunteers – preferably from the local community – should be encouraged to visit residents in aged care homes and assist with activities.

Volunteer engagement as visitor companions to frail elderly who are confined (by choice or necessity) to

their rooms. If palliative care organisations can work out how to use suitably trained volunteers, aged care should surely be able to do the same. (Participant 105)

Relatives observed that staff were often too busy to have an informal chat. Relatives suggested volunteers could have “normal” conversations with residents. In addition, regular visits from schools and childcare centres would be “good for both residents and the kids”.

Provide people who offer conversation. The only people who speak to my father are those who are providing personal care or health related matters. Dad hates being medicalised...The immobilised cannot participate in bingo. They just want to have a conversation about something other than their bowel movements. (Participant 20)

Types of activities

Relatives wanted aged care homes to provide activities that were mentally stimulating and meaningful. They also wanted activities that encouraged residents to exercise.

Meaningful

Relatives wanted residents to be offered meaningful activities rather than “kindergarten activities” and “rubbish activities to fill in time”. They suggested activity therapists “think outside the box of Bingo and word searches”. They suggested residents with low care needs could learn new skills such as how to use a computer, smart phone and ipad.

Relatives suggested a range of activities to accommodate the different capabilities of the residents. For example, residents who were able (and willing) could help with “chores” in aged care home, such as food preparation, setting dining room table, folding napkins and sweeping courtyard. Occupying residents with low care needs with “chores” had the additional benefit of allowing diversional staff to spend more time with residents with high care needs.

Relatives suggested more activities were required for those in high care units, noting that residents with dementia needed stimulation “in the moment”. They suggested music therapy and massage (e.g. foot and hand massages to improve health and wellbeing).

They also noted the need for rehabilitation activities for those who might have suffered a stroke/fall. Activities should also cater to residents’ cultural needs.

Exercise

In addition to activities that kept residents’ minds active, aged care homes needed to encourage residents to exercise. Staff should be encouraged to take residents for walks, preferably outside in the fresh air in the courtyard garden or local park.

Residents who were able could also have regular strength training exercise classes (yoga, Pilates, water aerobics, swimming, gym etc.). Relatives also suggested dancing, noting that music was a powerful motivator for physical activity.

Bus trips

Rather than offer sightseeing bus trips that take residents to the same sights, relatives suggested purposeful bus trips (e.g. a trip to shopping centres, cafes etc.)

Maybe take some people shopping or to a coffee shop, not coffee from a thermos on the bus. (Participant 29)

It was acknowledged that it was time consuming to get some residents on the bus. It was suggested that separate bus trips should cater for residents with high and low care needs.

Pets

Relatives would like aged care homes to have a resident pet (e.g. fish, cat, dog) to engage and interest residents. They also suggested a ‘Pets as Therapy’ program.

A facility-trained dog like those that I understand are being used in Europe and Israel (Participant 152)

Systemic change within the residential aged care sector

The final section of the findings relies heavily on relatives' voices. Relatives claimed the system needs increased government oversight to ensure elderly people have the highest possible quality of life during their 'twilight' years.

Moving into an aged care home

The current process for moving into an aged care home is complicated and time-consuming. Relatives suggested simplifying current bureaucratic processes.

In aged care facilities generally, I would change the complicated and time consuming processes to get into an aged care home. Currently it's a minefield trying to complete forms, juggle Centrelink, organise bond payments and secure a place at the preferred facility. (Participant 49)

To help families make an informed decision when choosing an aged care home, access to the following information may be helpful:

- Rosters (both weekdays and weekends) including the ratio of both PCAs-to-residents and registered nurses-to-residents
- Accreditation reports including reports of any unannounced visits
- History of complaints to Aged Care Complaints Scheme
- Recent menus
- The activities' schedule
- Minutes of resident meetings
- Company's annual report

Location

Relatives suggested policies are required to ensure those living in rural and remote areas receive appropriate aged care.

Elderly people in rural/farming communities usually have to move away from the environment and community they love, in order to find support and care if they don't have resident children nearby. It would be great to investigate the specific needs of rural elderly and to try and create aged care facilities in rural localities. Especially as our farming population is ageing rapidly. (Participant 141)

In response to the dearth of aged care homes in some rural and remote communities, the Multi-Purpose Services Program was introduced. It is a joint initiative of the Commonwealth Government and state/territory governments to provide integrated health and aged care

services for some small rural and remote communities. The Multi-Purpose Services Program enables services to exist in regions that cannot viably support stand-alone aged care homes.

Current model

The experience of visiting an elderly person in an aged care home had left several relatives with no confidence in the current aged care system. They believed the current model does not guarantee a resident has a high quality of life during the last year, or years, of their life.

If we are going to maintain the lives of our loved ones by supplying quantity of life then we must supply quality of life at the same time. (Participant 87)

Some expressed a preference for euthanasia rather than to live the last part of their life in an aged care home.

I'd rather shoot myself than end up in one! (Participant 40)

My experience has left me with no confidence in the aged care system. It is predicated on big profits and providing the minimum service they can get away with. There is no value for money, there is no dignity, and quite frankly I would rather take my own life than ever be forced into one of these. (Participant 79)

Preferring to be euthanised than live the latter part of life in an aged care home suggests that the current model is not working as well as it should.

The high rise ensuite hostel room model of aged care residence is stripping elderly people of their capacity to watch the world go by from a safe place where they can decide what they eat and the hours they will keep. (Participant 105)

Some relatives claimed the government needed to "overhaul" the residential aged care sector. They claimed some providers were making "record profits" from government subsidies.

We need to have a massive overhaul of this most terrible situation... need the laws to change and stop this 'gravy train' in its tracks. I can't begin to imagine the cost to the public purse. (Participant 131)

These facilities are not going to change whilst they are bringing in record profits. They need to be judged by an independent and objective third party and to be held accountable. Families need to be included in this process...they are the ones dealing with this on

a daily basis, having to fight for the rights of their loved ones, with nothing to indicate that there is any positive change on the horizon. This industry needs a wake up - we will all be old one day if we are lucky enough and this is not how I would like to live out my life. Time to address and enforce positive change. (Participant 15)

The whole system has to be overhauled and governments to be accountable by making stiffer laws for anyone to operate a nursing home and facilities heavily fined if there any founded complaints made against them. (Participant 18)

Some relatives suggested studying different models of residential aged care, including those that were being implemented overseas.

Nothing I've seen to date gives me anything but a sense of dread for reaching an age or time or situation where I would need to be in an Aged Care facility. I have been giving it a lot of thought in the last 24 months and I'm already exploring the idea of creating a private residence with like minded friends. We have to take some responsibility for this and highlight what works well and identify what the break-even costs are for creating best practise aged care. We need more models to study. (Participant 128)

Aged care industry

Relatives believed aged care should be motivated by 'care-giving' rather than 'profit-seeking'. They were appalled that aged care had become a profit seeking "industry".

There are too many horror stories about aged care and the mistreatment of aged residents. It is not an industry that I trust at face value in part because I don't believe it should be an industry. My experience this far has been one of money grabbing rather than communicating value. (Participant 111)

Several relatives disagreed with the privatisation of aged care homes: they believed aged care homes should be in public, not private, hands. In addition, they believed local councils rather than the federal government should manage aged care homes.

Remove the profit motive. Aged care should be government run, not for greedy corporates to profit from our aged. (Participant 79)

Less than 6% of people aged over 65 years old need residential aged care. It should just be free; recognised as a responsibility of society. The whole system needs reform and the creation of an aged care industry is monstrous. No one should profit from the most vulnerable people in our community and all respect should be shown to the aged. (Participant 111)

The government needs to take them over. There needs to be greater regulation and accountability by appropriately qualified persons who are not part

of the aged care industry... My mother's and my experience of this aged care facility over a 5 year period can only be described as horrific for everyone involved. Immediate government intervention is needed to ensure that our elderly relatives are treated in the same way as other citizens are. The current system is a disgrace. (Participant 32)

I am a strong supporter of local councils and community groups owning and operating nursing homes. The profit driver of private sector providers compromises quality of care for residents as they try to reduce costs to maximise profits. I think the child care sector is a prime example of what happens when the private sectors operates in the industry- unaffordable child care, even though child care sector workers are very low paid. I am worried that the aged care sector is going down the same route and in 10 years only the wealthy will be able to afford nursing homes. With the state government going out of service provision for aged and disability care, the responsibility of service delivery now falls on local governments with federal government funding. I think local governments are best placed to provide these services anyway because they employ local people who often know the residents in their local community and the care is better. (Participant 24)

Profits

Some relatives had studied providers' annual reports. They alleged some aged care homes were making large profits based on government subsidies, accommodation bonds, and daily fees (including extra and additional fees).

Relatives believed there should be less emphasis on profits and more emphasis on providing a high quality of life for residents. A relative suggested there should be a limit on the amount of profit any one aged care home could make per year. Another suggested providers should be obliged under contract or consumer law to provide services for which residents had paid.

If providers had to prove to relatives that they had actually provided the services for which their relative had paid, then they might actually do it. The gulf between the rhetoric about aged care in this country and the reality is vast. I would like governments to serve the interests of the frail aged, and not the corporate interests of the providers, both private and church run. You don't mind paying if your relative is actually being cared for; but mostly, he is not. He might as well be in a prison, albeit a prison with a very fancy foyer. There is a fiction in this country that providers are going broke. This is not true. (Participant 81)

Transparency and accountability

According to relatives, the aged care sector requires increased transparency and accountability. For example, a relative suggested the names of aged care homes that had complaints made against it, the nature of the complaint and how the complaint was resolved should all be on the public record. Access to this information would enable people to check the aged care home's history of complaints before a resident moved in and signed the contract.

Given the correlation between staffing levels and standards of care, some relatives wanted access to aged care homes' staff rosters. They believed they had a right to know the ratio of both registered/enrolled nurses-to residents and PCAs-to-residents before choosing an aged care home. One relative suggested this ratio should be included in the contract. If the aged care home reduced staffing levels, the resident could sue for breach of contract.

Accreditation

Relatives believed the current accreditation system needed to be improved to ensure providers were accountable for standards to care in aged care homes. Rather than the current "vague outcomes", the accreditation process required measureable outcomes. The Quality Agency should have the power to issue a "substantial fine" to aged care homes in breach of standards.

Greater accountability is needed in the accreditation process. Currently facilities put on a great show for the accreditors – policy and procedures are pulled out and on show. The rest of the time they are not adhered to. Facilities should be fined if they are found to be in breach of any of the standards once they have been accredited. This can only be done under a system such as Worksafe. (Participant 26)

I want to see government policy that pays attention to the quality of services to residents - as assessed by residents wherever possible (are they ever surveyed during government accreditation processes??) - rather than some government regulation tick box system. (Participant 154)

For the Quality Agency to not announce weeks ahead when they will be coming so that the facility can put extra staff on and be prepared. For the Quality Agency to do what it's intended to do and provide real reviews...and where necessary step in and advocate. (Participant 15)

Care data must be collected so that care can be measured, benchmarked and improved across the whole sector. (Participant 28)

Unannounced visits

Relatives believed the Australian Aged Care Quality Agency should do more unannounced visits to aged care homes, including during weekends and at night. Under no circumstances should there be prior notification of these "spot checks".

Government intervention

Relatives claim that both residents who live in an aged care home and staff who work in an aged care home are currently vulnerable to providers exploiting them. For example, residents may not receive the personal care and services for which they have paid; staff may be forced to work in unsafe workplaces.

Both residents and aged care workers are vulnerable because of the lack of legalised, regulatory oversight in this sector. (Participant 25)

Probity

Relatives wanted the government to undertake thorough probity checks of local and multinational providers to avoid unscrupulous providers obtaining licences to provide residential aged care.

There needs to be more scrutiny around who is given a licence to own or run a nursing home. (Participant 119)

Regulation

Although the Aged Care Roadmap recommends decreased regulation, relatives advocate for "much, much stronger regulation". Relatives believe deregulation has been "good for providers but not for residents".

Relatives believed regulations should enforce minimum standards of care and staff ratios in residential aged care like they do in schools, child-care centres and hospitals.

The facilities need to be regulated like schools and hospitals. They need to be taken over by the government and safe guards provided that ensure these facilities provide the care that our old people require including nursing staff to resident ratios and financial and workplace health and safety accountability. A doctor needs to be on site. (Participant 32)

The Aged Care Legislation needs to be similar to Child Care Legislation. You need more Registered Nurses and carers and you need to pay them a salary reflecting this important and difficult job. (Participant 107)

I'm wanting to see a major change in the way the Government overseas these institutions... There seems to be the same denominator in all aged care facilities. They manipulate the system to suit them not to actually care for the elderly. It is a money making business. They take big money, for little return. (Participant 27)

Funding

Relatives acknowledged that residential aged care homes needed more resources. However, there was disagreement about who should provide the additional funding. Some claimed governments should invest more money into residential aged care so providers “are able to offer dignified, quality care for people”. Others claimed companies and their shareholders should make less profit so aged care homes “are able to offer dignified, quality care for people”.

Relatives suggested the federal government should mandate a proportion of profits to be spent on improving standards of care in aged care homes.

Since the changes of 1 July 2014 providers have had massive increases in profit/surplus. In my father's aged care place, they went from a surplus of \$1.68m in 2014 to over \$9m in 2015... Government needs to get this right and fast. Aged Care is a cash cow up here in middle class Sydney. Even that would be okay, except that my father does not get the care he pays for, and that the Commonwealth pay for. He does not get it, most of the time. I have moved him once and do not wish to do so again; but if what happened to other residents here happens to my father, I will not be engaging with the toothless complaints scheme. I will be going to the courts, and I will be suing under contract law, not torts. I am no longer interested in meaningless talk about 'care'. There is no care. (Participant 81)

Relatives had the following innovative ideas:

- Tie government funding to standards of care;
- Allocate funds to residents not the aged care home;
- Introduce a Medicare type levy; and
- Introduce a type of ‘aged care fund’ (similar to a ‘superannuation fund’).

I wish I knew the solution to making life happy and productive for those elderly people in care. More money is needed in the system but not sure how to achieve this. I fear for the future as the relative numbers of aged increase. The government cannot fund everything. Perhaps some sort of super type fund for workers to assist catering for aged care or a Medicare type levy. (Participant 164)

Funds (e.g. ACFI) should be allocated to individuals and not the facility. Residents or their representative should be involved, approved and know what funding is approved in their name. (Participant 6)

Fines

Relatives wanted the government to impose “real financial penalties” for repeated failures to provide services as defined under the Aged Care Act 1997. They also wanted substantial fines to be imposed on those who rort subsidies from the government by incorrectly claiming residents have high care needs.

They falsely claimed Dad had Parkinson's Disease, and related health deficits, for which the provider claimed the maximum subsidy. When I complained of fraud, the government Wallahs told me they “must be able to trust the word of the health care professionals at the aged care facility”. (Participant 81)

A relative compared the current fine of \$10,800 for providers who repeatedly make false claims against the potential gains. Working with the calculation that the maximum subsidy per resident was around \$211.40 per day, an aged care home with 60 residents all classified as high care needs in the three ACFI domains could receive as much as \$12,684 per day from the government. The relative doubted the new fines would prove much of a deterrent when such profits are in the offing.

Mandate staff ratios

Relatives want the Aged Care Act 1997 to mandate a staff-to-resident ratio. They recommended replacing the stipulation for “an adequate number of suitably qualified staff” with a specific ratio of staff to residents (similar to the Victorian government’s ‘Safe Patient Care Act’). The Age Care Act 1997 should also specify the level of training of staff.

I would like to see a definition for "an adequate number of suitably qualified staff" as stated in the Act, and that laws were introduced to ensure aged care providers were charged with neglect if they do not meet their obligations to provide such staff. (Participant 25)

Rather than rely upon providers to “do the right thing”, relatives believed the government must mandate ratios.

Increase the number of "suitably qualified" staff who work in aged care facilities by having an "adequate" Government Legislated staff (on the floor) to resident ratio in place - taking into account - as aged care residents age and become high care - more staff are required. (Participant 17)

Government mandated staffing ratios are essential for aged care sector. Private operators too often cut numbers of staff or numbers of staff with high level qualifications - this needs to be reversed via legislation... Make it mandatory to have registered, well-trained nurses on every shift. (Participant 154)

A relative stated “government needs to get some backbone on this issue”. Relying on the free market to regulate the residential aged care sector, or the providers to self regulate, was considered to be in the interests of providers not residents.

We need legislation that dictates staffing ratios rather than leaving it in the hands of management who really only care about their bottom line, some of these issues might be alleviated. (Participant 15)

Personal care will only improve when the regulator regulates. Providers will not self-regulate. (Participant 81)

Training

Relatives put the onus on the federal government to improve training of PCAs. They also wanted the federal government to legislate to make it compulsory for every aged care home to provide ongoing training.

Unless the government puts more money into training carers in nursing homes, we will continue to have poor quality staff. These people do an amazing job, are poorly paid, and need to be up-skilled to increase their desire to stay and be committed to their patients. (Participant 163)

The staff should be better trained and re trained from time to time. (Participant 165)

Pay rates

Relatives wanted the government to ensure staff working in aged care homes were paid appropriately. They believed proper remuneration would help to foster best practice standards of care in aged care homes.

Royal Commission

Some relatives believed a Royal Commission into residential aged care was needed to identify the extent of the maladministration in residential aged care sector.

Unless a comprehensive inquiry is undertaken into residential aged care, we will continue to see significant numbers of residents dying through neglect and poor care. (Participant 108)

I honestly think that in time there will be a Royal Commission to find out how it was possible for the frail aged to cough up \$850,000 and (in our case) \$1000 a week, and be as consistently neglected as my father is. I note that the bond was meant to be capped at \$500,000 after 1 July 2014. Nowhere anywhere around here, I can tell you. For myself, I have been entirely radicalized after what happened to my father at the hands of the health, hospital and aged care systems. I no longer have any confidence that government acts in the interests of the citizen. I am dismayed and disturbed that government is so willing to facilitate a massive transfer of assets from the Depression generation to Aged Care Inc/Church, and yet so unwilling to hold these institutions to account... We have had four little old ladies who died in the last two months because they were neglected. You know what? None of the authorities care about neglect. I do not mind if my father dies. I care a great deal if he is left to rot. To avoid that, I must go every day to provide the care that the [aged care home] does not, I assure you, provide. (Participant 81)

In an email to Sussan Ley as the then Federal Minister for Aged Care, a relative gave the following list of reasons for why there should be a Royal Commission.

1. The extent of abuse and mal-administration Australia-wide is needed to surface the depth and nature of the crisis.
2. The community is conditioned to Inquiries first and solutions later; (e.g. Catholic Church, Aboriginal land rights, the banking sector etc.).
3. Until an Inquiry is conducted – the key areas for expenditure and improvement will not be fully known nor understood.
4. More government money is not the answer to known problems in the sector; It is more effective regulation, accreditation and monitoring – coupled with mandating of nursing ratios etc.
5. Governments have to be made to feel the heat on this issue as well; Royal Commissions are not just for media / voters.
6. The aged care sector needs to pause, recalibrate itself and start afresh following the findings of a fully constituted Royal Commission.
7. Our elderly (just like the very young) deserve the integrity and impact only a Royal Commission can deliver.
8. The industry is on the cusp of becoming a very significant employer and economic contributor – it is therefore essential that Government set the ground rules for an industry which hitherto has shown a willingness to cut corners and treat residents with callous disregard – in some instances which we know about.
9. Residents (especially High Care residents) are silent to the internet and only a Royal Commission will shine a light of sufficient brightness on the worst aspects of this sector.
10. The community needs to know just how bad things actually are before sustainable, effective solutions can be put in place.
11. The scale of the suspected neglect and abuse, the increasing size of the industry and the scale of the forecast profits over the forthcoming 20 years – suggest to me that a full Royal Commission is appropriate to this sector.

The relative did not receive a response to his email.

Conclusion

This report highlights the variability in standards of care in aged care homes. It challenges the overly optimistic picture of a 'world class' residential aged care sector in Australia we hear from politicians, government, providers and peak bodies.

The value of this report is that it provides evidence that some aged care homes deliver high standards of care while others do not. It also provides insights into how some aged care homes are able to assist residents to live well while others hinder residents' wellbeing.

This research demonstrates why the federal government must make systemic changes so the community can be reassured that all residents in all aged care homes receive an acceptable standard of care. The worst aged care home in Australia must be at a 'good enough' standard.

Relatives in this study highlight the importance of positive relationships between managers, staff, residents and relatives. Like all health and community services, well-trained, empathetic staff are the cornerstone of an aged care home.

This study identified specific factors that contribute to high standards of care in an aged care home. The most important factor is for all residential aged care homes to be required by law to have systems, processes and protocols in place that staff must follow. Other factors include:

- A sufficient number of staff (registered and enrolled nurses, personal care attendants, as well as kitchen, reception and activities staff)
- Competent medical, nursing and personal care
- Person-centred care
- Access to health professionals (GPs, physiotherapists, occupational therapists, pharmacists, psychologists and social workers)
- PCA supervision (e.g. duty manager)
- Minimum of one registered nurse on site 24 hours per day
- Ongoing training and professional development for all staff
- Managers and staff who work collaboratively with residents and their families
- Nutritious meals
- Comfortable, clean physical environment
- Meaningful, enjoyable activities, including outdoor activities in sunlight and gardens
- Access to hairdressers, pedicurist, massage therapists who attend regularly

- Engagement with local community
- Pastoral care
- Laughter

How do we ensure all aged care homes provide high standards of care? Will this be achieved by a "light touch approach to regulation", as suggested by The Aged Care Roadmap (2016)? Or does the residential aged care sector require more effective regulation, as suggested by relatives in this study? It is anticipated that government reviews currently in process may provide some definitive answers to these questions.

Relatives were clear: they want more transparency and accountability in residential aged care. They believed the care of vulnerable older people should not be left in the hands of providers seeking to maximise profits. They also believed the care residents received in aged care homes was too important to be left to the whims of the free market.

According to Hudson (2016), the aged care home market has characteristics of an inefficient market – entry is often unplanned, made in response to a personal crisis, and there are low rates of changing providers in the event of dissatisfaction. There is also inadequate information for consumers to make an informed decision on the product.

A free market requires consumers who can access information to inform their choice of product. For example, to make an informed decision when choosing an aged care home, consumers require information about its standards of care. However, aged care homes are not required to disclose their rosters/staffing levels. How can people make informed decisions about an aged care home's standards of care when they do not have access to this vital piece of information?

The irony of the move towards a free market system in residential aged care is that private businesses rely on government subsidies. Sloan (2016) refers to this type of system as "crony capitalism".

When taxpayers are subsidising the care of elderly people in aged care homes, relatives believe the public's investment needs to be protected with increased government oversight. They believe aged care homes require effective regulation, transparency, mandated ratios of both registered nurses and PCAs, better training of PCAs, meaningful accreditation standards, a better complaints' system and a more rigorous Aged Care Funding Instrument (ACFI).

Relatives expressed concern that the ACFI is currently built on an honesty system. In an era of fraudulent behaviour in private colleges (Bachelard, 2015), it is clear that profit-based systems that rely on government

subsidies cannot rely on honesty. Relatives wanted access to more detailed information about how providers (both for-profit and not-for-profit) spend government subsidies.

Rather than make a long list of recommendations, this report concludes with a request for:

1. Greater transparency in residential aged care.

The public needs access to evidence-based information. It is noteworthy that both the United Kingdom and United States publish extensive information without claims of “burdensome” requirements. The US, for example, publishes extensive information on the government website including deficiencies, ownership, penalties and staffing levels¹³. In the UK, the Care Quality Commission (CQC) also publishes extensive information including all visits, the provider’s response and actions¹⁴. This information enables informed discussions about how to provide residents with the best possible care.

It is important to have data about staffing levels in aged care homes. Public access to all aged care homes’ weekly rosters would provide certainty about the number of staff on each shift, including registered nurses. This would facilitate informed discussions about optimal staffing models and levels in aged care homes.

Other data that should be in the public domain are: (1) information about complaints made to the Aged Care Complaints Commissioner including the name of the aged care home that had complaints made against it, the nature of the complaint and how the complaint was resolved; (2) accreditation reports (including unannounced visits); (3) financial audits of each aged care home. This information is vital for evidence-based discussions about how to provide the best possible care for frail, elderly people who live in aged care homes. It is also important for consumers/users to make informed decisions when choosing an aged care home.

2. Deeds not words

Several government inquiries, roundtable discussions, forums and ‘think tanks’ have been held recently. All this talking is positive only if it leads to action.

It is encouraging that there has been engagement with users of the service, including those who offer a critical perspective. The next step is to include genuine consumer representation on government committees. Currently, politicians, bureaucrats, providers and professional groups largely determine policy and practice in the aged care sector in the absence of people who use the system.

To ensure high standards of care in aged care homes, governments, the private and not-for-profit sector, families, community members and older people themselves need to work together. Working collaboratively may ensure that Australia does indeed have a ‘world class’ residential aged care system.

13 <https://data.medicare.gov/data/nursing-home-compare>

14 <https://www.cqc.org.uk/location/1-130113159>

References

- Aged Care Financing Authority (2016) Fourth report on the funding and financing of the aged care sector, Department of Health, Canberra
- Aged Care Financing Authority (2015) Third report on the funding and financing of the aged care sector, Department of Health, Canberra
- Aged Care Sector Committee (2016) Aged care roadmap, Department of Health, Canberra.
- Ansell C (2014) Investing in Aged Care The Second Wave Ansell Strategic
- Australian Government Productivity Commission (2011) Caring for Older Australians Report No 53, Final Inquiry Report, Canberra
- Australian Skills Quality Authority (2013) Training for aged and community care in Australia Sydney
- Bachelard M (2015) Privatisation turned vocational education into a den of shonks and shysters The Age 3 December
- Backhaus R, Verbeek H, van Rossum E, Capezuti E, Hamer J. (2014) Nursing staffing impact on quality of care in nursing homes: a systemic review of longitudinal studies Journal of the American Medical Directors Association 15(6): 383-393
- Bostick J, Rantz M, Flesner M, Riggs C (2006) Systematic review of studies of staffing and quality in nursing homes. Journal of the American Medical Directors Association 7: 366-376
- Brasher K (2016) Our elderly need homes, not warehousing The Age 11 January
- Castle N (2008) Nursing home caregiver staffing levels and quality of care: a literature review Journal of Applied Gerontology 27:375-405
- Colyer S (2017) Aged care falls deaths: a question of balance MJA Insight 20: 29 May
- Commonwealth of Australia The Treasury (2015) 2015 Intergenerational Report: Australia in 2055, Canberra
- Dellefield M, Castle N, McGilton K, Spilsbury K (2015) The relationship between registered nurses and nursing home quality: an integrative review (2008–2014) Nursing Economics 33(2): 95-108
- Department of Health (2016) 2015-16 Report on the Operation of the Aged Care Act 1997, Department of Health, Canberra
- Department of Health (2017) Legislated Review of Aged Care 2017, Commonwealth of Australia, Canberra
- Edwards V (2017) Aged care Get Into pilot program aimed at the young unemployed The Australian 10 June, 2017
- Harrington C, Schnelle J, McGregor M and Simmons S (2016) The Need for Higher Minimum Staffing Standards in U.S. Nursing Homes Health Services Insights 9: 13-19
- Harris J (2016) Here's why some Dutch university students are living in nursing homes The Conversation 29 November
- Hitchcock K (2015) Dear life: on caring for the elderly Quarterly Essay Issue 57 March
- Hongsoo K, Kovner C, Harrington C, Greene W and Mezey M (2011) A Panel Data Analysis of the Relationships of Nursing Home Staffing Levels and Standards to Regulatory Deficiencies The journals of gerontology. Series B, Psychological sciences and social sciences 64B(2): 269–278
- Horn S, Buerhaus P, Bergstrom N et al. (2005) RN staffing time and outcomes of long-stay nursing home residents: pressure ulcers and other adverse outcomes are less likely as RNs spend more time on direct patient care American Journal of Nursing 105 (11): 58-70

- Hudson B (2016) The failure of privatised adult social care in England: what is to be done? Centre for health and the public interest
- Ibrahim J, Bugeja L, Willoughby M et al. (2017) Premature deaths of nursing home residents: an epidemiological analysis *Medical Journal of Australia* 206 (10): 442-447
- Martin B and King D (2008) A Picture of the Residential and Community based Aged Care Workforce, 2007 National Institute of Labour Studies Flinders University
- Mavromaras K, Knight G, Isherwood L et al. (2017) 2016 National Aged Care Workforce Census and Survey – The Aged Care Workforce, Department of Health
- McCosker, R (2017) Residents fear high-rise aged-care development will destroy a Brisbane suburb *Brisbane Times* 6 August
- Russell S (2017) The Project <https://www.facebook.com/TheProjectTV/videos/10154636058203441/>
- Russell S (2012) An aged care home in crisis: consumer action to improve standards of care *Research Matters Melbourne*
- Sloan J (2016) Taxpayers lose as crony capitalism takes over childcare, hospitals *The Australian* September 10
- Stewart M and Johnson M (2017) What happened when we introduced four-year-olds to an old people's home *The Conversation* 7 August
- The Senate Community Affairs References Committee (2017) Future of Australia's aged care sector workforce, Canberra
- Underwood J (2016) Aged Care Saturday Extra ABC Radio National 11 June
- World Health Organisation (2002) Active Ageing: A Policy Framework WHO, Geneva.

Appendix 1: Recruitment Flyer

Do you know anyone living in an aged care facility?
Would you like to help with a research project?

Sarah Russell is collecting ideas about how to make aged care facilities better for residents. I want to hear from people like you who visit an aged care facility, irrespective of how often you visit.

You are invited to share your ideas about:

- What you like about the aged care facility that you visit?
- What things need to change?
- How can things be done better?

My mother lives in an aged care facility, and I visit her often. All of us who visit relatives, friends and neighbours in an aged care facility have a wealth of knowledge. We see what works well, and what doesn't work.

I'd like to hear what you think about the facilities you visit and what would make them a better place to live. Your suggestions will contribute to a book I plan to publish about how to improve Australian aged care facilities. You and the facilities you visit will not be identified in the book.

I completed my doctorate in public health at the University of Melbourne in 1990s. I am an experienced researcher who enjoys talking with people about social issues.

This research project is designed to explore a wide range of views from people who have first hand experiences of aged care facilities. I am surveying visitors, staff, academics and those working in aged care policy. I am also interviewing residents.

If you would like to take part in this useful project please [click here](#) for the online survey.



Research Matters
researching issues of health and illness

Appendix 2:

A personal story of living well in an aged care home

In 2010, my parents, Joan and Roy Russell, moved into an aged care home together. They chose the aged care home primarily because they could sleep together in the same bed. After Dad's death in January 2012, I visited Mum most days until her death in September 2015.

Mum was happy living in the aged care home. Many staff treated her with kindness, respect and love. She had her favourites – Charlotte, Alex, Argus, Vicky, Kunal and Jenny...

Mum made lifelong friends with several residents – though many of her new friends did not live for long. Her good friend, Trudi, died in 2014. Soon after, so too did Sam, Greg, Heather, Val and Alma.

I visited Mum around lunchtime. I sat at Mum's dining table with Trudi, Lorraine, Marion and Etta. Mum did not have a large appetite – but she was always given a full portion at lunchtime so that I could eat her leftovers. The food was excellent. The kitchen staff were all very kind to Mum, especially Tony.

I wanted Mum's quality of life in the aged care home to be as good as it could be. Mum had already lost her husband and most of her independence, and I wanted her to feel valued in her 'twilight years'. Mum established 'her seat' in the communal lounge room from where she observed everything with a registered nurse's eye. She gently rebuked staff who did not treat her respectfully: *"Please don't talk to me as if I am a child"* or *"My name is Joan, not sweetie"*.

Every Tuesday afternoon, Mum, Etta, Marion and I played bridge. Etta was once a State Champion. Although her hearing and eyesight were impaired, Etta could remember every card that had been played. She was a formidable opponent. Unfortunately, Etta hung up her cards after having a fall. Mum and I then started playing bridge on an iPad, though more commonly we did The Age crossword with Lorraine and Kay.

Lorraine and Kay had done The Age crossword for more than 60 years. These women had an excellent knowledge of synonyms. They also easily adapted to the increasing inclusion of short phrases in the crossword. There was laughter when we finally came up with "trip of a lifetime" for the clue "most remembered tour". However, the obscure general knowledge questions often left them bewildered. Rather than complain, these older women would ask me to pull out the gadget in my pocket and "google" the answers.

Mum looked forward to her monthly trips to her beach house, away from the routines of the aged care home. She came alive sitting on the deck, or in front of the fire, surrounded by people and dogs, chatting and reminiscing. At her beach house, she peeled the potatoes, top and tailed the beans – activities considered 'too risky' at the aged care home.

In 2012, a relative approached my brother and me to express her concerns that standards of care had declined since Pam had retired as the manager. Jane was forming a relatives' group. My brother did not want to get involved, but I did. The grievances mostly related to management, staff morale and standards of care (Russell, 2012). To the owner's credit, he responded quickly. The manager was replaced and staff morale and standards of care were restored. This incident demonstrated the vital role a manager plays in any aged care home.

After a year or so of visiting the aged care home, I was concerned that the media only reported negative stories about aged care homes. Surely Mum was not living in the *only* good aged care home in Australia. My plan was to write a positive story about an aged care home. However, things changed dramatically during the last month of Mum's life.

When Mum was dying, I sat at her bedside in the aged care home to protect her from inflexible routines and policies. I ensured she slept as long as she needed, and ate when (and if) she wanted. I had once worked as a critical care nurse – so I knew how to care for a dying woman.

Only a few PCAs had the skills required to care for Mum when she was dying. Michelle and Cheryl provided excellent care. However, some PCAs provided thoughtless task-oriented care. On one occasion, a PCA tried to change Mum's night incontinence pad when Mum was asleep. I asked her to let Mum sleep. She replied: *"It is policy. She must have a day incontinence pad because it is day time."* I questioned this so-called policy, and the PCA replied: *"I just work here. I do what I am told."*

Soon after this incident, I received an email from the Manager. She demanded that I leave Mum's bedside. *"I need you to let my staff do their jobs... Interfering with Mum's care is not helping her."* I replied:

I hope you will re-consider your comments in your email and perhaps educate your less experienced staff

about working in partnership with family members. Some relatives want to be involved in 'hands-on' care, others don't. I believe this should be our decision, not yours.

I did not have confidence that staff could do their jobs and refused to budge from Mum's bedside. Mum died peacefully, with a smile on her face. On the morning of her death, she said to me: "*Darling, you really do need a hair cut*".

The day after Mum's death, the aged care home's GP phoned me to confirm the time of death. Staff had told him she had died at 6.30pm. I told him it was in fact 5.35pm. He also asked me what he should write on her death certificate. After visiting Mum monthly for several years, I expected him to at least know her medical history. I suggested he wrote: "*broken heart*", but that is another story.

I doubt I would have become an aged care advocate if the manager had not emailed me a week or so before Mum died. As an aged care advocate, I have heard countless heart-breaking stories about aged care homes from both relatives and residents. I remind myself that these stories are only part of the story.

Sarah Russell

Dr Sarah Russell



Joan Russell celebrated her 91st birthday with family and staff at Victoria By The Park



Sarah and Joan Russell



A place was set for Sarah in the dining room at lunchtime



A group of older women at the aged care home knitted a baby blanket for Joan's eldest great grandson.



Nutritious meals in aged care home were supplemented with the occasional McDonald's burger, fries and chocolate shake.



Joan playing with her great-granddaughter.



A carer stopping for a chat as she passes through the lounge room.

Living Well in an Aged Care Home

Sarah Russell
October 2017

