

Submission to the Royal Commission into Aged Care Quality and Safety

Dr Sarah Russell, Director Aged Care Matters

Introduction

I am a public health researcher and former registered nurse (critical care). I have been the Principal Researcher at *Research Matters* since 1999. *Research Matters* has considerable experience in qualitative research, consumer participation and community engagement.

In 2016, a small group of people formed *Aged Care Matters*. We are a voluntary advocacy group. Members of the Executive of *Aged Care Matters* are citizens who are deeply concerned about the quality of residential aged care services and in-home care. We focus on evidence-based solutions and dialogue with different stakeholders (older people and their family, staff, providers, public servants, unions, other advocacy groups and politicians).

I also administer *Aged Care Matters Advocacy Facebook Group*. This group has over 2,000 members. My aim is to encourage respectful discussion among members. The Facebook group contains many interesting discussions about a range of issues pertinent to the Royal Commission.

Submission overview

My submission begins with some background about why I became a voluntary aged care advocate in 2016. I discuss my contribution to the public debate over the past 3 years. In addition to publishing over 20 opinion pieces, radio discussions and TV appearances, I have also undertaken several qualitative research projects in my capacity as the Principal Researcher at *Research Matters*. These projects include:

1. Relatives' views of aged care homes (Appendix 1)
2. Recipients' experiences of home care packages and Commonwealth Home Support Programme (Appendix 2)
3. Staff's experience working in an aged care home (in progress)¹

The 2nd section discusses the impact of the numerous inquiries over the past decade. These inquiries have resulted in a large number of recommendations, most of which have been ignored by successive governments. I believe we would not have required a Royal Commission if governments (both LNP and ALP) had acted on the recommendations of these inquiries.

¹ 360 staff recently responded to an open-ended survey (Appendix 3). I have approached unions, providers and peak bodies to fund the analysis of the data. However, I have been unsuccessful. I am able to give the raw data to the Royal Commission though it may be more useful if the data were analysed.

The 3rd section discusses the lack of transparency in the aged care sector. The Aged Care Act 1997 allows providers to treat data as commercial-in-confidence. The lack of access to data not only limits evidence-based policy and practice but also limits the capacity of older people and their family to make an informed decision when choosing an aged care home.

In the next section, I provide a critical perspective of the Aged Care Workforce Strategy Taskforce and the Review of National Aged Care Quality Regulatory Processes. I believe the Final Reports of both the taskforce and the review failed to accurately represent the views of older people and their family, staff and advocacy groups.

In the final section, I make some critical observations of My Aged Care. It is scandalous that an expensive navigator network is required to support the public to use My Aged Care. In my opinion, the Commissioners should 'follow the money'.

1 Background

My mother and father moved into Victoria By The Park in 2010. Mum and Dad were very happy living at the aged care home. Most staff treated them with kindness, respect and love. After Dad's death in January 2012, I visited Mum most days until her death in September 2015.

In June 2012, 25 relatives met to discuss the deterioration in the standards of care since the manager had retired. I documented our grievances in a 60-page report (Appendix 4). I met Shane Moran, the owner of Victoria By The Park, to discuss the grievances. He gave us a genuine apology and replaced the manger.

I include this report because it is an example of how relatives can achieve improved standards of care in an aged care home. It also illustrates:

1. The importance of a quick and genuine apology.
2. The importance of the provider taking relatives' concerns seriously – and taking action.
3. The vital role a manager plays in any aged care home.

After resolving the problems at Victoria By The Park, I began analysing systemic issues in residential aged care. With my background as a public health researcher who had previously worked as a registered nurse, I observed the aged care sector through a critical and clinical lens.

² This section has been submitted to the Royal Commission in confidence.

I began writing regular letters to *The Age*. I wrote about: staffing, accreditation, Aged Care Funding Instrument, complaints scheme, financial elder abuse, living wills, and polypharmacy. In 2016, my first opinion piece on aged care was published in *The Age*. *The Aged Care Gravy Train* catapulted me into aged care advocacy. Since then, I have published over 20 Opinion Pieces about the aged care system (Appendix 5).

After each opinion piece is published, numerous older people and their relatives contact me with their heart-breaking stories about standards of care in aged care homes. They tell me they contact *Aged Care Matters* because they feel unsupported by the publicly funded consumer organisations (e.g. COTA, National Seniors, OPAN).

The media has been reporting heart-breaking stories about residential aged care for over 20 years. If publicly funded consumer organisations had advocated effectively for systemic changes in the aged care sector, there would be no need for volunteer organisations such as *Aged Care Matters* to exist.

Solution

1. Encourage aged care managers and providers to accept critical feedback without the situation escalating.
2. Educate aged care managers and providers about the importance of a genuine apology when appropriate.
3. Allow government funded agencies to advocate for systemic changes

2 Previous inquiries

During the past decade, there have been numerous inquiries, reviews, consultations, think tanks and a taskforce into aged care (Appendix 6). These inquiries have received submissions from residents, relatives and staff that described inadequate personal care, negligence, neglect, abuse and assault in aged care homes. These inquiries have resulted in a large number of recommendations, most of which have been ignored by successive governments.

The Future of Australia's aged care sector workforce inquiry, for example, received submissions from registered nurses who claimed the aged care home in which they worked was understaffed. These nurses expressed concern for the health and safety of residents, though this was mostly done anonymously to avoid negative consequences for speaking out.

The Future of Australia's aged care sector workforce final report (2017) made two important recommendations. Recommendation 8 suggested the government examine the introduction of a minimum nursing requirement for aged care homes. Recommendation 10 suggested the government require aged care service providers to publish and update their staff to resident ratios “in order to facilitate informed decision making by aged care consumers”.

Rather than action the Future of Australia's aged care sector workforce's recommendations, the government/Commonwealth Department of Health established yet another departmental review – this time a \$2 million Aged Care Workforce Strategy Taskforce. The taskforce relied on “wide engagement and consultation” rather than research evidence (see Section 5)

The most dispiriting aspect of all these inquiries is the number of submissions by residents, relatives and staff (people at the ‘coalface’) that have been ignored. Submissions to the recent Review of National Aged Care Quality Regulatory Processes indicated strong support for mandatory staff ratios in aged care homes and for registered nurse to be on duty at all times. However, this was not mentioned in the final report (See Section 6).

Despite the lack of action, these inquiries have clearly identified the primary causes of the systemic problems in aged care. The three main causes are:

1. Staffing levels and training.
2. Ineffective regulation
3. Inadequate funding.

The Royal Commission is an opportunity to understand the ‘causes of the causes’.

The cause of the causes is the Aged Care Act 1997.

Solution

1. Legislation is required that ensures the highest possible standards of care in all aged care homes.
2. The only way to ensure high standards of care in every aged care home is for the government to replace the Aged Care Act 1997 with a new Aged Care Act.
3. The government should work with providers, staff, unions, residents and their families to write a new Aged Care Act.
4. The new Aged Care Act should use a human rights’ framework.
5. A new Aged Care Act should focus on the care of residents not the profits of the providers.
6. A new Aged Care Act should ensure transparency rather than the current ‘commercial in-confidence’.

3 Lack of data

Without rigorous data, it is not possible to have informed evidence-based discussions about aged care homes. Instead, most debate is informed by opinions. For example, politicians and providers claim Australia has “world class” aged care homes without providing any evidence to support this claim. In contrast, the media, unions, residents and relatives report negligence, neglect and abuse in aged care homes. Who is correct? Without data, we simply don't know.

For the past 2 years, I have tried (unsuccessfully) to get data on the incidence in aged care homes of:

1. Staffing levels and training
2. Pressure injuries
3. Dehydration
4. Malnutrition
5. Medication errors
6. Falls

This data is not publicly available.

The Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018 requires every aged-care home to disclose and publish quarterly staff/resident ratios. This bill is a start. It would provide transparency about staffing in aged care homes. Accurate staffing data would enable research on the correlation between staffing levels/skills and standards of care in aged care homes (particularly if quality indicators were also made public).

In the absence of legislation specifying required staffing levels or skills, Sharkie's Staffing Disclosure Bill is important. It should be strongly supported. However, submissions to the Inquiry into the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018 demonstrate providers' opposition to the Bill because staffing and care are "too complex".

StewartBrown collects both financial and clinical data. In November 2017, I asked Grant Corderoy, Senior Partner, StewartBrown, to share the clinical data with me.

To date, I have not had access to any clinical data that would inform an evidence-based discussion on standards of care in aged care homes.

When choosing an aged care home, it is also important to know about complaints made against the aged care home, and how these complaints were resolved. Providers are not obliged to share this information.

Solution

1. All aged care homes be required to publish quarterly clinical data about standards of care in aged care homes.
2. The Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018 should be supported.
3. Policies are based on evidence rather than opinion.

5 Aged Care Workforce Strategy Taskforce

The recent Aged Care Workforce Strategy Taskforce was an opportunity to explore the international evidence on staffing levels and training in aged care homes. However, rather than undertake a systematic review of the evidence, the Aged Care Workforce Strategy Taskforce relied on further local consultation and stakeholder opinions.

The Aged Care Workforce Strategy Taskforce became known at the *Industry led* Aged Care Workforce Strategy Taskforce because the focus was on the views of those who provide aged care services rather than residents, relatives and staff. The Final Report also alienated those of us who do not understand modern management language.

The taskforce was an opportunity to consult with staff who work in aged care homes – to understand what they like and don't like about their work and to hear their suggestions for improving the aged care system. Given the taskforce did not undertake this work, I have collected the views of 360 staff via an online survey (Appendix 3). The data has not yet been analysed.

I attended the taskforce's introductory Summit at the Melbourne Exhibition Centre. Upon arrival, I was given a lanyard inscribed with the slogan 'Think. Collaborate. Innovate'. I considered these lanyards silly and a waste of money.

The Summit began with a session by Simon Hammond from Hammond Thinking. Simon is a cultural anthropologist and global brand strategist. Simon began his session by showing us a video about Free Hugs. This left me feeling discombobulated. Simon then told us that aged care is all about the "vision" and "journey" and asked us to discuss our "fears, frustrations and desires".

Simon later ran some daylong workshops "searching for a common belief into why the aged care sector matters". These workshops created "an opportunity for people from all parts of the sector to unite around insights, truths and beliefs pertaining to ageing and the aged care industry". Many people contacted me with complaints about these workshops.

HammondThinking received \$69,300 for "Strategic Planning Consultation Services". Later, his costs increased to \$79,695.17, though no explanation was given for this increase on AusTender website.

In the afternoon, I attended two so-called "Breakout" sessions. The first 'Enhancing safety and quality' demonstrated a dissonance between the participants who wanted to discuss 'standards of care' and 'quality of life' and the facilitator who was focused on 'safety and quality' in industries such as manufacturing and aviation.

The facilitator's interest on more traditional 'industries was not surprising given he is a forensic economist (employee of APIS). APIS received \$210,633.00 for their contribution to the Workforce Taskforce (a significant amount of money that would employ many PCAs for a year in an aged care home).

My attempts to find out what APIS contributed to the Workforce Taskforce were unsuccessful. Despite several emails to the Commonwealth Department of Health, I still do not know (1) what a forensic economist does and (2) what insights APIS brought to the aged care workforce strategy taskforce.

The second “Breakout” session I attended was: “Translating research and technology into models of care and practice”. This session was even more frustrating than the first session. There is national and international research on optimal workforce (both numbers and skill set), models of care etc. This was not referred to during the session. Instead we shared our “opinions”.

Several researchers, including those at the Australian Association of Gerontology, encouraged the Chair of the taskforce to undertake a robust analysis of the national and international evidence on the aged care workforce. This evidence would have enabled the Workforce Taskforce to better evaluate the merits of key stakeholders’ opinions. Instead, the department opted for further consultation and engagement.

The lunch at the summit was delicious. However, was such an expensive lunch required? Event Planet was initially paid \$217,125 to provide event management services for the Aged Care Workforce Strategy Taskforce. The costs for Event Planet increased by \$67,474.90 to a total of \$284,599.90. The reasons stated for this increase are: “extreme urgency or events unforeseen.”

I encourage the commissioners to read the Aged Care Workforce Strategy Taskforce Final Report: *A matter of care*. I have a PhD yet found it very difficult to understand the content of this report because it is written using jargon, modern management language and Don Watson’s so-called weasel words

With a \$2 million dollar budget (courtesy of the Australian tax-payer), I expected the taskforce to answer the million-dollar question: Will standards of care be improved by the government mandating staffing ratios in aged care homes?

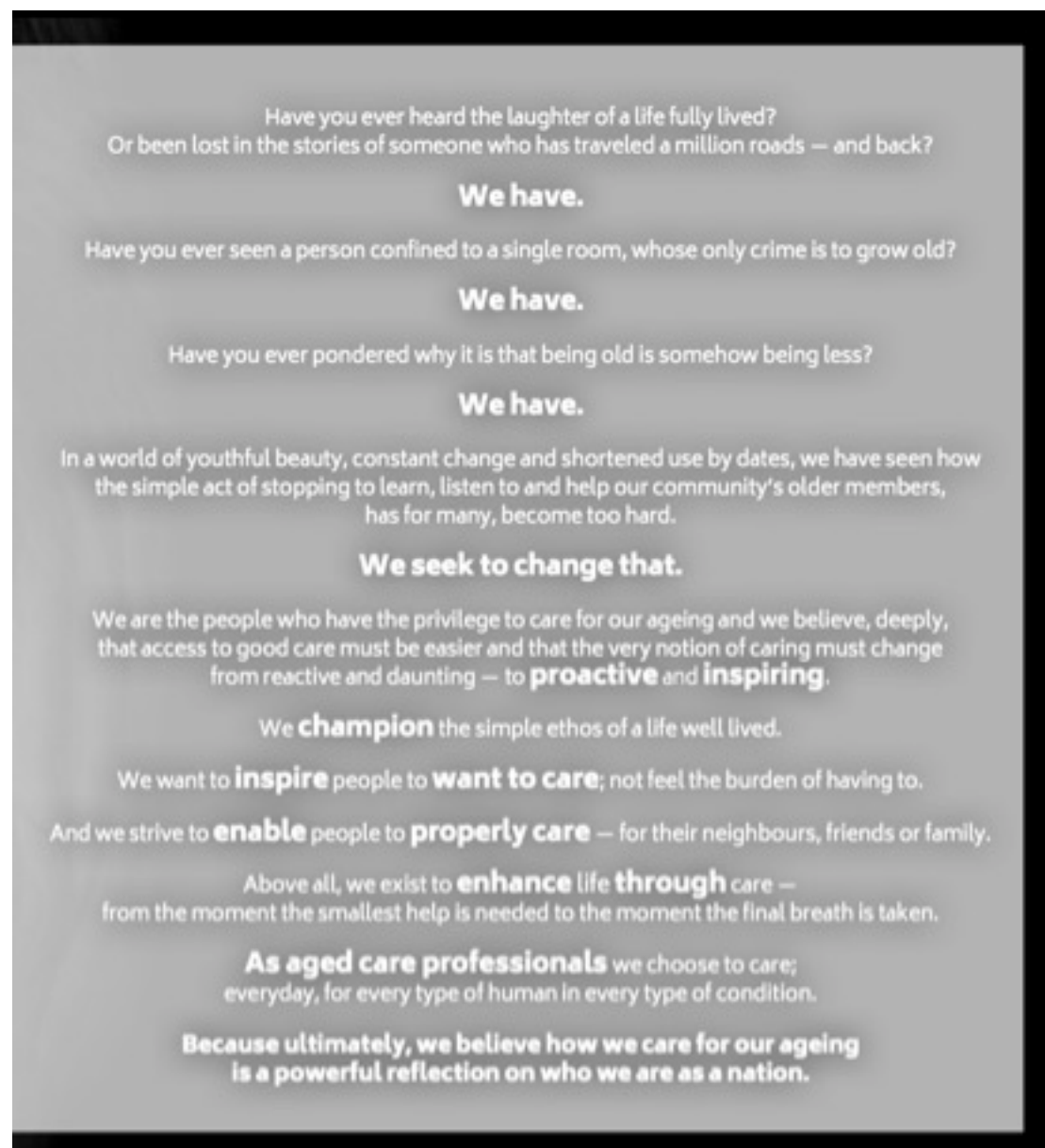
However, rather than rely on evidence, the taskforce regurgitated industry “opinions” about staffing ratios cited in the Productivity Commission and Tune Reports. The Report of the Aged Care Workforce Strategy Taskforce dismissed staffing ratios with only one sentence. “Static models or set staffing ratios will not assist in meeting these expectations or necessarily result in better quality of care outcomes.”³

Rather than focus on the evidence, the report provided a transformational ‘Belief Statement’: “*We exist to inspire people to want to care, enable people to properly care and enhance life through care. Because how we care for our ageing is a reflection of who we are as a nation.*”

³John Pollaers, Chair of the Aged Care Workforce Strategy Taskforce, has subsequently changed his position on ratios. He now publicly supports mandating ratios in aged care homes.

This belief statement and the Unifying Vision of Care (P 13) set the tone for this 40,000-word report. The unifying vision of care was certainly not the outcome I had expected from a workforce strategy taskforce.

A Unifying Vision of Care (Report of the Aged Care Workforce Strategy Taskforce, P 13)



It is not my intention to be disrespectful, but I could not understand the taskforce's approach to building the workforce strategy: *"The taskforce recognised that the strategy must be disruptive in its thinking, transformational in its approach, pragmatic to implement, and supportive of immediate improvements"*.

I also did not understand the section on 'looking forward': *"Looking to the future, the aged care industry requires a coherent strategy and key enabling infrastructure to support the strategic investment, translation and uptake of innovations designed to improve workforce capability, care quality and effectiveness"*.

I am also unfamiliar with the jargon: *"touchpoints for consumers in their ageing journey", "a well-supported research translation pipeline" and "the creation of a research translation ecosystem"*.

Not surprisingly, given the report's abstruse language, the taskforce developed complex processes to address staffing issues. The success of these recommendations depends, in part, on a voluntary code of conduct by industry (i.e. the codes only apply to those providers who sign up to them).

I was dismayed that *Korn Ferry*, a US corporate giant, was commissioned by the taskforce to undertake The Annual Aged Care Survey. They received \$90,750 to do a tick-a-box survey and then run the responses through a statistical computer program.

According to the report: *"Korn Ferry knows more about human performance in the workplace than any other organisation."* Apparently *"in order to open up career pathways, there are well-established and research-backed corporate methodologies that can be utilised to enable interaction between job families and opportunities to move across job families"*.

Without explaining who or what are *"job families"*, or indeed the *"Job Family Framework"* methodology, Korn Ferry produced a colourful report. However, the analysis is poorly explained. Even with my expertise as a researcher, I could not understand it.

Solutions

1. Consult with staff who work in aged care homes and in-home care about workforce issues.
2. The Commonwealth Department of Health must, as a matter of urgency, commission a systematic review of the literature on optimum staffing levels and training
3. Reports should be written in plain English so members of the public can understand them.
4. Bureaucrats should remain mindful they are spending taxpayers' money.

6 Review of National Aged Care Quality Regulatory Processes

There were over 300 submissions to the Review of National Aged Care Quality Regulatory Processes. These submissions indicated strong support for mandatory staff ratios in aged care homes and for registered nurse to be on duty at all times. However, there was no mention of this in the report.

Like others in the industry, the authors of the Final Report made the following claim without providing any evidence to support this claim: "Evidence suggests that the residential aged care system as a whole is one of relatively high-quality care?" (p 38).

I wrote to Kate Carnell to express my disappointment that views expressed in these submissions were not reflected in the Final Report (Appendix 7). In my letter, I asked Kate Carnell whether she knew the proportion of aged care homes that provide high standards of care.

I did not receive a reply to my letter.

My Aged Care

In the past, older Australians and their family accessed information about aged care from their local GP and local councils. They now get this information from My Aged Care.

My Aged Care was introduced on 1 July 2013. It was designed as a 'one-stop-shop' to assist older Australians and their family access information about aged care. This information was obtained either via the My Aged Care website or contact centre.

My Aged Care is so complex and difficult to use that the government tendered for an organisation to trial a new aged care 'navigator network'. This 'navigator network' includes information hubs, community hubs and one-on-one support from specialist workers, to streamline and simplify aged care service access.

It is disappointing that the government establishes a new service (My Aged Care) that requires a second service to help people navigate the first service. This is something one expects to see on an episode of Utopia.

I note with interest that the first discussion paper from the Royal Commission is titled: *Navigating the maze: an overview of Australia's current aged care system*. But it was not a maze when local councils, the Royal District Nursing Service and other not-for-profit and for-profit organisations delivered services to older people in their home. How did the aged care system become so complex that older people and their family need help to navigate it?

Solutions

1. Provide 'consumer training' to staff at My Aged Care.
2. Consumers should co-design the My Aged Care web-site

Conclusion

The Royal Commission into Aged Care Quality and Safety is an opportunity to improve the quality of life of older people who receive care in residential aged care or in-home care. It is also an opportunity for those who have not yet encountered the system to learn how some older people are treated in our society.

The quality of life of older people receiving residential and in-home care will improve if governments, the private and not-for-profit sector, unions, staff, families, community members, advocates and older people all work together.

Currently, aged care policies are based on consultation processes dominated by the views and interests of powerful stakeholders, rather than on (1) objective and scientific evidence and (2) experiences of resident, relative and staff. 'Consumer' views are essential to improve the quality of aged care services.

According to Annie Butler (ANMF): "There are some providers out there really trying to do a good thing but it is very much a minority". This statement contradicts government and CEOs of peak bodies (ACSA, LASA, Aged Care Guild) who say: "The overwhelming majority of aged care providers deliver high standards of care". Who is correct? Without data, we simply don't know.

Increased transparency is vital for evidence-based discussions about how to provide the best possible care for frail, elderly people who live in aged care homes. Good aged care providers should welcome transparency while unscrupulous providers who value profits over care may not.

It is extremely important the unscrupulous providers in both residential and in-home care leave the aged care sector.

The care of older people is a human rights issue. We urgently need a new Aged Care Act that focuses on the human rights of older Australians not the profits of providers.

Living Well in an Aged Care Home



Sarah Russell
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Living Well in an Aged Care Home

Research report

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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.

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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.

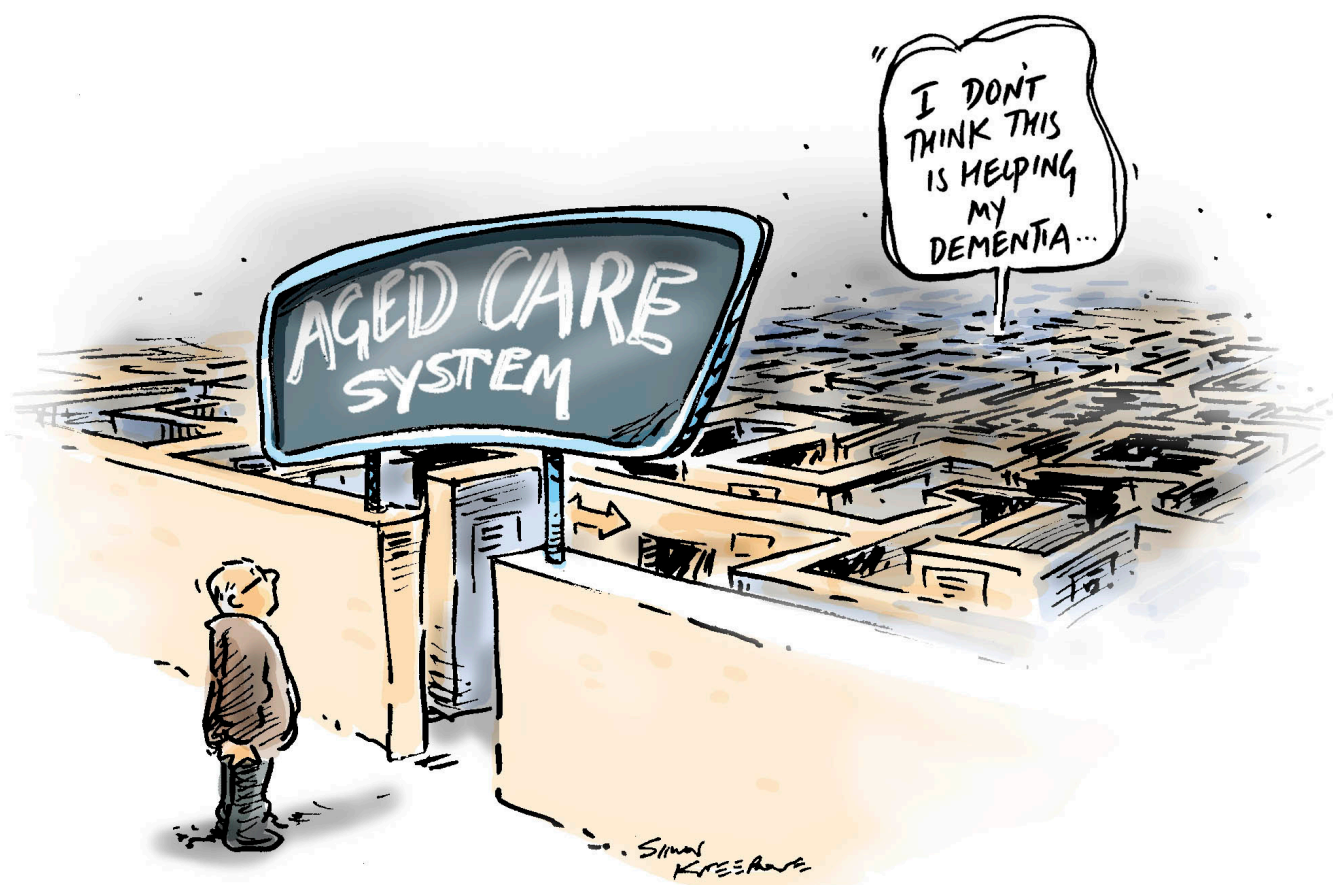
For many residents, meals are the highlight of their day. Relatives spoke positively about meals prepared by a trained cook in an aged care home's kitchen. Some cooks provide a nutritious, varied menu, cater for individual dietary requirements, are mindful of residents' likes/dislikes and serve appropriate 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

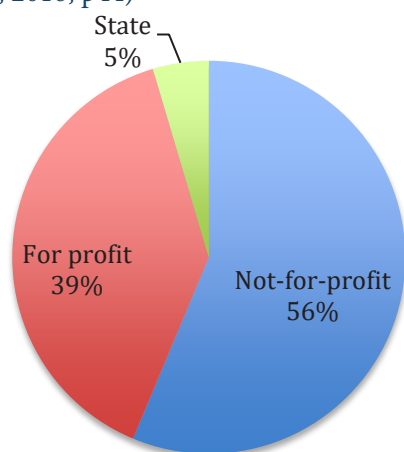
Statistics

- 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

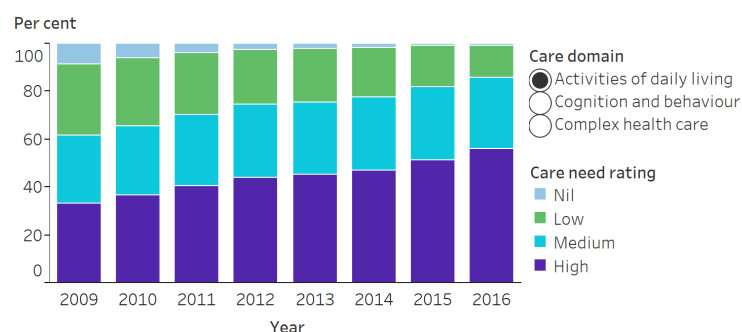


Figure 3: Care need ratings of people in permanent residential care for Cognition and behaviour, 30 June 2009–2016

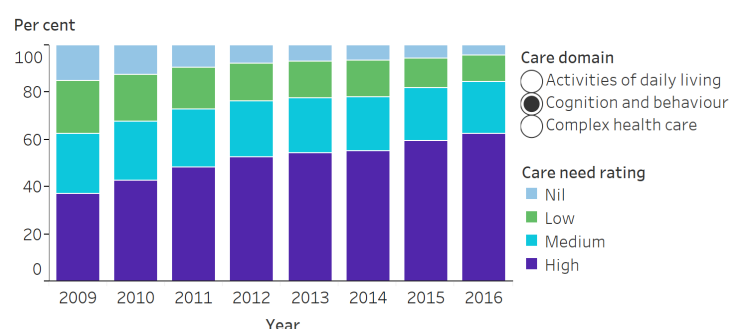
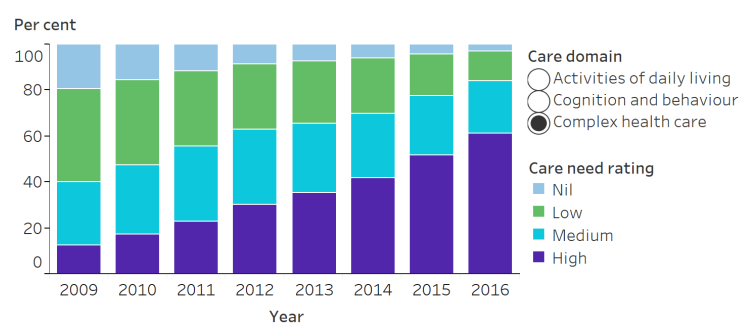


Figure 4: Care need ratings of people in permanent residential care for Complex health care, 30 June 2009–2016



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.

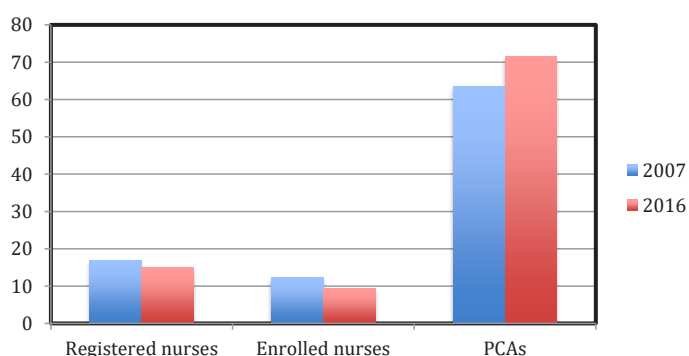
When the higher funding is used to provide extra care (e.g. registered nurse, physiotherapist), residents whose needs increase can be managed well at the aged care home. However, when this higher funding is not spent on extra care, residents may have unnecessary transfers to hospital when their health 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 ambiance 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>

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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



Older People Living Well with In-Home Support



Sarah Russell
March 2019



Research Matters
researching issues of health and illness

Older people living well with in-home support

Research report
March 2019

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The research was funded by the Australian Government via the Commonwealth Department of Health.

The research findings and recommendations outlined in this report do not reflect the position of the Australian Government or the Department of Health. Rather, they reflect the participants’ understanding of their experiences of receiving in-home care. In addition, the research does not consider work currently under way to implement a range of federal budget measures to improve the system for older people who receive in-home care.

Executive Summary

Report overview

The report begins with some background information about the aged care reforms, the different types of in-home care, consumer directed care, the wellness and reablement model and recent research.

The next section describes the research method, including its strengths and limitations. The strength of this research is that the researcher does not work in the aged care sector, for a government agency or for an agency that receives federal funding. This enabled participants to speak frankly and without fear of repercussions.

Participants were recruited through Peninsula Health, an aged care forum and via an online invitation posted on the Aged Care Matters' website. A sample size of 40 allows some confidence that the research represents a wide range of views. However, the results of the research are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

The research findings are divided into three main sections. The first section describes what is working well for those who receive in-home care. The second section describes older people and their family's perception about what is not working well. In the final section, participants share their suggestions about how to improve both home care packages and the Commonwealth Home Support Programme. Some suggestions for improvement have already been funded through the *More Choices for a Longer Life* budget measure.

Executive summary

Significant changes have been made to the way in-home support for older people is delivered in Australia. The Australian Government via the Commonwealth Department of Health funded Dr Russell to investigate the impact of these changes from the 'consumer' perspective. Dr Russell partnered with Peninsula Health to undertake this research.

Involving 'consumers' in an investigation of the way aged care services are delivered is recommended as a means of improving the quality of these services. In a system where the perspectives of government, bureaucrats, providers and professional groups dominate policy and practice, it is helpful to read the views and experiences of recipients of in-home care.

Forty older people and/or their support person described what is working well with in-home care – both the Commonwealth Home Support Programme and home care packages. They also described what is not working well. Participants made practical suggestions to improve in-home care.

When asked to describe the best thing about in-home care, participants unanimously replied: *"It enables me to live at home."* Some described in-home care as a *"godsend"*. Without the government subsidy, many older people would be unable to remain in their own homes.

Participants agreed that the concept of the home care package was *"fantastic"*. However, they expressed concerns about how some providers deliver it. Several participants suggested some companies should not have licences to be in-home care providers.

Providers of both the Commonwealth Home Support Programme and home care packages must be approved to deliver services. For the Commonwealth Home Support Programme, this is done through competitive growth funding rounds. For home care packages, an application is submitted to the Commonwealth Department of Health to review suitability as per criteria stipulated in the *Aged Care Act 1997*.

Participants suggested the government should restrict licences to only those companies that can demonstrate expertise in aged care. This would include providers that employ qualified staff and provide ongoing staff training.

Participants receiving home care packages suggested it should be mandatory for them to be given a schedule of fees before they signed the Home Care Agreement. Although providers are expected to do this, not all did.

Participants receiving home care packages described the case manager as integral in determining the quality of the in-home service. A case manager who explained entitlements, was easy to contact and met regularly with recipients to ensure the services were meeting their needs was described as *"a good case manager"*.

Participants appreciated case managers who listened to the older person and their families, understood their needs and matched them with compatible support workers. They suggested case managers should receive specific training in both person-centred and consumer-directed care.

Participants also appreciated personal support workers who were well trained, experienced, respectful, empathetic and punctual. Some case managers matched the older person with a specific support worker. This often enabled a genuine friendship to develop.

Participants described the hours of support they received on the different levels of home care packages. They were surprised that a Level 4 home care package (worth more than \$50,000) purchased approximately 14 hours of support per week, depending on the type of service they received. Some participants on lower level

packages described receiving better services, including more hours of support, on the Commonwealth Home Support Programme than on a Level 2 home care package.

Participants perceived several systemic problems with home care packages. These systemic problems are discussed under the following headings:

- Unable to access reliable information
- High fees
- Unclear financial statements
- No benchmark for costs (e.g. hourly rates)
- Lack of audits
- Poor quality of some services
- Poor communication
- Staffing issues
 - Inadequate training
 - Insufficient numbers of staff
 - High turnover of case managers and support workers
- Ineffective complaints system
- Policy of full cost recovery

Unable to access reliable information

Participants found the numerous fact sheets, brochures and pamphlets helpful. However, when they had “tricky” questions about policy, processes and the Aged Care Act 1997, they found it difficult to access reliable information from staff at My Aged Care, the Australian Aged Care Quality Agency, the Aged Care Complaints Commissioner and the Commonwealth Department of Health. Each time they phoned My Aged Care, for example, they would speak to a different member of staff. Some were knowledgeable; others less so. They described their frustrations at the “merry-go-round” – when staff at My Aged Care referred them to the Australian Aged Care Quality Agency or the Commonwealth Department of Health or the Aged Care Complaints Commissioner who in turn referred them back to My Aged Care.

High fees

Participants accepted that providers – including not-for profit providers – had to make a profit to remain in business. They objected, however, to “obscene profits”.

Participants said it was reasonable for providers to charge fees to cover overheads and operational costs, such as insurance, workers compensation, care co-ordination and travel costs.

Participants said it was unreasonable for 50 per cent or more of the home care package funds to go into “providers’ pockets”. Provider KK, for example, charged \$607.56 in case management and administration fees (51.6 per cent of a Level 2 package) to supply one service valued at \$130.22 (Appendix 5, Example 6).

Data indicated significant differences among providers in both case management and administration fees. The amount ranged from 9 per cent (Appendix 5, Example 2) to 53 per cent (Appendix 5, Example 6). This may indicate differences in the health needs of the older person and the complexity of providing case management. Alternatively, it may suggest overcharging.

There were also significant differences in hourly rates for support workers. The amount ranged from \$39 to \$61 per hour for a support worker on a weekday. Provider A charged \$136 per hour for a support worker on a public holiday (Appendix 5, Example 5).

When a provider took a large percentage of the home care package funds, the recipient did not receive the support they needed – and the support the government and taxpayers intended them to receive. Some participants received less than 10 hours of personal/domestic support on a Level 4 home care package.

Several participants said they were happy to pay for a case manager if a worthwhile service was provided. However, some participants described receiving minimal or no case management. One participant questioned why Provider M charged more than \$600 per month for case management during the period she did not have a case manager (Appendix 5, Example 1).

Participants said it was wrong to be charged a fixed cost for case management irrespective of how much case management was used. Those on a Level 2 package questioned why they were charged \$400 to \$500 per month for case management and administration (Appendix 5, Examples 3 and 4). In their opinion, organising three hours of ongoing support per week (e.g. personal care, cleaning, shopping) required minimal work.

Some participants were charged the ‘basic daily fee’ of 17.5 per cent of the pension. This fee is the client’s contribution to their budget for services, calculated on a daily basis. Some participants were concerned about being charged for seven days when they only received support for one or two days a week. In some cases, this daily fee made it financially unviable to receive a lower level package. Rather than accept a Level 2 home care package, some participants chose to privately fund in-home care.

Unclear financial statements

The monthly financial statements, designed to increase transparency, often lacked clarity. Participants described not being able to make “head or tail” of their financial statements. Even participants with business and accountancy experience found the financial statements “bamboozling”. Participants suggested the case manager should explain the monthly statement to those who had trouble understanding it.

Not understanding the statements was stressful for older people and their families. Several participants also found it extremely stressful challenging providers when costs for services that had not been delivered appeared on their statements. Some participants said they did not have the energy to question these costs.

No benchmark for costs

A recent letter from the Minister for Senior Australians and Aged Care, the Hon Ken Wyatt AM, MP, to all home care providers outlined a phased approach to improving home care pricing information. As part of this approach, all home care providers had to publish their existing pricing information on the My Aged Care Service Finder by November 30, 2018. Disappointingly, some providers with the highest case management and administration fees in this sample (e.g. Provider B – 53 per cent) have not yet done so (Appendix 6).

The interviews for this study were conducted before November 30, 2018. Participants said that determining how much a service should cost was difficult without any benchmarks. They expressed concern at what they saw as inflated costs for labour, equipment and supplies. They questioned whether costs were inflated because home care packages were subsidised by the government.

Participants noted the disparity between what they paid the provider for support workers and what the provider paid support workers. Participants gave examples of providers who allegedly paid support workers below the award rate yet charged the older person more than \$60 per hour on a weekday. On a public holiday, Provider A charged \$136.10 per hour for a personal support worker and \$241.20 per hour for a registered nurse (Appendix 5, Example 5).

Lack of audits

Participants wanted providers to be transparent and accountable and have their accounts audited.

In 2016–17, home care providers submitted their financial performance reports to the Department of Health using the Aged Care Financial Reports. Based on these reports, the Aged Care Funding Authority (2018) provides an overview of the 2016–17 financial performance of home care providers. However, the analysis is limited because it relates “only to those who submitted their useable financial reports” (p 69).

Participants expressed concern about some providers – both for-profit and not-for profit – taking a large proportion of their home care package. According to the Aged Care Financing Authority’s (2018), profits in the home care sector increased by \$43.4 million during past year: from \$141.7 million (2015–2016) to \$185.1 million (2016–2017).

According to the Aged Care Financing Authority’s (2018, p 69), there was a significant difference between the profits made in the for-profit and not-for-profit sector. For-profit providers made an average profit per ‘consumer’ of \$6,767; not-for-profit providers made an average profit per ‘consumer’ of \$2,621. Government sector providers made a profit per ‘consumer’ of \$1,883.

Poor quality of some services

Some participants receiving home care packages described working hard to receive services from their chosen provider. They described it as like “*pulling teeth*”. They said “*fighting*” for their entitlements was “*exhausting*”.

The data from this research indicates that the government is giving home care package licences to companies with no expertise in delivering aged care services (e.g. insurance companies). Participants described these providers as delivering poor quality services, primarily due to a high turnover of inexperienced and poorly trained staff. Although a pseudonym is used to describe providers in this report (Provider A, B, C etc.), the name of each provider has been given to the Minister for Senior Australians and Aged Care, the Commonwealth Department of Health and the Royal Commission into Aged Care Quality and Safety.

Poor communication

Participants described many instances of poor communication between providers and recipients. Some case managers did not respond promptly to telephone or email messages.

Providers with policies that prevent recipients contacting their support workers also obstruct clear communication. For example, if older people want a support worker to buy them milk, many providers require the person to phone head office, hoping the support worker will receive the message in time.

This study also found that large providers with a centralised administration were more prone to communication problems than small, local providers. Participants preferred speaking with local people, not people on the other side of the country.

Staffing issues

Participants described several staffing issues. These findings challenge the claim made in the report *Accentuating the positive: consumer experiences of aged care at home*, commissioned by the Aged Care Workforce Strategy Taskforce, that support workers “are well trained” (p 5). Several participants described inadequate training, an insufficient number of staff and a high turnover of staff.

Inadequate training

Some participants asked support workers to describe their qualifications. They were shocked when they learnt that not all support workers were qualified. According to participants, some providers (e.g. Provider O) required only a police check.

Participants were annoyed when young, inexperienced and untrained support workers came to their home. Three participants described the older person’s family having to train a support worker to use equipment safely (e.g.

a hoist). This increased the stress not only for the older person and their family but also for the support worker.

Participants expressed concern when support workers had not been trained to care for people with dementia, including early onset dementia. Some support workers had undertaken online training courses during unpaid time (e.g. the University of Tasmania's Massive Open Online Course). However, participants described face-to-face training as much better for a support worker than online training.

Insufficient number

Participants were concerned that some providers accepted too many clients without hiring enough staff. This resulted in providers being unable to deliver the services they had undertaken to supply.

Several large providers either do not employ their own staff or employ insufficient staff. They employ support workers from another provider. This was a particular problem for participants who chose a faith-based provider because they expected support workers to share their faith and culture.

High turnover

Participants complained about the number of different support workers who were sent to work in their home. Participants were upset when a stranger turned up at their door. Some felt unsafe inviting strangers into their home. They were also dissatisfied when support workers did not arrive on time or, in some cases, did not turn up at all.

Participants said it was difficult to form relationships with case managers and support workers who did not remain in the job for long. High staff turnover disrupts continuity of care. Most importantly, it limits the ability to recognise, and respond to, an older person's changing needs.

In contrast, a case manager who visits clients regularly – and gets to know them – recognises when needs change and a higher level of home care package is required.

Ineffective complaints system

Participants were disappointed by some providers' responses to their feedback. Some were also dissatisfied with the formal complaints system.

There was some confusion about whether the Aged Care Complaints Commissioner covered home care. When one participant contacted the Aged Care Complaints Commissioner, she understood they only dealt with residential aged care. This is, in fact, incorrect.

Policy of full cost recovery

For many people, ageing well requires access to social activities and community life. However, the policy of full cost recovery prevented some participants from being involved in the same number of community social activities as they were prior to accepting a home care package.

Participants who received a higher level home care package (Level 3 and Level 4) described being required to pay the full cost of community social activities. Before receiving a home care package, an activity such as a bus trip or Men's Shed cost around \$10. With a higher-level home care package, participants said the cost increased to \$100.

A participant on a Level 4 home care package said a bus trip cost her about the same as an hour of personal care. She described being forced to choose between an hour of personal care or a social activity.

Participants also described the policy of full cost recovery as limiting access to nursing and allied health services for those on Level 3 and Level 4 home care packages. Some participants who required nursing services were advised to remain on a Level 2 home care package. They were told they would need to pay full price for nursing services on the higher-level home care packages. Data suggests the policy of full cost recovery may reduce access to nursing services for those on a higher-level home care package.

Royal Commission into Aged Care Quality and Safety

This report contains critical views of home care packages and the Commonwealth Home Support Programme – that is its value and significance. Unlike *Accentuating the positive: consumer experiences of aged care* at home, commissioned by the Aged Care Workforce Strategy Taskforce, which identified “a high degree of positivity about aged care services delivered in the home” (p 5), this report highlights systemic problems.

This study used qualitative methods. Participants were asked open-ended questions (Appendix 4). Rather than ask participants to comment on their degree of positivity/negativity about aged care services at home, participants were asked to describe their experiences with the aged care home care system. The researcher then analysed these experiences as positive or negative.

This research coincided with the announcement of a Royal Commission into Aged Care Quality and Safety. The Royal Commission will focus on both residential aged care and in-home care. The findings of this research will contribute to the Commissioners' investigation into in-home care.

Glossary and definitions

Participants described the home care system as “*inundated with acronyms*”. To assist the reader, this report includes an introductory glossary.

It is also necessary to define the terms ‘person-centred care’ and ‘consumer directed care’ because some people use these terms interchangeably. For example, Sean Rooney described “consumer-centred reforms being rolled out by Government” (LASA, 2017). The government has rolled out consumer directed, not person-centred, care.

Glossary

ACAS	Aged Care Assessment Service (Victoria only)
ACAT	Aged Care Assessment Team
ACES	Aboriginal Community Elders Services
AIN	Assistant in nursing
AMR	AMR (research organisation)
ATSI	Aboriginal and Torres Strait Islander peoples
CEO	Chief executive officer
CHSP	Commonwealth Home Support Programme
CDC	Consumer-directed care
EBITDA	Earnings before interest, tax, depreciation and amortization
EN	Enrolled nurse
ERA	Elder Rights Advocacy
HCP	Home care packages
LGBTI	Lesbian Gay Bisexual Transgender or Intersex
MAC	My Aged Care
MC	Master of ceremonies
MOOC	The University of Tasmania's massive open online course
NDIS	National Disability Insurance Scheme
OPAN	Older Persons Advocacy Network
PAS	Psychogeriatric Assessment Scales
PCA	Personal care attendant
RAS	Regional Assessment Service
RN	Registered nurse
TIS	Translating and Interpreting Service

Definitions

Person-centred care and consumer directed care

Consumer directed care and person-centred care are distinct concepts.

1. **Person-centred care** is focused on developing partnerships between health care professionals and people they treat. Rather than health care professionals telling people what to do, the focus is on shared decision making. With person-centred care, people have an opportunity to actively participate in their own health care in close cooperation with health professionals (Russell, 2018).
2. **Consumer directed care** describes a model of service delivery and financing. Allowing people to be in charge of their own funding enables them to make choices about the types of services they need and who provides them (Russell, 2018). Home care packages and the National Disability Insurance Scheme are both examples of a consumer directed care funding model.

Case management

Case management refers to the process whereby a person (i.e. the case manager) is responsible for managing all aspects of recipients' home care services. Different organisations have different titles for the person responsible for case management: coordinators, case managers and care advisors all provide case management services.

Aged care ‘consumer’

Single quotation marks are used in this report when older people are described as ‘consumers’. Although older people who receive aged care services are increasingly described as “aged care consumers”, there is disagreement about this term being used.

Some claim this language positions older people as active participants in an economic transaction – that is, purchasing aged care services (COTA, 2018). Others claim the trend to use economic market-based terms is creating an environment in which the older person is being de-humanised (Denniss, 2018; Watts, 2018).

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Introduction

In June 2015, the Commonwealth Government introduced significant changes to the aged care home care system. The aged care reforms are designed to increase consumer choice and flexibility and create a more sustainable aged care system.

In the past, home care providers competed for government funding and then offered older people home care packages. Now, it is expected that older people should be able to not only choose a provider that gives them the best value for money, but also have control over what services are provided, when they are provided and who provides them. But do they have this control?

The aim of the research project was to explore firsthand experiences of both home care packages and the Commonwealth Home Support Programme. Qualitative methods were used. Forty older people from around Australia were interviewed. A family member was also invited to participate in the interview. The criteria for inclusion was (1) having been assessed as needing a home care package, irrespective of whether a home care package had been assigned or (2) receiving home care via the Commonwealth Home Support Programme.

The interviews explored from the participants' perspective what was working well and what was not working well. Interviews also sought participants' ideas about how to improve in-home care.

This research provides in-depth feedback, insights and reflections of in-home care services. The sample includes special needs groups such as older people who are socially isolated, on low incomes and at risk of homelessness. It also includes a veteran, an Aboriginal and Torres Strait Islander person and older people from the Lesbian Gay Bisexual Transgender or Intersex communities.

Importantly, this research provides insights into why some recipients of home care packages are not spending their monthly subsidy. According to the Aged Care Funding Authority (2018), there is approximately \$330 million in unused funds. One participant described why she had a surplus of more than \$30,000. She described several systemic problems in the implementation of her home care package. Stories like hers provide an opportunity for government, Commonwealth Health Department and providers to tackle some of the systemic problems.

The aged care reforms enable people to change providers if they are dissatisfied with the service. However, recipients of in-home care are often frail older people. As a participant said: *"By the time you're this age, and you have some disabilities, you couldn't be fagged changing."*

Some participants changed providers – but it was only when they and their families were *"at the end of their tether"* that they started to look around for another provider. Those who changed providers were often happier with their new provider. However, it is unfortunate they had to go through the initial stressful experience.

Participants described the hours of personal care they received on the different levels of home care packages. On average, these were:

- 2 hours per week on Level 1 package;
- 3 hours per week on a Level 2 package;
- 8 hours per week on a Level 3 package; and
- 14 hours per week on a Level 4 package.

Participants described fourteen (14) hours of personal care per week on a Level 4 home care package as insufficient support for frail older people to remain at home. Several said an older person required additional family and/or community support to remain at home.

Several participants acknowledged they would not have been able to remain at home without family support. Although some husbands, wives, sons and daughters received either a Carer Payment or Carer Allowance, several participants provided unpaid labour to support their older relative. Not surprisingly, women predominantly undertook this unpaid labour.

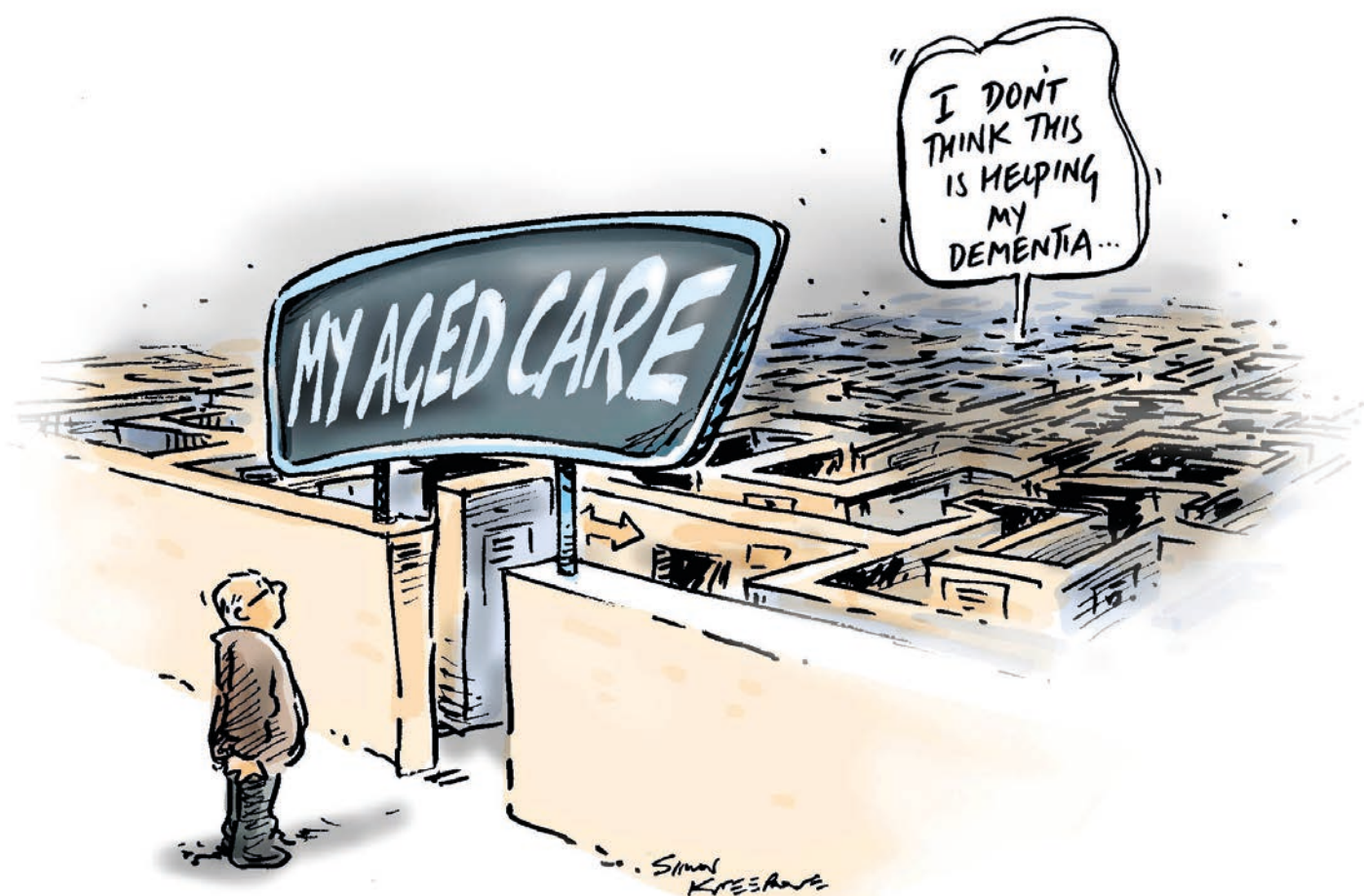
Only two participants were aware of the option of self-managing their home care package. One participant managed her home care package; the other managed her mother's home care package. Both were able to significantly increase the hours of personal care – and, perhaps more importantly, choose regular support workers with whom they were compatible.

Home care has a long history of services being provided to older people rather than with them. 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." The aged care reforms (e.g. consumer directed care and a focus on wellness and reablement) indicate a shift towards policies that empower older people.

Several participants had experienced the old and new system. They questioned why the government chose to fix a system that was not broken. Although the new system gives the 'consumer' more control than in the past, they described not having full control over how their home care package was spent, what services were provided, when they were provided and who provided them.

The title of this report, *Older people living well with in-home support*, was chosen because the author believes in-home care should assist older people to experience the highest possible quality of life. The living well concept is based on the World Health Organisation's Active Ageing framework (World Health Organisation, 2002). This framework emphasises six areas of life: social, physical, economic, civic, cultural and spiritual.

Many older people have indicated they prefer to stay at home rather than move into residential aged care. In-home care also costs taxpayers substantially less than residential aged care. It is imperative, therefore, that all providers of in-home care deliver high standards of services that are both consumer directed and person-centred.



Background

Aged Care Reforms

The Federal Government is the primary funder and regulator of the aged care system. The Aged Care Act 1997 and associated Aged Care Principles set out the legislative framework. The provision of home care packages is covered under the Act. The Commonwealth Home Support Programme is not.

In-home care is currently provided by a variety of providers – local councils and not-for-profit and for-profit providers.

Home care packages have no minimum age requirements or residency restrictions. However, the packages are not intended for visitors to Australia or people requiring temporary or short-term care. People are eligible for a home care package if they are:

- An older person who needs coordinated services to help them to remain living at home; or
- A younger person with a disability, dementia or other special care needs that are not met through other specialist services.

In 1984, federal and state governments implemented the Home and Community Care (HACC) program. Organisations eligible to provide Home and Community Care services included local councils, community organisations, religious and charitable bodies, health agencies and private for-profit organisations.

Under the Home and Community Care program, funds were allocated to the organisation, not the individual. Local councils, for example, received “block funding” (i.e. a fixed amount of money) from the government. Local councils decided how to spend this money on services for older people.

In 2011, the Productivity Commission’s inquiry report *Caring for Older Australians* recommended fundamental reform of the aged care system. The *Living Longer Living Better* reforms were introduced in 2013 with bipartisan support.

The aim of the *Increasing Choice in Home Care* reforms is to enable better ‘consumer’ choice. The ability for older people to choose who provides support is designed to create a more competitive and innovative market (Aged Care Sector Committee, 2017).

The Federal Government has made a commitment to continue to provide block funding under the Commonwealth Support Home Support Programme until 2020. After that, who knows? ¹

Types of home care

There are two types of home care services.

1. The Commonwealth Home Support Programme (CHSP)
2. Home Care Packages (HCP)

The Commonwealth Home Support Programme is the entry-level tier of support. It is designed to provide a small amount of care and support to a large number of older people to help them to remain living at home and in their communities. Underpinned by a ‘wellness and re-ablement model’, the Commonwealth Home Support Programme focuses on activities that support independence and social connectedness.

Home care packages provide a higher level of care. They are designed for older people with more intensive, multiple or complex needs to remain living in their homes. The Home Care Packages program provides four levels of packages (1 – 4).

- Home Care Level 1 – to support people with basic care needs
- Home Care Level 2 – to support people with low level care needs
- Home Care Level 3 – to support people with intermediate care needs
- Home Care Level 4 – to support people with high care needs.

My Aged Care is the entry point to the aged care system. Clients are initially screened for the type of assessment that is required. There are two types of assessments: (1) Regional Assessment Service (RAS); and (2) Aged Care Assessment Team/Service (ACAT/ACAS). The Regional Assessment Service assesses eligibility for Commonwealth Home Support Programme and the Aged Care Assessment Team/Service assesses for Home Care Packages.

The Federal Government subsidises the Commonwealth Home Support Programme and the home care packages. In 2016–17, the government provided \$2.4 billion for home support and \$1.6 billion for home care packages (Aged Care Financing Authority, 2018). The budget for home care packages increased from \$1.6 billion in 2016–17 to \$2.0 billion in 2017–18, an increase of 28.1 per cent (Department of Health, 2018).

¹ Due to the uncertainty around funding, I am aware that some councils in Victoria are decreasing their provision of aged care services. I am also aware that other councils are exploring ways to increase their provision of aged care services by becoming providers of Home Care Packages.

The home care package's daily subsidy is calculated as follows:

1. The basic subsidy amount (Table 1); plus
2. Any primary supplements (oxygen supplement, enteral feeding supplement, dementia and cognition supplement, veterans' supplement); less
3. Reductions in subsidy; plus
4. Any other supplement (hardship supplement, viability supplement).

Table 1: The daily and annual rates of home care packages (applicable from 1 July 2018 to 30 June 2019).

Home Care Package Level	Subsidy Rate (per day)	Subsidy rate (per day)
Level 1	\$22.66	\$8,248.24
Level 2	\$41.22	\$15,004.08
Level 3	\$90.62	\$32,985.68
Level 4	\$137.77	\$50,148.28

According to the Commonwealth Department of Health *Home Care Packages Data Report* (October 2018):

- At 31 March 2018, 84,971 people had a home care package;
- At 30 June 2018, there were 869 approved home care providers with a home care service;
- At 30 June 2018, there were 64,668 people in the National Prioritisation Queue (the queue), who were either in, or assigned, a home care package. Therefore, it is estimated that about 75 per cent of all people queued were receiving some form of Commonwealth subsidised home care support; either through a lower level home care package or Commonwealth Home Support Programme (CHSP) services;
- At 30 June 2018, 40,345 (70.5 per cent) of people on the queue for a Level 4 package were either in, or assigned, a lower level home care packages, providing them with Commonwealth subsidised home care service; and
- The average maximum exit amount was \$244 at 30 June 2018.

Table 2: Summary of financial performance of home care providers who submitted their Aged Care Financial Report, 2016–17 (Aged Care Funding Authority, 2018, p69)

	Not-for-profit	For-profit	Government
Total revenue (\$ m)	\$1,397.2	\$239.5	\$96.8
Total expenses (\$ m)	\$1,264.3	\$195.7	\$88.5
Profit (\$ m)	\$132.9	\$43.8	\$8.3
EBITDA (\$ m)	\$141.7	\$44.8	\$8.7
Average EBITDA per consumer	\$2,621	\$6,767	\$1,883

Consumer-directed care

Consumer-directed care (CDC) aims to provide older people who receive support in their home (i.e. community aged care 'consumers') with greater control of their lives by allowing them to make informed choices about (1) the types of services they access, and (2) the delivery of those services, including who will deliver the services and when they are delivered (KPMG, 2012). This change was designed to increase competition among providers, deliver higher quality services and give recipients better value for money than the previous system.

Prior to the *Increasing Choice in Home Care* reforms, providers were approved to provide a set number of home care places through the Aged Care Approvals Round. To access home care services, older people needed to find a provider with packages available at the right level. This was sometimes difficult. Although there may have been a number of providers in the local area, they may not have had a home care package available.

Home care package funding is now assigned to the recipient rather than the provider. Now, older people and their families must choose which provider they want to administer their home care package.

Prior to November 30 2018, it was difficult to determine how much services should cost as there was no benchmark. Older people and their families were required to shop around to find the provider that offered the best deal.

Wellness and re-ablement model

Home care has a long history of services being provided to older people rather than with them. The shift towards wellness and re-ablement is significant. It is designed to empower older people. For example, older people are now encouraged to work with health professionals to design the goals for their own care.

A recent review (Nous Group, 2018) found many older people do not understand the wellness and re-ablement model. According to Nous Group “many consumers don’t really get it yet” (p 7). They described older people who receive in-home care as the least prepared part of the sector.

To be able to make decisions about the services delivered in their home, older people and their families need to be informed about the aged care reforms, including the shift towards a wellness and re-ablement model. They also need to understand the reason for these reforms.

Previous research

Consumer directed care is being embraced internationally to promote autonomy and choice. However, it has largely developed in the absence of evidence on the views and preferences of older people (Kaambwa et al. 2015). Although there have been numerous ‘consumer’ consultations in Australia, these are often online. Online surveys limit participation from older people (i.e. community aged care ‘consumers’) who are not computer literate.

Ottmann et al.’s (2013) literature review suggested consumer directed care approaches have the potential to empower older people. However, when Simons et al. (2016) interviewed 45 older people to determine how well they understood the changes in home care, the study found about 50 per cent were confused about the term consumer directed care.

Kaambwa et al. (2015) used a discrete choice experiment approach. This quantitative study found participants preferred a consumer directed care approach that allowed them to: save unused funds for future use; have support workers that were flexible in terms of changing activities; and choose the support workers that provide their day-to-day care.

Gill et al. (2017) identified the issues and challenges experienced by staff, their clients and informal carers with the introduction of consumer directed care. Their investigation occurred during the period in which services were transitioning to the new model of service provision. They found the current culture and practice within home care services made translation of the objectives of consumer directed care difficult.

McCaffrey et al. (2015) determined what features of consumer directed, home-based support services were important to older people and their informal carers. Eight themes were identified:

1. Information and knowledge
2. Choice and control
3. Self-managed continuum
4. Effective co-ordination
5. Effective communication
6. Responsiveness and flexibility
7. Continuity
8. Planning

Six salient service features characterising consumer preferences for the provision of home-based support services models were identified:

1. Choice of provider
2. Choice of support worker
3. Flexibility in care activities provided
4. Contact with the service coordinator
5. Managing the budget
6. Saving unspent funds

Day et al. (2017) interviewed five people who were receiving home care packages. Semi-structured questions and emotional “touchpoints” relating to home care were used to guide the interview conversation. The researchers identified four emergent themes: seeking quality and reciprocity in carer relationships; patchworking services; the waiting game; and technology with utility. Continuity of carers was central to the development of a trusting relationship and perceptions of care quality among older consumers.

The Commonwealth Department of Health (2018) commissioned AMR, an independent research agency, to conduct research among home care package clients and service providers in August and September 2017. AMR measured experiences and perceptions after the *Increasing Choice in Home Care* reforms were introduced on 27 February 2017. Participants indicated high satisfaction with: the services they received (85 per cent); the services matching these expectations (86 per cent); and the general standard and suitability of the aged care services. About 80 per cent were satisfied with the information received from My Aged Care.

Most participants (74 per cent) considered the waiting time to be approved for a home care package as satisfactory and 65 per cent indicated satisfaction with the length of time they had to decide which provider would deliver the services.

AMR found the most valued service was domestic support (41 per cent), followed by transport, social and personal support. Although 68 per cent agreed the reforms would make it easier to move to a new provider, only 7 per cent in the sample were contemplating changing providers.

The Aged Care Workforce Strategy Taskforce commissioned National Seniors to undertake research on in-home care. McCallum, Rees and Maccora (2018) collected data from (1) a questionnaire survey of National Seniors members aged 50 and over and (2) qualitative interviews of client/care worker dyads.

McCallum, Rees and Maccora (2018) reported that older people receiving the Commonwealth Home Support Programme and Home Care Packages were satisfied with the service. However, evidence suggests most people are satisfied with their health care service regardless of the quality of the care they receive – even those who have negative experiences are satisfied with the care they received (Worth 2013; Haggerty 2010; Kalucy et al. 2009). This is particularly the case for older people. A US study of older patients found that their level of satisfaction with the quality of their health care was not a good measure of the quality or effectiveness of the health service (Mold et al. 2012).

McCallum, Rees and Maccora's (2018) qualitative interviews of client/care worker dyads reported "*strong agreement that aged care workers treat the household with respect, know what they're doing, and are well trained*". However, interviewing clients and carers together can be problematic. Clients might have feared retribution if they spoke honestly in front of a carer (Coyle and Williams, 1999). Also, a health service's culture may prevent staff being critical, particularly when a client is present during the interview (Moore, 2012).

Although McCallum, Rees and Maccora (2018) reported "a strong positive accent to consumers experiences" (p 4), they identified a range of issues including:

- Waiting too long to be assessed, and having to accept a lower level package until a higher one became available;
- Services being delivered at times or in ways that were inconvenient to the client;
- A lack of continuity of care for older people with dementia and poor training for dementia care;
- Lack of duty of care and the occurrence of theft;
- Poor communication from the provider, and poor administration of services generally; and
- Failures in the delivery of consumer directed care

Research method

Ethics

Peninsula Health's Human Research Ethics Committee (HREC) approved this research.

Recruitment

The aim of the recruitment strategy was to inform recipients of in-home care in Australia and their family members about this study. Those who were interested in participating were invited to contact the researcher.

The following recruitment strategies were used:

1. Invitation letter

Peninsula Health sent a letter to clients inviting them to participate in the study (Appendix 1).

2. Community engagement

A community engagement method was used to recruit older people who receive in-home care and their family members. Opinion pieces in newspapers, television appearances and radio interviews encouraged people to visit the Aged Care Matters' website and Aged Care Matters Advocacy Facebook Page. The recruitment flyer was published on the Aged Care Matters website (Appendix 2). Information about the research was also published on the Aged Care Matters Advocacy Facebook Page.

Those who expressed an interest in the research contacted the researcher. They were emailed a Participant Information Sheet to help them decide whether they wanted to be interviewed about their experiences of in-home care.

3. Flyers

Flyers were circulated to colleagues via email.

4. Community forum

A community forum was held to discuss the changes in the provision of home care services and how these changes may affect residents who live in the City of Darebin, Melbourne, Victoria. Dr Russell was the master of ceremonies (MC). Audience members who were interested in participating in the research later contacted Dr Russell.

5. Snowball technique

This widely used qualitative research technique involved asking participants to tell other potential participants about the project.

Inclusion criteria

To be included in the study, participants must (1) have been assessed for a home care package, irrespective of whether the home care package had been assigned or (2) receive the Commonwealth Home Support Programme.

Data collection

Data was collected via either face-to-face or phone interviews between September 25 and November 20, 2018. Some older people were interviewed alone; others chose to have a family member present. In several cases (e.g. recipient was cognitively impaired, asleep during time of the interview) the family member spoke on behalf of the older person. One participant had died recently – his wife spoke about the in-home care he had received. Most interviews were between a half and one-hour duration. Four interviews (Participants 3, 9, 15 and 17) were longer – between one and three hours.

Participants 3, 17, 19 and 21 communicated with the researcher via email after the interview. This correspondence has been included in the data.

The interview schedule was semi-structured with open-ended questions (Appendix 4). Participants were asked to reflect on their experiences of in-home care.

With participants' permission, the interviews were tape-recorded. The recordings were transcribed, though not verbatim. Only data relevant to the research questions were transcribed.

Sample

The sample contained 40 participants from urban, regional and rural Australia.

The average age of participants was 80 years (range 66 – 95 years; median 83 years).

Table 2 describes the type of in-home care that has been approved and assigned at the time of interview. Several participants had transitioned from the Commonwealth Home Support Programme to a home care package. In addition, several participants had transitioned from lower-level packages to higher-level packages.

Table 2: Participants' age and details about their home care package/Community Home Support Programme

Participant Number	Age	Approved	Assigned
1	81	4	4
2	81	2	CHSP
3	75	4	4
4	72	4	4
5	83	2	2
6	94	4	2
7	85	3	CHSP
8	91	3	3
9	67	4	4
10	89	CHSP	CHSP
11	75	2	2
12	83	4	4
13	90	3	3
14	88	4	4
15	68	4	4
16	87	4	4
17	72	4	4
18	88	2	2
19	88	2	2
20	95	3	3
21	69	4	4
22	79	4	2
23	74	4	4
24	86	4	No Package
25	92	4	4
26	89	4	2
27	81	3	2
28	70	4	4
29	72	CHSP	CHSP
30	85	4	4
31	85	4	4
32	Did not meet inclusion criteria		
33	77	3	2
34	82	2	No Package
35	86	4	3
36	71	CHSP	CHSP
37	90	2	2
38	66	2	2
39	92	2	2
40	85	4	4
41	83	2	2

At the time of interview, three participants had been approved for the Commonwealth Home Support Programme. The other 37 participants had been approved for a home care package.

All three participants approved for the Commonwealth Home Support Programme were receiving services from this programme.

Of the 37 participants who had been approved for a home care package, 33 were assigned a home care package, two were assigned the Commonwealth Home Support Programme and two did not receive any services funded by the Australian Government.

Participants were not always assigned a home care package at the level at which they had been approved (Table 2).

For example, although 22 participants were approved for a Level 4 home care package, 16 were assigned a home care package at Level 4, two participants at Level 3 and three participants at Level 2. One participant who had been approved for a Level 4 package was not assigned a home care package. He funded private support services. This participant died before being assigned a home care package.

Data analysis

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

On 27 November 2018, a draft report was sent to five participants, the Commonwealth Department of Health and three colleagues at Peninsula Health for feedback. Their feedback was included in the final report.

The final report was submitted to the Commonwealth Department of Health on 19 December 2018. On 18 January 2019 and 12 February 2019, the Department of Health provided additional feedback.

Strengths and limitations of the research

A sample size of 40 allows some confidence that a wide range of views has been captured. However, the results of the research are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

A strength of this research is that it explored non-professional perspectives of in-home aged care. A further strength is that the researcher does not work in the aged care sector or for a government agency. This enabled participants to speak frankly. Research shows a disinclination for people to be critical of health services in face-to-face interviews with staff who work in the sector because of not wanting to jeopardise their treatment/care or a fear of consequences (Wessel et al. 2012; Coyle and Williams, 1999).

A researcher who does not work in the aged care sector or for a government agency also ensures data is analysed without any conflicts of interest.

Another strength of the study is that respondents volunteered to participate in the research. Unlike surveys that are sent to all members of a 'consumer' organisation (including those who are uninformed about an issue), self-selected samples ensure that 'consumers' who volunteer are informed about the issue.

Self-selected samples may be biased toward people with strong opinions – both positive and negative. In addition, self-selected samples may have included people who want to improve the future delivery of

Home care packages and Commonwealth Home Support Programme. This was noted in Part 1, Section 6 of the Participant Information Sheet/Consent Form: "a potential benefit is you will be contributing to research that may help to improve the future delivery of Home Care Packages and Commonwealth Home Support Programme" (Appendix 3).

Finally, Dr Russell is a public health researcher and an aged care advocate. Her role as an aged care advocate may have encouraged participation from older people and their family with negative experiences of home care packages to volunteer.



Findings

In this section, all text in quotation marks and italics are direct quotes from a participant. In longer quotes, a number identifies the specific participant.

Effort has been made to ensure that all participants have a voice, and that no individual participant dominates the discussion. However, interviews with four participants (Participants 3, 9, 15 and 17) were much longer than the other interviews. This was due to the amount of information they wished to share. Their insights have been quoted extensively.

It is also worth noting that Participant 24's daughter works in the aged care sector. Her business helps clients to find the most suitable home care provider. During the interview, she spoke from the perspective of a 'consumer' and a provider.

As is customary in reporting qualitative data, terms such as "most", "the majority" and "more than 50 per cent" 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 20 participants. When more than 20 participants share a specific insight, a general descriptor "participants" is used.

Both participants and providers have been de-identified.

This section is divided into three parts:

- A. Positive experiences of in-home care
- B. Negative experiences of in-home care
- C. Ideas for improving in-home care

Several participants had received in-home care for more than five years. They had experienced the system before and after the aged care reforms. They questioned why the government chose to fix a system that was not broken.

Sometimes I wonder: "Why fix something that's not broken?" I think it was because the providers were holding on to the cash, and gouging. I spoke with one provider who boasted: "We are holding \$3 million in the bank. That is going to be our profit." I was thinking: "That is terrible. The people are needing the care." That was when providers were holding on to the money and divvied it up. (Participant 24)

Positive experiences of in-home care

Remain living at home

When asked what was the best thing about in-home care, participants unanimously replied: "It enables me to live at home."

The best thing about home care packages is that you are able to get support to live as well as you're able for as long you're able in your own home, if that's what you want to do. (Participant 15)

I am very grateful for this package. It has enabled me to live in my home. Without these services, I wouldn't have been able to stay here. I couldn't do it all myself. I am delighted with the help I get. It has been a godsend. (Participant 18)

It was not only personal services (e.g. personal care, cleaning, shopping, gardening) that assisted older people to stay at home. Some older people also benefitted from home modifications, equipment, technologies and other products.

Having the package is great with all the things I can get to help me at home – products. That is fantastic. If I had to pay for all the things I need to keep my husband at home, we couldn't do it. The package money is a great help. (Participant 21)

The ability of older people to remain in their own homes benefits not only individuals but also families and the local community.

Without home care support, Dad would be fully dependent on me. (Participant 20)

This scheme for the elderly is god's gift. It gives my son in Queensland peace of mind. It gives our daughter peace of mind. It goes much further than the individual. The community – most people know me. It is hopeful that I am still giving to my community – not as much as I'd like – but I'm still giving. You can't put a price on those things. (Participant 7)

Several participants acknowledged that without in-home support, they would need to move into residential aged care.

I couldn't live at home without help. I have no one to help me. Now that I am paralysed on my left side, the home care package is like a second hand for me... Best thing – it helps me to live independently. If I don't have this help, I can't do anything. I am on a pension – I couldn't afford to get help. I would have to move to one of those institutions. (Participant 4)

Several participants expressed fear about moving into an aged care home. An older woman said she would prefer to kill herself than “go into one of those hellholes”. Recent negative stories in the media had made her terrified of moving into an aged care home.

What I did know was I was not going into a nursing home. I was coming home. I absolutely wanted to stay home. (Participant 1)

Indigenous Australians were also reluctant to move elders into an aged care home.

Aboriginal people do not want to put their loved ones away. That's why the packages are good. We have packages at Aboriginal Community Elders Services. We have about 60 packages at the moment. (Participant 41)

My Aged Care

Staff at My Aged Care were described as “friendly”, “efficient” and “empathetic” people who answered phones promptly.

On the phone, they were quite helpful and very polite. And thank goodness you don't have to hold on for too long. (Participant 16)

Planning ahead

Some participants arranged a home care package in advance of needing help in the home. They knew they were ageing, and they knew sometime in the near future they would need support to stay at home. They decided it was better to get into the queue early.

I work on the philosophy of being prepared for things. I knew I was getting older. And I know how bureaucratic systems work. I thought I should find out about the system, and get involved, in case I should need it. (Participant 11)

We were advised to apply for a Level 4 package now – even though Dad doesn't need it yet. It will take about a year to come through. (Participant 8)

My sister insisted I apply for a package. I live alone and have had a few falls. My sister arranged an assessment. I've been approved for a Level 2 package. But I don't need any help yet which is lucky because I have been told it will take at least nine months before I get it. (Participant 34)

Some participants were advised by others to get some support in their home.

It wasn't so much me realising I needed help but other people realised...I was in a mainstream package at first. Other people said at my age with all that I've done I needed to be looked after. One of the non-Aboriginal nursing supervisors at Aboriginal Community Elders Services phoned me to say: “Auntie, I'd like to set up an assessment interview because I think it would be good for you to have some support.” That was about 10 years ago. (Participant 41)

Paperwork

Participants described the written material (e.g. brochures) they received with their approval letter as “helpful”.

They sent me a lot of paperwork – brochures, advance care planning. It was a substantial package. One of the brochures has a check list for researching home care providers. That is helpful. And a check list for entering a home care agreement. (Participant 2)

Approval letter

A participant described receiving the approval letter as “like winning Tattsлото”.

By the time Level 4 came through, all I cared about was the first page. “You're approved.” And it would have been thrown in the drawer after that. (Participant 3)

After receiving the approval letter, several participants accessed the Commonwealth Home Support Programme while they waited for their package to be assigned. Others relied on family support.

While we were waiting, we had no help except from our family. (Participant 12)

Family support

Participants who described their in-home care working well invariably had family support.

How could home care work without supportive children? (Participant 19)

Several participants said they would not have been able to remain at home without their family supporting them.

My husband can't be left alone. My sister-in-law was on standby if I needed to go out to look after my sick mother during the night. (Participant 28)

I could not survive on the home care package without my husband. You have to have a daughter or partner to manage the home care package. (Participant 17)

Dad manages on the package because he lives with my partner and me. He wouldn't be able to manage on his own. (Participant 8)

Some participants said the home care package was meeting the needs of their parent/partner because a family member advocated on their behalf.

It is meeting Dad's needs because I spend so much time advocating, checking everything, challenging the system and asking questions. Every day, I am doing something. If I wasn't here, I have no doubt that Dad could not stay at home. (Participant 19)

A participant said he and his wife would not have known “where to start”.

My daughter does too much. But we couldn't manage without her. We wouldn't have known where to start. (Participant 19)

Another participant described her father as “dependently independent”.

Dad is 'dependently independent'. He can still shower himself and put food that I have cooked in the microwave. The carer does seven hours and I do about the same. Plus I do office work. As long as everything is done for him, his life runs like clockwork. He has a good social life – goes out for meals, is a member of Rotary and the Melbourne Cricket Club. (Participant 20)

A participant who requires assistance in the morning and evening said her Level 4 home care package is not sufficient to buy the care she requires. Fortunately, her husband is able to assist her on the evenings the support workers are unavailable.

I'm on a Level 4 package. I get help to get out of bed in the morning, shower and dress. And in the evening, they help me to bed. Seven days a week in the morning, five days in the evening. My husband helps me the other two evenings. It is very expensive on weekends. It all gets back to money. I can't afford carers in the evenings on weekends and public holidays. (Participant 1)

Waiting for a home care package to be assigned

Commonwealth Home Support Programme

Several participants described receiving the Commonwealth Home Support Programme while waiting for their home care package to be assigned. At Budget estimates (June, 2018), the department stated that about a quarter of the 105,000 older people in the home care queue were accessing the Commonwealth Home Support Programme.

Local councils, private for-profit providers and not-for-profit providers deliver the Commonwealth Home Support Programme. Some participants described the services with the Commonwealth Home Support Programme and a home care package as “similar”. Home care packages, however, have the advantage of allowing people to “save up money”.

After Mum's stroke, I became Mum's full time carer. We were on a waiting list for a long time for a Level 4. So Provider X offered us a Commonwealth Home Support Programme until we got the package. Carers came in five mornings a week for an hour. She also had regular physiotherapy. Also an occupational therapist recommended specific equipment. We got everything we needed. The only thing we had to buy ourselves was the hospital bed. They serviced all the equipment. It was brilliant. I learnt a lot from the carer, including how to use the hoist. We were also given a lot of information about our entitlements. I found the case manager of the Commonwealth Home Support Programme much more proactive than the home care package case manager. (Participant 30)

A participant described the services he received from his local council (under the previous Home and Community Care program in Victoria) as better than services he received on a Level 1 home care package from a private provider.

While I waited in the queue, the social worker at the hospital arranged for the local council to help me. I got meals on wheels, someone came twice a week to

help me shower, and they cleaned my house. Several months after I left hospital, I got assigned a Level 1 package. The council help finished. The council's case manager said to me: "Now you must find your own provider." She recommended Provider I. Someone came twice a week to help me shower and cleaned a little bit – but it was not enough. It was better with the council. (Participant 4)

Self-funding services

Several participants paid for services while waiting for their home care package to be assigned.

I employed a care provider 12 hours a week to help Dad's partner. He also had other family support... Dad put money aside for a rainy day. So we are using it to purchase care for him. (Participant 24)

After being assessed for Level 4 plus, we had to wait for six months. We were told we had to wait until someone who had a package died or went to a home. My partner was placed as a priority. While we were waiting, I got hold of a community provider who gave us four hours a week. We paid for that ourselves. (Participant 15)

Choice

Choosing providers

Some participants chose providers purely on cost. Others based their choice on the quality of the service.

I compared the costs of Provider E with Provider K and there was a 25 per cent difference. Provider K was much more expensive. And that didn't include the daily care fee (\$10.17 per day) that Provider E has never charged. (Participant 20)

Even though I am paying more, I'm happy because they are giving me such a good service. I am happy with every aspect of this provider. (Participant 28)

A participant described "loving" the philosophy of a specific provider.

I love the philosophy of Provider F. They match regular carers with the person's situation. And try to keep that regularity. They are also the only providers to have an app – and the app has GPS on it. It can notify the care recipient or carer that the staff is 2km away. The GPS also provides reassurance. You know by the GPS that support workers are in the home for the time they say they are in the home. (Participant 3)

Several participants used personal and professional contacts to help them choose a provider. Others used more objective information.

I used some of my professional contacts to find out who are the best providers. They replied: "Who knows?" I phoned lots of them. In the end, it boiled down to cost. This is where it gets complicated. Provider E was cheaper but really short staffed. They told me they don't have many carers – they outsource them. It was in my best interests to keep the same carers Dad had on the Commonwealth Home Support Programme. So I requested Provider V even though their fees were higher. (Participant 19)

I attended a wellness Expo. All the providers were there. The ones that got kicked off my list were the big companies. They don't have their own staff. I put four providers on a short-list. They came to my home to interview me. And I made up my mind to go with a smaller provider – the woman was extremely helpful and explained everything that I was entitled to and what they could do for me. (Participant 26)

Several participants said hospital staff recommended they use a large provider. They were told that large providers were less likely than smaller providers to go broke.

We were given a list of providers. It was impossible to decide which one was which. So we went with the social worker's recommendation. She went through the ups and downs of each one. The strongest factor in favour of L provider was they are the biggest supplier in Australia. A lot of the other ones were small operations. We could rely on the bigger one not to go bust. And also we expected them to have stand-ins if someone was sick. (Participant 8)

Several participants suggested the large providers all offered a similar service.

Provider BB is taking a very large cut for themselves. But all the big providers seem to do that. I phoned three of the biggest providers in our area, and they all said Level 2 gives three hours of support a week. (Participant 26)

Choosing how package is spent

Several participants were unsure about how they could spend their home care package. Those participants who asked questions, challenged case managers and advocated strongly were often told: "Yes."

When I asked the case manager: “What can we use the package for?” she just skimmed the surface. However when I asked if we could use the package for this or that, she would say “yes”. I asked Provider E if they could reimburse Dad’s nutritional supplements. The case manager initially said: “No.” I challenged this – and then the case manager said “yes”. I am constantly advocating for Dad. (Participant 19)

When it became hard to walk, I got an electric wheelchair on a trial. During the trial period, a case manager told me I should be able to get that in my package. I hadn’t thought of that. You just don’t know what you can get. So I asked and I got it through my package. (Participant 1)

A participant described herself “pushing the boundaries” when spending the money in his home care package.

I had \$3,000 in my package. I requested a clothes dryer for the winter. The case manager said: “No, it’s not on the schedule.” I asked: “What schedule?” As far as I know, there isn’t one. I had been able to get an air conditioner, vacuum cleaner, computer but not a clothes dryer. I was going on the philosophy of customer directed care. So I gave them good reasons for why I wanted it, and why I needed it. (Participant 11)

Changing providers

Participants understood the process of changing providers. The difficulty, however, was how to be confident another provider would deliver a better service.

I think I just have to say to them: “I’m changing providers.” But I have to find another provider and somehow assess them to be a better proposition than what I am getting now. That is a big question mark. How do you know they are better? You don’t know what they are like until you start using them. (Participant 1)

Some participants were conflicted about changing providers. Although they described their current fees as “excessive”, some participants had formed a relationship with their support workers. Other participants focused only on the fees.

When changing providers, the only thing I asked about was their fees. (Participant 11)

I’d change providers but I’d lose these lovely girls. I don’t want to rock the boat. (Participant 5)

I know there are other providers who don’t take so much money out in fees as Provider JJ. But she likes the support person who visits her. (Participant 37)

I was concerned that I would lose my support person. She was so good. I asked my new provider if I could continue with her – and they said “yes”. (Participant 18)

Several participants subsequently moved from a big provider to a smaller one. They found the smaller provider provided better, more person-centred care than the large providers.

Provider Z was a brand new company. She sounded so nice on the phone. She had no health background but had issues with a relative in a nursing home and decided to get into home care packages. They offered 20 hours a week of personal care on a Level 4 package. This is more than the big providers offered. More importantly, they offered us these two amazing women who had experience with dementia care. Mum loves them. Her face lights up when she sees them. (Participant 23)

Changing to a smaller provider has allowed my partner to have more hours of care with more suitable staff. Most importantly staff have dementia training. Provider O did not provide any training to their staff. (Participant 15)

I changed to a much smaller provider. I could not believe the difference between Providers Q and J. Firstly, the case manager is in contact weekly to check how things are going. She makes suggestions about services for my husband – things I did not know he was entitled to have. She also recommended a male carer who is so good. (Participant 16)

Participants who changed providers described being much happier with their new provider than with their previous provider.

I wanted to change provider so I phoned Provider J. I was on Level 2 at the time. She asked me what services I wanted. She gave me all the information. I had to wait a month before I could swap over. And then I got a carer to look after me. It was the same person each time... I told the new provider: “I need someone who understands what I need. I need the same person so I don’t have to explain everything each time. Provider J was able to do this. So when the carer arrives, she starts to work immediately – she knows what I want done and how I like it done.

If we run out of cleaning supplies, she writes it on my shopping list. (Participant 4)

Exit fee

Participants did not consider the exit fee an obstacle for changing providers.

We've heard of a small provider who seems very caring. We will wait until she builds up her business a bit. Mum is very attached to one of the care workers. That is the only thing that keeps us with Provider X at the moment. Provider X has an exit fee – but that is not the obstacle. (Participant 30)

Consumer directed care

Participants who were informed about consumer directed care felt they were in a stronger position to negotiate with providers.

At one stage Provider GG said they were going to rotate the roster. I told them if they take [name of care worker] away, I would take my funding elsewhere. I work in the sector so I know I can take Dad's funding anywhere I like. I know I can negotiate. Most people wouldn't know that. (Participant 40)

Self-managed care

Some providers offered self-management as an option – though still charged case management fees.

Provider E offers self-managed as one of their options. However, Provider E charges the advisor fee \$272 even though I am not using it. I would be happy to pay an hourly rate if I ever needed to contact the advisor/case manager – on a client-initiated basis. So everywhere they can, they are making money. (Participant 20)

Two participants genuinely self-managed their home care package. The provider was described as “brokering” the money rather than “controlling it”. The providers of self-managed packages charged somewhere between 10-13 per cent of the package in fees. Participants considered the fees for a self-managed package much more reasonable than the fees they had paid their previous provider.

The self-managing is like a gift from heaven. I do not have that middleman. So I can create space for just the carer and myself to make my own arrangements as we see fit. (Participant 17)

A few months after her interview, Participant 17 wrote:

“I am constantly being rewarded with my self-managed package. Yesterday I tried a new carer while one of mine is away. I can't believe what amazing people I am meeting who have compassion, empathy and intellect. Yesterday my carer was a social worker unable to now work full time who lives right near me. I really like the ones who can come any time for you and are not stressed going from one job after another. After being house-bound for so many years, it's such a pleasure now to go out in the world and share my social support time with like-minded people who nurture me. I woke up today feeling so blessed. I now am making some really nice friendships and it's all about me and not obeying the providers rules.” (25th October, 2018)

Hiring support workers

The two participants who self-managed their home care package employed support workers via an internet platform. They considered the hourly rates more reasonable than the hourly rates they had paid their previous provider.

Because I'm paying the carer half what I used to pay the agency, I can afford to have her here twice as long... and because they are working for themselves, they are so eager to please. (Participant 17)

The biggest problem with carers on these platforms is most want time blocks. They want three- or four-hour shifts. The aim is to try to find someone within a kilometre of the local area. You figure if they live a few streets away, they won't mind doing half or one-hour shifts ... It took me ages to find regular carers through [platform]. But once you find those gems, then you've got them. Mum had three regular people per week through that platform that remained consistent. I found them as local as possible, and they were prepared to do short shifts. The reliability of private carers is brilliant because I hired them and have gotten to know them. (Participant 3)

Spending funds creatively

A participant who self-manages her mother's home care package describes spending the money “creatively” to assist her mother's quality of life. Although the participant refers to “guidelines”, the Commonwealth Health Department publishes “booklets, videos, newsletters, fact sheets, other supporting websites and interpretive services”, not guidelines.

The guidelines of what you can have are quite grey. And that greyness works to the consumers' advantage. You can push the boundaries a bit. Provider D says: "We've never seen anyone spend so creatively." Because I buy a lot of technology products to help my Mum. People don't realise they are entitled to make their own choices. I also use a company H – another great company. They digitalise the photos and give Mum iPad lessons. Mum adores the company H worker. I have also paid a company to do a storyboard of Mum's likes and dislikes. This is so important in Mum's case – because staff only see the angry, hostile older face in front of them now. (Participant 3)

Staff

Case managers

Participants described the case manager as integral to the quality of the service, particularly in the early days of receiving a home care package.

The case manager was excellent. She helped us a lot at the beginning. Now that everything is in place, I don't need to call her. She visits me once every six months to check that everything is OK. (Participant 8)

Participants said they valued case managers who provided information about services and other entitlements.

I can't believe how good the case manager has been to me. She gives me information I don't even know I need – you can't ask questions if you don't know what to ask. The case manager told me about the cognitive and dementia supplement and arranged the test so we could apply. Without her telling us about it, we would have missed out. (Participant 28)

The case manager is very informative. She comes out once every three months to see how things are going. Each time she reminds me of things I am entitled to have. She recommends I leave my hours as they are so I can accumulate some funds to get the equipment I may need down the track. She is really good. (Participant 28)

Participants appreciated case managers who visited their home regularly. These case managers made suggestions about support services, including recommending an assessment for a higher-level package when an older person's health deteriorated and/or needs increased.

I met regularly with the case manager as Mum's dementia worsened, and her needs changed. The case managers were pretty good – offering good ideas on what would support Mum. (Participant 40)

Provider J's case manager is proactive. I don't feel like I'm on my own. She regularly visits and asks how things are going. Is there anything I need? (Participant 16)

My case manager is Aboriginal. She is not a registered nurse but has had a lot of training in aged care. I feel comfortable to phone her. I have her mobile. Even if I wanted to talk about something that I know she is not going to be able to respond to – it might be something I just want to get off my chest, I can. She's a good listener. She also visits me here once a month – or more often if I want. (Participant 41)

Participants were grateful when they were able to form positive relationships with case managers. Participants considered themselves lucky when they had the same case manager for a considerable length of time.

It's important for case managers to form relationships with families. It is extremely important that there is a go-to person. That you have a name and an email that is a go to. Someone to talk with when I am concerned about Dad. (Participant 40)

The case manager at Aboriginal Community Elders Services phones a couple of times a week to see how I am. The other mainstream provider never ever did that. It was like they were a business and I was just a number. They were there to make money. That's where Aboriginal Community Elders Services is different. It is a community-minded program. They are not there to make a profit. They concentrate on our wellbeing. If you ask for something and they can't give it – they will explain it. They don't say: "Yes we'll get that for you and then leave you sitting on a limb waiting." (Participant 41)

Participants appreciated case managers who were easy to contact and responded promptly to phone calls and emails.

I feel comfortable to phone my case manager. If I ring during hours, the girls on the phone tell me whether my case manager is in the office. If she is out, she phones when she comes back. She is pretty good; 3-4 out of 5 for phoning back. If she doesn't phone me back, I phone again. (Participant 1)

Provider J's case manager has given me her mobile number. I don't have to leave messages at the office. I can talk with her any time. She comes here every month to give me the statement and explain it to me. We talk a little bit about how things are going. If I want to change anything – if something's missing, or I want to stop something. If I want to do something different, I tell her. I plan my support with her. (Participant 4)

We have good communication. I email and she always replies within 24 hours. I can see how this may not work for older people. (Participant 20)

Support workers

Participants who lived alone described the support workers as their only visitor on some days. They valued the social contact as much as the personal care.

They are wonderful, they are good company, cheerful, do anything for me. These women are like my daughters. (Participant 27)

The council staff usually come a bit earlier and stay a bit longer to chat with me. They are often the only people I see during the day. (Participant 5)

If you live on your own, it's like company and something to look forward to... I look forward to the visit from my carer. Knowing there is someone there who I can lean on. It's not so much they will come in and clean my house – I know some people on packages look for that type of support. But it's having a friend who I can lean on, turn to, go out with. It's company. (Participant 41)

Some participants appreciated being able to choose their support workers.

We got council help first. That was quite good. We got cleaning and gardening. The best thing about the package is we can choose who can come to our house. We didn't have that choice with council. (Participant 14)

We were lucky. Provider E allowed us to use our own carer. (Participant 20)

I always ask for older carers. Some are very good because they have worked in nursing homes. (Participant 19)

Participants appreciated meeting the new support workers before they began working in their home. They also liked it when new support workers spent some time “buddying” with the regular support worker. They also valued a support worker who provided a handover to a new support worker.

Prior to getting a package, the local council and a charitable organisation (Provider N) supported us. A manager always introduced us to a new person. We would all sit down together and the new person would decide if they were comfortable with us and we would also decide. It was civilised. Provider M was supposed to do that but they never did. (Participant 9)

When new staff are employed, they buddy with the regular person so Dad gets to know them. (Participant 40)

When I changed support worker, there was a handover. “Auntie likes this, she doesn't like that. Don't bother with this.” It was helpful. (Participant 41)

Participants appreciated knowing in advance who would be working in their home and when they were expected to arrive.

The case manager emails me the roster every week to confirm who's coming. If it's someone new, I leave a list. If it's someone who comes here all the time, I am able to just walk out the door. (Participant 28)

Since I've changed provider, my carer is always on time. I have the same carer each time. Since the day I started with Provider J, my carer has never missed a shift. (Participant 4)

Participants preferred to be able to communicate directly with their support workers rather than via a case manager or a receptionist.

One of the best things about Provider J is I don't have to communicate via the case manager. I talk directly with the carer. (Participant 4)

I talk to Dad's support workers every day. Some places you have to go through the case manager. As a family member, it's important that I can talk directly with the person who is directly supporting my Dad. (Participant 40)

We have a communication book. They write the times they were there. We can write in red if they need to know something. (Participant 39)

A participant was impressed with a support worker's professionalism.

Provider J has sent a carer to be with my husband a couple of times so I can go out. He spends the entire time just looking after my husband. That is exactly what he is supposed to do. He is professional. He is not texting on his phone like the other ones from Provider R – some were even on their computers. (Participant 16)

Participants appreciated support workers who stayed a bit longer than they were meant to stay. In some cases, a genuine friendship developed.

She sometimes stays more than an hour. But I am always only charged an hour. (Participant 4)

One of the girls who comes is like a friend. I like my own company but I do look forward to her visits. (Participant 5)

Participants appreciated support workers who were flexible.

If I need something different – I need to change my bed sheets – I just have to ask and she does this. (Participant 4)

A participant described what she thinks makes a good support worker.

The way they handle the whole situation. Some of them are quite chatty that I like. They are confident when they help me in the bathroom. They are experienced. (Participant 13)

Participants appreciated a case manager who matched the support worker with the recipient.

[Name of carer] is patient, non-intrusive. It's her personality. She is a very good fit for my parents. (Participant 40)

Some participants who did not speak English as their first language preferred the support worker to speak their language. Others considered the support workers' abilities more important than speaking their language.

The council came first. But Provider J is better because the case manager speaks Mandarin. She arranges people to come to my home who also speak Mandarin. It is difficult for council to get this type of staff. (Participant 6)

We felt the carer's abilities were more important than them speaking Greek. We tried some Greek-speaking carers, but Mum and Dad thought they wanted to know too much. (Participant 19)

Several participants changed providers because they valued support workers who spoke their language or shared their culture.

Both my wife and I on a package – Level 4 and 3. We changed providers because we found a provider with carers who speak Mandarin. They are also able to cook Chinese food – which is good. Provider J not only gives us a statement in both English and Mandarin but the case manager explains it to us. We could not understand the statements we received from the previous provider. (Participant 12)

Some participants organised extra shifts with their support worker. They funded these extra shifts privately.

I employ the carer for an extra four hours. I pay her more than the agency pays her, but less than I pay the agency. So it works well for us both. (Participant 23)

A participant described staying in touch with her support worker after the support worker left her job.

When my support worker left, her boss told her not to contact me. She was my friend. It must be something to do with them being worried I would follow her to her new provider. But she was moving miles away. We couldn't work it out. She still phones me, but she feels a bit nervous about it. (Participant 41)

Home Care Agreement

Some case managers explained the content of the Home Care Agreement before asking participants to sign it. Even so, some participants had difficulties understanding all the details.

I have a new contract now with Provider J. The case manager has explained the contract to me. This time, I understood what I signed. With the previous provider, I just signed it without understanding what I had signed. (Participant 4)

It was important for the provider to go through all of that with us. But I wasn't paying a lot of attention to the detail. (Participant 9)

Daily fee

Everyone receiving a home care package may be asked to pay a basic fee. This fee is 17.5 per cent of the single age pension rate per week. Recipients are also means tested to determine whether they are required to contribute an additional amount, known as the 'consumer' contribution.

Several participants said their provider waived their daily fee and means tested contribution.

Some providers charge a daily care fee and some don't. Provider O did. My partner was losing \$115 from her pension. Our new provider doesn't take the daily care fee. (Participant 15)

The provider waived our contribution and our day cost. (Participant 14)

Some participants described their daily fee and means-tested contribution ceasing when they received a higher-level package.

Provider Q charged us a daily care fee when my husband was on Level 2 but we pay nothing on Level 4. (Participant 16)

Once Mum moved to Level 3, they stopped charging the contribution. That must mean they get more money. (Participant 13)

Palliative care

A participant described receiving all the help she needed to support her husband to die at home.

They were absolutely wonderful. We got all the help we needed. It gave me the confidence and support so my husband could die at home. The only problem for me was getting enough sleep. At one point, our GP insisted I take a break. The provider offered 24-hour care for three days but my brother offered to sleep here overnight. The carers came for two hours morning, lunch and evening – to help with showering, dressing, meals. And the nurse came to attend his wound care. They also arranged for the podiatrist to come to the house. My brother had to go to hospital for a day, so they sent a carer for 10 hours. I didn't take much notice of the invoices. All I cared about was he got all the care he needed. (Participant 31)

Person-centred care

Some participants described their experiences of person-centred care. Participant 40 was thrilled when the home care package provider agreed to allow her father's support worker to be with him when he visited his wife in an aged care home. During her shift, the support worker is responsible for the father and the aged care home is responsible for the mother. The participant was delighted when the provider and aged care home gave permission for the support worker to take the mother and father for outings.

Seven days a week, the same two women come for about 30 minutes to make Dad a cup of tea, make him a sandwich and have a chat. While there, they check he had his morning medications. I phone every day at 5pm – they answer the phone. Dad's deaf so they pass the phone to him. And they help Dad feed the cats. On a Wednesday, [name of carer] comes for about three hours to clean. She also does Dad's shopping, takes him to appointments – generally checks on him. She also comes for two hours on Friday. On a Thursday [same carer] comes to Mum's nursing home around 9am – she spends about five hours there with both Mum and Dad. As an example of Provider GG becoming more person-centred, they allow me to also pay [same carer] privately (in addition to the five hours) so she can take both Mum and Dad out in the car. We had to get that approved by management because it was the first time they had done that. It was a bit complex – with the package she is responsible for Dad. But now she is also responsible to take Mum. I was over the moon that they allowed it. (Participant 40)

Connecting older people

A participant praised a program that connected people with early onset dementia who live at home. This program enabled peer support.

At that time what was then Alzheimer's Australia had a program called Young Onset Dementia Key Worker program. The key worker for our region contacted us. That allowed us to meet other people living with young onset dementia – and for peer support. (Participant 15)

Ageing well

Re-ablement

Several participants described an older person's health improving with in-home care.

Dad would have been in a nursing home. By staying at home, he has improved quite a lot since the accident. (Participant 19)

Social engagement

Some participants described feeling lonely and socially isolated in their homes. Some providers arranged social activities. Providing subsidised transport also assisted participants to engage with their community.

My new case manager was here the other day. She asked me if I was lonely. I replied: "Sometimes. Most times I am fine here on my own." She thought I needed more people with whom to talk. They are going to start me on a weekly outing. The bus is coming to take me to a talk tomorrow and there is lunch afterwards. (Participant 18)

The worst thing for me was not having any transport. The package provided a taxi account. So long as I'm within my budget, I can use them as much as I like. (Participant 27)

Aboriginal Community Elders Services

An Aboriginal elder transferred her home care package from a mainstream provider to Aboriginal Community Elders Services. This occurred before the 2017 reforms were introduced.

I asked to get my mainstream package transferred to Aboriginal Community Elders Services. That wasn't possible. However, they had a vacant package – and they put me on that. The difference was amazing. An Aboriginal elder going to an Aboriginal program was the way to go because they respect you. With the mainstream package, I was just a number. We're used to different things too. We're used to being respected. We're used to telling our story and letting people know who we are. I mean really know who we are. (Participant 41)

Negative experiences of in-home care

Participants agreed that the concept of the home care package is "fantastic". However, some expressed concern about how some providers deliver it.

In concept, the home care package is fantastic. Brilliant. But there are not enough hours in it. These service providers are ripping off the government. (Participant 14)

Beginning the home care journey

When participants became aware they needed support to stay at home, many contacted their local council. For a long time, councils had been the first port of call for older people seeking assistance to live at home. Several participants had never heard of My Aged Care.

I didn't know anything about these things. I only knew there was council help. (Participant 1)

Years ago, when my grandmother needed help to stay at home, she used the local council and the district nurses. They were fantastic. She died at home. Now we have all this choice. But is it any better? (Participant 36)

Local councils

Several participants were disappointed to find their local council no longer provided aged care services.

We used to go to the council. We trusted the council. But now they have given the contract to Provider H. (Participant 7)

I had two years with the local council. I was very happy with the girls who helped me to shower and get dressed. And then I was told the council could not provide this service any more. I had to find someone else to do it. (Participant 8)

Some participants described feeling angry that their council had outsourced their services to private providers. In the past, Participant 10 had used a council worker to clean her gutters and windows. The council no longer provided this service. Instead, she is now required to employ a private provider to do this work. She is reimbursed a proportion of the cost.

The council has outsourced some of their services to private providers. Rather than clean gutters and windows, the council offers us a subsidy. I have to choose a service provider and then the council will reimburse half the fee. I don't want to choose a private provider. I trust the council maintenance people to do this. It seems to me that our council wants to get out of delivering essential aged care services. They want to focus on an aged friendly city. But it's not very friendly if council can't provide older residents with essential services... The councillors came to a community meeting and told us it would be good for older people to do social activities outside the home. That's all very well, but not if it means they won't help me with shopping and cleaning. The council has to do the essential things – particularly the people who need more help than I do – showers and things. It sounded to me like these councillors want to shove us over to the private providers. I don't like that idea. I've been a ratepayer here for 60 years. I feel angry that the council may not help me to stay at home. (Participant 10)

When my husband was dying, I had support from the council. I had no concerns with the council whatsoever. I've had a lovely man for the past six years. After my husband died, I was told I could continue with council services for cleaning until I got the package. Then out of the blue, I found out that the council had given the contract to Provider K. I am not as comfortable with them. They send young girls who don't know how to clean. And they often leave messages on my answering machine to change the day and time. (Participant 7)

Another participant was upset when she was unable to choose the local council as her home care package provider. She trusted the council support workers.

(Prior to being assigned a package), we used the local council and Provider N. And they were charging a minimal fee. We had two support workers coming for three hours each. They were great. We also had someone who would come to clean the gutters and other 'manly' things around the house – things we couldn't do. He was wonderful. But when we got a Level 2 home care package, the Provider M's district manager told us we couldn't use the council services any more. We had to use Provider M's services. I was upset about this... What really galled me was when the district manager cancelled them. She didn't say that she would be ringing the council. I felt really abused by phone calls being

made behind our back. I was furious. One person who had been coming for two to three years never got the opportunity to say goodbye to us... With the council it was: "How can we help you?" They were just lovely. You could ring them up – and there was this friendly respectful communication that you'd have. And with Provider M it was always difficult, strained – they always made me feel as though I was being unreasonable. (Participant 9)

Rationing services

Prior to needing assistance, several participants were uninformed about the aged care system and their entitlements.

Prior to the social worker at hospital telling me about home care packages, I didn't know I was entitled to anything. (Participant 17)

Some participants suggested ignorance about their entitlements helped the government to ration services.

None of my friends who are all in their 80s know anything about these packages. They didn't think it applied to them. People here in the retirement village have no idea how to apply for it. I think that's the way the government wants it. They already have this long queue. If people don't apply, that's better for the government. (Participant 27)

Dementia and Cognition Supplement

People with dementia are entitled to access a Dementia and Cognition Supplement. For example, those on a Level 4 home care package receive an extra \$5,015.92 per year.

As anyone would attest, dementia is an extremely expensive disease. Many things are a lot cheaper to do with someone who is elderly and frail – but people with dementia require extra services. I can't pop Mum in a taxi and send her to an appointment. She has to be supervised and watched the whole time. So that totally blows out the care costs. (Participant 3)

Several participants described health professionals being unaware of the availability of the Dementia and Cognition Supplement and the special test that is required to access the financial supplement. The Psychogeriatric Assessment Scales (PAS) is no longer used in hospitals or most memory clinics. This raises questions about why it is chosen as the test necessary to be eligible for the supplement.

Hardly anyone seems to know about the Dementia and Cognition Supplement. Because I'm resourceful, I knew that My Aged Care required the Psychogeriatric Assessment Scales (PAS). The minimal test that all geriatricians do is not valid in terms of getting that extra funding. So I raised this with Mum's geriatrician in hospital. I needed them to do the PAS test so Mum was eligible for the Dementia and Cognition Supplement. The geriatrician told me that that it doesn't exist any more – He said: "There is no Dementia and Cognition Supplement." I replied: "Actually there is and I just need this paperwork to be completed." I had to jump up and down for probably another month until Mum finally had the PAS test done. So eventually when she got her Level 4, we had that extra 10 per cent of funding. (Participant 3)

Participant 3 expressed her frustration about geriatricians working in a major public hospital not knowing to do the Psychogeriatric Assessment Scales (PAS) test. She was concerned older people with dementia may not be eligible for the Dementia and Cognition Supplement because health professionals were not doing the correct test.

Health professionals are all doing a mini-mental state exam. Under the legislation, the mini-mental state exam doesn't qualify someone for the Dementia and Cognition Supplement. If GPs and geriatricians working in a major public hospital don't know the PAS test is the correct one to be administered, how is government getting this information to them? It has crossed my mind that they don't make it known so people don't access it. (Participant 3)

After being informed about the availability of the supplement, a participant had difficulty finding someone with expertise to do the assessment.

The case manager told us that my husband would be eligible for the Dementia and Cognition Supplement. So I replied: "That's good. How do we get it done?" So she said that I should get the GP to do it. When I asked the GP, he said: "I don't know how to do this. I've never done this before. You need to speak with a geriatrician." So I wait until our next appointment with geriatrician. I ask her to do the test so we can get the extra supplement. She says: "No I can't do it. The GP has to do it. So I went back to GP and she said she would look it up, and do it. So she did it. Whatever she did, he didn't pass to get the supplement. I went back to geriatrician and told her the results. She said I must

get it. I went backwards and forwards. After a lot of performance, my case manager found someone to do it. They didn't tell me that it would cost extra. It took six months. (Participant 28)

Family support

Several participants said they would not be able to remain at home without family support. A participant suggested the home care system explicitly relies on family support.

There is a document about a personal alarm service (MePACS) that describes everything going to the family first, rather than rely on the system. So the system is heavily geared towards all the responsibility falling on family. (Participant 3)

Children who are not available to support their parents had to trust that the home care support being provided was sufficient.

So many kids are caring from a distance – they are overseas, interstate or across other side of town. You literally have to have good faith that care is being provided. (Participant 3)

My Aged Care Staff

Each time participants phoned My Aged Care, they spoke to a different member of staff. Some were knowledgeable; others less so. This made it difficult to access the required information.

I couldn't speak to a specific person. So each time I phoned My Aged Care, I spoke with a different person who gave different answers to my questions. I would hang up and phone again until I got the answer I knew was correct. (Participant 24)

I am totally stressed out talking to all these people on the phone at My Aged Care. They all tell me something different. It's crazy making. (Participant 25)

I phoned My Aged Care several times to ask them questions about this package. And they were completely and utterly hopeless. (Participant 17)

Participants described staff at My Aged Care as “call centre people”. They also described poor communication between staff at My Aged Care.

When I phone My Aged Care, no one ever knows what's going on. I get passed around the world. I recently had messages to phone My Aged Care about a referral. When I phoned, they did not know what referral I was talking about. This happened half a dozen times. (Participant 25)

Some participants described staff at My Aged Care as “inadequately trained”.

With My Aged Care, someone answered the phone quickly, unlike my experiences with Centrelink. They were friendly and efficient. However as soon as I mentioned dementia, it was assumed that the person was incompetent. I put my partner on the line, but the person seemed tongue-tied. Didn't know what to say. Remarkable. (Participant 15)

My Aged Care is not a well-informed service. I question the qualifications, skills and knowledge of staff. Many provide a rote response. (Participant 19)

Complex system

Participants described the in-home aged care system as “complex and complicated”.

I've had two experiences – the first with my mother and more recently with Dad. I've had to deal with Department of Veterans' Affairs, Centrelink and

now My Aged Care. The My Aged Care system is far more complex and complicated. There is a lot more bureaucracy involved. (Participant 20)

I have a lot of experience in the disability sector. Aged care system is more difficult to navigate than disability. It breaks my heart to see the number of people who would be lost in this system. (Participant 40)

Overwhelmed

Several participants described their experience with My Aged Care as “learning as we go” and a “steep learning curve”. They described feeling “overwhelmed”.

This is all foreign to me. I don't have a clue what is going on. I have a big L on my forehead. (Participant 16)

People are overwhelmed – they get this letter that says they have 56 days. This may sound like a lot of time, but when my neighbour transitioned from council services to a Level 3 package, her daughter went in to such overwhelm that she lost her Mum's package... Most of us are in complete overwhelm... As Mum's carer, I am not elderly and frail, and I don't have dementia, but it is all still overwhelming for me... You can go on to the My Aged Care website and find out providers available in your area. It can spit out 50 or 100 results. Who is going to sit on the phone? How do they know what to ask them? They are brand new. (Participant 3)

Reliable information

Participants said they had many questions about in-home care. However, some found it difficult to get answers from staff at My Aged Care, Australian Aged Care Quality Agency or Commonwealth Department of Health.

This is all way too much for frail elderly people to do on their own. And there is no single hot line you can phone that can answer every question ... I'll make 20 phone calls if I have to - to get to the bottom of a situation. Some people would think I was exaggerating if I said I was on the phone for eight hours but I cannot tell you how many days I've spent eight hours on the phone. Mostly because you get bounced from place to place. The commissioner will say: “You're not quite us.” They might send you to the Quality Care Agency. Then they will say: “Technically that doesn't fall under us.” So who does it fall under? I even email questions to the [Commonwealth] Health Department. They are supposed to respond within 10 days but they don't. (Participant 3)

I would be transferred from My Aged Care to department to department and then back to My Aged Care. I would spend five hours on the phone trying to find answers to my questions. It was like stepping on to a merry-go-round. (Participant 37)

At the beginning of their “journey”, several participants described being inundated with information.

The trouble when you first start out with all this is too much information. It's all given to you in pamphlets. I was given all these phone numbers and pamphlets. And then providers started phoning me. I would reply: “I'm sorry but I don't know why you're calling me.” Everything is abbreviated – and I would have no idea what that is for. I realised some people were phoning me because they were being kind (e.g. Alzheimer's Australia or someone following up from a help line), or someone from a service provider. I couldn't distinguish. (Participant 28)

Despite the numerous fact sheets, brochures and pamphlets, participants had many questions. They described finding it difficult to get reliable and consistent information.

It is really hard to get correct and consistent information. The people with whom we interact need to be better informed. My Aged Care, Centrelink, case managers, Department of Human Services. Everybody does their little bit and it is left up to us to join the dots. Half the time, I didn't know what dots to join. And then you find out from others what they have done – and I didn't even know that was available. I don't know what I don't know. (Participant 22)

There is not a standardised approach. I am not clear about their procedures. I expected Provider E to say: “This is what we do. This is how we do it. If you have this issue, you need to go here. If you have that issue, you need to go there. When you experience this problem, please go here.” There is none of that. (Participant 19)

Some participants suggested access to information depended on “who you know”.

There is no one way to find information. A lot of it is dependent on who you know and who you talk to. A lot of us have friends whose parents are going through similar things. So you learn stuff from your friends. You're lucky if you talk with the right person. It shouldn't be dependent on who you know. There should be a central place you can go. This should be My Aged Care – but it's not. My Aged Care depends on who you talk to. (Participant 39)

Several participants described professionals who helped them access My Aged Care. In some cases, participants needed ongoing professional support to understand the information they received from My Aged Care.

I was homeless. So I went to the Department of Human Services to try to arrange some housing. A very helpful woman registered me at My Aged Care. She organised for someone to interview me. (Participant 26)

I was put in touch with a grief and loss counsellor. I was going to see her once a week. She knew a lot about this system. I would take all this paperwork with me to ask: “What is this? What do I have to do?” (Participant 28)

Some participants found it difficult to access information that would have enabled them to make an informed choice of provider.

I asked around – there were not many people who knew much. I had no way of knowing if a provider was good or bad. (Participant 11)

Lack of power

Participants were disappointed that staff at My Aged Care did not have the power to move them “up the queue”.

When I call to see where Mum is in the queue, they are very sympathetic. But they can't do anything to move her up the queue. (Participant 26)

I phoned My Aged Care and told them the story how Mum had been on a package and then spent some time in residential care and was now in hospital. I wanted to bring her home. He was quite helpful but said he couldn't promise anything. (Participant 23)

Referral service

A participant described the role of My Aged Care as a “referral service” rather than a one-stop-shop where people can access information and receive answers to their questions

My Aged Care staff are extremely limited in their knowledge and what they can do. So there is really nowhere to go to get answers when you need to. Everywhere you go, people say: “Have you tried My Aged Care?” And you just want to scream and say: “Do you people understand that staff at My Aged Care don't know anything. They really don't. They are pretty much a referral service... I've been told they have six minute KPIs and their main aim

at the end of the six minutes is to have referred someone on to somewhere else. (Participant 3)

Outdated processes

A participant complained about My Aged Care's outdated processes (e.g. using fax not email) as “crazy in this day and age”.

I was blown away by the 1980s attitude. I had to get forms posted to me. Or download them from the My Aged Care website, print them out and either post or fax them back. This is crazy in this day and age. (Participant 24)

Paperwork

Several participants commented on the large amount of paperwork. Some older people kept all the paperwork from My Aged Care – in boxes, filing cabinets and spread across the dining room table. Others relied on family members to take responsibility for all the paperwork.

An important piece of paperwork was the approval letter. Some participants questioned whether they might be dead before they received their letter.

I had the assessment in January. It's now September – and I haven't had a letter to say it's been approved. I don't think I'm even in the queue yet. The assessor told me I may have to wait 12 months. I said I could be dead in that time. And she didn't contradict me. (Participant 7)

Website

Although the website provides a search function to help people find local providers, this search engine is not refined. When participants tried to find local providers, they were given a long list of providers from around Australia. Participants said this was not helpful.

I found the My Aged Care website is a complete disaster. It is very crude. It has no finesse. This searching thing is hopeless. I put in my postcode – and I got providers from all over Australia. All the large national providers – that's why you get so many of them. I just wanted the local ones. (Participant 11)

Foreign languages

Although some written material is accessible for those who speak languages other than English, the staff at My Aged Care spoke only English. Participants who spoke languages other than English were unaware they could

access the National Translating and Interpreting Service free of charge.

It is very difficult to phone them if you don't speak English. I always get other people who speak English to phone. (Participant 6)

Some participants noted the approval letter was written in English. Although the letter has an insert (with various translations of the information) advising recipients they can contact the National Translating and Interpreting Service, participants who spoke languages other than English had a family member or friend translate the letter. The family member/friend explained the content of the letter to them.

The letter was in English but our son could translate it. (Participant 6)

Assessments

Number of assessments

Participants were cognisant of the large number of assessments. Several participants discussed the unnecessary expense of “all these assessments”.

She's had at least four ACAS assessments. She's also had an interview with council just to get on a bus trip. I can't even get Mum on a council bus trip unless someone comes out to do an assessment. It's ridiculous. (Participant 3)

The person who assessed me came from miles away. It must have taken her half the day just to get here. (Participant 7)

A participant questioned the resources spent on assessments. She described assessments as a “profitable industry”.

Here we are saying we don't have enough resources and money within system to release more packages. But we are wasting so many resources. All of this red tape. It's not just all the phone calls, they physically send people out. This is like wasting several hours out of someone's day to assess just one person... Instead of saying we've already ticked all of those boxes. They prefer to constantly send people out to people's homes driving around all day. Grossly inefficient. (Participant 3)

Process

Participants described a long process before getting an assessment. This process included different people asking the same questions.

At the beginning of June, I talked to [name] at My Aged Care. It was a phone interview. She gave me an ID number. On the basis of that phone interview, she said she would refer me on for a more in-depth assessment. A few days later, I got a call from [name] who was part of the assessment team. She asked some more questions. I told her that she should already have most of this in her notes. She referred me on to the next step – another phone call with some more questions. As a result, I was told me that I would have an interview with the assessor on 1st August. So after three phone calls and a two-month wait, I had an assessment. (Participant 2)

A participant was concerned that the information given to My Aged Care was not given to the assessor. As a result, information had to be repeated to the assessor.

The girl who came to do the assessment looked about 16 years old. She told me she had been a registered nurse for two years but not in aged care... She asked Dad about his cardiac issues. I told her Dad had vascular dementia. She said: "Does he?" All the information was sent to My Aged Care – including that Dad has lost capacity. She replied: "I don't have access to the My Aged Care portal because of privacy. We only get told what is wrong with the person over the phone." This explains why we have to repeat all the information again and again... The Aged Care Assessment Service and My Aged Care are just not speaking to each other. The Aged Care Assessment Service should have access to his file and do an analysis of his condition before they visited. (Participant 24)

Some participants described the questions asked during the assessment as "irrelevant". They were also concerned that the assessor was not qualified to correctly interpret the answers.

They asked Mum questions like "Who is the Prime Minister of Australia?". Mum doesn't follow politics. Asking that sort of question is meaningless to her. The questions were asked by clerical-type people, not people who are able to interpret the answers. (Participant 22)

They asked: "Can you feed yourself?" If you answer "yes", they go on to the next question. What they don't ask you is: "How do you get the food? Can you go shopping? How do you cook it?" (Participant 29)

A participant expressed concern that the assessment questions were not "personalised".

They are not personalised. You all must fit into this box. They might ask a question about my father's mobility. Can he walk? Yes. Does he use an aid? Yes. However, it doesn't go into the detail that he can only walk about two feet. Is it likely to get better/not get better? No room for that type of detail. (Participant 40)

She told me that she just follows the template of questions to be asked. I thought: "Anyone could do that. A customer service representative could do that. Why are we using registered nurses to do aged care assessments if that is all they are doing?" (Participant 24)

Assessment duration

Several participants described the assessment interview as "too long". They were also concerned that the assessments were rigid.

Mum has now had many assessments. They are way too long. Two hours. Stressful. You don't grill an elderly person – what was your last address, what is your phone number... The nursing staff who assessed Mum seemed interested only in ticking the boxes. (Participant 14)

Mum found the assessment extremely stressful. She put her head in her hands. A couple of times she almost fell asleep. It was far too long for her to cope with. (Participant 35)

I've had several assessments. Always by the same person. I had one of those mini-mentals sprung on me – it was not 'a mini' – it was nearly an hour. I got quite agitated by the end. (Participant 13)

Assessment outcome

Several participants suggested that having a daughter available to help their elderly parents influenced the outcome of the assessment.

I think they assessed Dad as medium priority and not high because he has a daughter. I challenged this. I have to go to work. (Participant 19)

Approval

After receiving the approval letter, several participants were unclear about what they had to do.

The social worker had to explain it to us. Have you ever had a letter from government that you can understand? (Participant 8)

I read the letter and wondered how my parents were supposed to know what they had to do. How on earth could they find a provider? (Participant 19)

He was recommended for Level 4. But they approved only a Level 2. But I stupidly didn't take it up. I didn't understand what I had to do. When I got back on to My Aged Care, they told me I had to find a provider. (Participant 16)

Assigned a package Queue

Participants expressed confusion about how people in the national queue were assigned packages.

You can log in to My Aged Care and it will give you an estimate. In my Mum's case, it started at 6-9 months, then it said a further 3-6 months and then one day it dropped to 30 days. And then out of the blue, she finally got her package. But there is no way to really know how this queue operates. (Participant 3)

Participants wanted to know exactly where they were in the queue and how long it would take for their package to be assigned.

I'd look online and I'd phone. But no one could tell me how long it would take. (Participant 16)

Some participants were concerned about the lack of transparency about how the queue works. They wanted to know whether a human being or a computer algorithm was responsible for assigning packages.

I wonder about this algorithm that sorts out the national queue. So you have people like my Mum that had high-priority urgent listed in her profile. Nobody can tell me whether a human manually reviews this, or if it is a computer-generated algorithm... I would hear stories that so and so only had assessment for a Level 4 package weeks ago, and they have already got it. My jaw would drop. How is that possible? My Mum was listed as high-priority urgent. How did Joe Blogs around the corner get it? This is something in the system that totally lacks transparency. (Participant 3)

A participant questioned the criteria that enabled some older people to be assigned a package much quicker than others.

Mum had been on a package prior to moving into an aged care facility. She was subsequently in hospital. I wanted to bring her home. Mum had an ACAT assessment the day before leaving hospital. The approval letter was online by the end of the week. Maybe there was priority for someone leaving a mental health ward. (Participant 23)

It's not like when you phone and you are told you're 10th in the queue. Why not? It's the same when I talk with aged care facilities - they tell me they have a triage system. Well, what is that triage? Triage based on urgency, needs, money? I'd say a lot of it is based on money. Why don't we have a right to know that? (Participant 3)

One problem with waiting so long for a package to be assigned was that older people's health status deteriorated. In some cases, they needed to be reassessed for a higher-level package. In other cases, they needed to move into a residential aged care home.

Dad was in the queue but nothing was happening. Dad had deteriorated. He was no longer Level 3. So I phoned My Aged Care to request an urgent assessment. The same young girl came back three weeks later. She agreed he had deteriorated and recommended Level 4. (Participant 24)

Dad is fretting terribly without Mum. He wants to bring her home. We sat with the provider and discussed getting the bathroom renovated and more support so maybe they could spend their last year together. I doubt they have much more to go. She could be at home rather than in the aged care facility. The provider told us quite rightly: "No chance." She is in the residential aged care system and we will be waiting over a year or more for a package. (Participant 40)

Lower level package

Some participants were assigned a package at a lower level than had been approved. In some cases, the lower package did not provide enough assistance for the older person to remain at home.

Mum is in an aged care home because I couldn't look after her on a Level 2 package. I want to bring her back home. However, she will go to the back of the queue. We have already waited two years for Level 4. I was told it might take a year before I can get any help. Our Level 2 package has gone. (Participant 6)

Transitioning from Commonwealth Home Support Programme

Several participants transitioned from the Commonwealth Home Support Programme to a home care package. They were surprised when the home care package did not provide more support than they had received with the Commonwealth Home Support Programme.

During the three months Dad was waiting for a package, he went on to CHSP. This was reasonable compared to all the rigmarole with the package. It was \$5 per day. Dad was getting an hour of care every morning. Then our Level 3 package came through and we chose Provider E. But it was no more support than CHSP. With Level 4, we noticed a difference. (Participant 19)

We were given similar services on Commonwealth Home Support Programme and home care package Level 4. Probably the home care package is better for us because we can save up our money if there is some equipment that would help Mum. Plus we have the freedom to change providers if we want. (Participant 30)

When we moved from Commonwealth Home Support Programme to home care package Level 2, the hours did not change. Maybe one extra hour. When I queried this, I was told in some cases it would be fewer hours. This didn't make any sense. (Participant 35)

Participants were disappointed that the transition from Commonwealth Home Support Programme to a home care package required them to stop receiving council services. They described the council providing excellent in-home services.

I realised we needed more support so we applied for a package. I didn't realise we had to stop the other services (and transfer all our services to the private provider). The council and a charitable organisation (Provider N) had provided us with excellent services for several years. We were much happier then. The relationships were important – people wanted to help. These organisations worked so much better because they are set up differently. The charitable organisation was established to support people. For profit wasn't part of the culture at all. The people they employed are different – a much higher standard. The quality of the support workers was so much better – they had done dementia training. (Participant 9)

I told My Aged Care in no uncertain terms that I wanted to stay with the council. I'm not happy with the move to private providers. In a council meeting, this young Greens' councillor spruiked the notion that we will be able to have choice. What type of choice? If I am not happy, I phone My Aged Care and talk with someone in Darwin or Sydney? I want to deal with local people. I want to deal with the local council who know the local area. I want to know who I am talking to. With My Aged Care, I could be talking to anyone. They couldn't care less about me. It's important to have a relationship. I have a relationship with the council. (Participant 10)

When a participant was sent a letter from Centrelink, he misunderstood the contents. He became very upset.

When we moved from the Commonwealth Home Support Programme to a home care package, there was an incredibly complicated form for registering income, savings. We tried to be scrupulously honest. They replied it may take us six months to determine how much Dad needed to contribute to his own care. We got a letter recently that we had to pay Centrelink \$200. And then we got another letter telling us Dad needed to complete tax returns. He's a 91-year-old pensioner who hasn't earned any money... Dad thought he was being asked to pay \$42,000 after the sale of his house. He was very upset. The thing that concerns me – if Dad was on his own when he got this letter. (Participant 8)

Full cost recovery

For many people, ageing well requires access to social activities and community life. However, participants described the policy of full cost recovery as preventing them from being involved in as many community social activities as they were prior to accepting a home care package.

Participants on a Level 3 and Level 4 home care package said they are required to pay the full cost of community social activities. They reported that a home care package is subsidised by the federal government whereas the social activity is subsidised by either the state government or a local council. Several participants had been told they could not “double dip”.

A participant on a Level 4 package described being forced to choose between an hour of personal care or a social activity. They said they could not afford both.

Social activities

Participants were shocked when the cost of social activities increased substantially when they transitioned from the Commonwealth Home Support Programme to a home care package. A participant who accessed four local social activities every week for many years was forced to reduce his local activities when he accepted a home care package. This negatively affected his mental health.

A participant decided to continue with the Commonwealth Home Support Programme rather than transition to a Level 2 home care package so she could continue to afford to access the local council's social activities.

I've decided to continue with Commonwealth Home Support Programme – I've had people who have been helping me for ages – with the cleaning and shopping. And it doesn't cost me much to do the council activities. To transfer to a package would cost me a lot more. I wouldn't get the same level of services I get now. I'd have to pay a lot for the District Nurse who comes. And I couldn't afford to do all the social activities that I currently enjoy. They charge about \$100 for the bus trip when you're on a package. I currently get it for \$10. It's a much better deal for me. (Participant 36)

I am in a men's group in a community centre. I used to pay \$10 a week to be there. But because my package pays for it, it now costs me \$100. (Participant 8)

Several participants previously participated in council activities but could no longer afford to do so on a home care package due to the policy of full cost recovery.

Sometimes I am so lonely, I don't want to live. I would like to join some council activities. They have bus trips and other clubs. But they are expensive. (Participant 4)

Some participants found a way around the problem of full cost recovery by continuing to pay cash for the social activities (i.e. not use the home care package to pay for the social activity).

Mum attended a day centre. It was only \$20 a day. They told me if it came out of her package, it would cost \$65. (Participant 23)

Mum goes on outings four times a week – they do different things. They take Mum to different venues to do different activities. Provider X couldn't offer her any social activities. I haven't pushed for a

Level 4 because I was told there was a risk she would lose the outings. These outings were in place before the package. After we signed the package, we just continued things as they were. The case manager told me they may have to cut back the outings because of the package. They told me the government is cracking down on them. They are currently charging \$15 but the full cost is \$60. This equates to an hour of personal care. I could afford that if it was just one outing – but Mum has four outings. She needs these outings – they are very social and she loves them. (Participant 35)

One of our big things is social isolation. Getting them out into the community to all those things that are listed as critical to wellbeing. Once you have a Level 4 package, all these activities shift to full cost recovery. So Mum's \$15 bus trip is now \$95. There is no money there for that. So on the one hand we are saying that one of the critical things for older people to stay in their home for longer is wellbeing activities, social activities and participating in the community. How many \$95 bus trips do you think you can get out of the package if they are already requiring personal care seven days a week? None. (Participant 3)

Some participants chose not to tell their provider about the social activities. Some community organisations also “looked the other way” so the cost of the social activity was not taken from the home care package. Participants said the subsidised rate enabled them to continue the social activity.

I had been using services from a community organisation. They do a lot of social activities. They take me to hydro exercises. I'd been paying them directly long before My Aged Care came on the scene. It costs me about \$20 per session. The case manager said: “It should come out of the package, otherwise you're double dipping.” I asked the manager of the community organisation about this, and was told the case manager was right. If I charge the package, it is \$99 a session. So the manager of community organisation said: “We will look the other way and pretend we don't know you're on a package.” Then they came back and told me about a grandfather clause – that says you can keep getting services from an old provider from the old rate. So I just pay \$20. (Participant 11)

I've found this wonderful private day care centre. I pay them \$21 a day. We pay cash. We haven't told My Aged Care. (Participant 25)

Palliative care

The daughter of a woman who was dying needed expert palliative care. She was initially told it was free. However, when the palliative care service found out her mother was receiving a home care package, she was asked to pay the full price.

I've arranged palliative care for Mum. I was told it was free. They even offered to help with her showers. Then they found out she is on a Level 4 package. I was told she can't have a package and have free palliative care. We'd have to pay \$99 per hour. (Participant 14)

Nursing services

Participants said they were charged a reduced hourly rate for nursing services on the Commonwealth Home Support Programme and Level 1 and Level 2 home care package. Some participants were told they would be required to pay the full price for nursing services if they accepted a Level 3 or 4 home care package.

A participant was advised to remain on a Level 2 package because she required several hours of care from a registered nurse per week. She was told if she transitioned from a Level 2 home care package to a higher-level home care package, the hours of nursing care she received might be reduced.

Providers

Choosing a provider

Several participants described feeling “overwhelmed” by having to choose a provider.

At first it was overwhelming, because I didn't understand it. I had all these phone numbers I had to call. I phoned all the individual providers to see what they had to offer, how much it would cost. I didn't really understand any of it when I started. The provider I chose was the one that always answered the phone, returned my calls, responded to my messages. (Participant 28)

On the My Aged Care website, there are over 100 providers listed in Mornington alone. It is overwhelming. They don't tell you which ones have a good reputation. Am I expected to phone each one? (Participant 2)

As soon as you get assigned a package, you are told you have 56 days to find a provider. Providers marketing their wares attack you on all sides. You have to set up all these appointments. People in our area are getting quite frenzied. Mostly choices are made by word of mouth. (Participant 15)

Some participants described choosing a provider as time consuming. The main problem was not being able to compare “apples with apples”.

I had to put a spreadsheet together. I spent days. There is no easy way to do a comparison. And a lot of providers don't put necessary information on the My Aged Care website. I had to make a lot of phone calls. I was comparing apples with oranges. I worked in corporate for 30 years and I struggled. God help those who aren't as savvy as me in doing that type of analysis. (Participant 22)

All the providers call things by different names and structure things in different ways. (Participant 17)

You get the list from My Aged Care, and how do you know which ones are good? The biggest problem is you can't compare apples with apples. If we knew there were only two or three charges, case management, administration and exit fees – and your daily fee. If it was as clear as that, you could have four questions to ask each provider, fine. Maybe you'd just phone 10 of the providers on the list. You would come out the other end and make

your decision based on whether cost was important or quality of care or whatever. But it's not like that. Each one that I phoned had some other hidden fee that didn't come out in conversation until I had really grilled them. Sure enough I'd find out about this extra fee that wasn't clear from their website. So it's overwhelming for people. (Participant 3)

Contact by providers

Several participants described receiving phone calls from providers soon after they were assigned a home care package.

As soon as my partner's approval came through, we were contacted by phone by a range of providers. The first were council services – but they didn't have anyone who was trained in dementia. And the second lot was Provider O. They told us they were dementia specialists. And they had the only early onset dementia cottage in the country. (Participant 15)

After we got the package, Provider P called us straight away. They came to us with the contract. (Participant 12)

I was assessed for a Level 3. This pushy woman put heat on me to take Level 2 while I waited for Level 3 – so I could have it sooner. The village I live in has a contract of some sort with Provider CC. We were all urged to sign up with them. I wasn't all that happy about being pushed into a specific provider. I wanted to make my own choice. (Participant 27)

Some participants described receiving phone calls from providers before they had received their approval letter. One participant described feeling “bullied” into signing with a provider.

Provider JJ provided a cleaner under CHSP. They phoned to tell us Mum had been approved for a Level 2 package before she got the approval letter. Mum just wanted cleaning – so we were not going to accept the package. But Provider JJ told us they could not continue to provide cleaning unless we accepted a package. Mum really liked the cleaner. We felt bullied into accepting the cleaner. Provider JJ was intending to give the paperwork for Mum to sign without any family member being there. I felt this was wrong given Mum has dementia. (Participant 37)

Some providers provided incentives to encourage older people to sign a Home Care Agreement with their company.

A provider I spoke with was offering a new Dyson vacuum cleaner if I signed with them. There is heavy persuasion going on. (Participant 3)

Overpromise and under-deliver

Participants described providers' advertisements about home care services as misleading.

The providers use typical marketing ploys. When I read all their glossy brochures, I thought "wow". Provider E advertise "trained carers". After Dad signed the contract, they phoned me to say they had no carers and would have to outsource for carers. (Participant 19)

Provider M's services were very limited. That's been the ongoing problem. It would have been so helpful if they could have offered us an overnight – so my partner could have stayed at home, and I had a night/weekend off. We had lots of money for that. But they refused to provide it. They didn't have the staff to do it. (Participant 9)

A participant felt the provider made promises simply to "shut her up".

They promised me things and I never got them. It was like they promised me things to shut me up. That happened to me quite often. It was really disturbing. (Participant 41)

A participant described feeling shocked when the provider appeared to be more focused on profits than care.

We don't understand what we are entering into. Profit motives are far from our minds. [When we sign up], we think they really have our best interests at heart... The system cannot work as it is when there is so much financial gain. (Participant 17)

Battles with providers

Several participants described dealing with providers in the home care system as a "battle".

It is an uphill battle. I don't know how people who are unwell deal with some of these administrators. (Participant 30)

I needed a bed for Mum. They said we had to hire it, not buy it. I've battled with them for over a year about this. (Participant 14)

Some participants described having "to insist" to make services happen. They described "pulling teeth" and "fighting" for their entitlements as "exhausting".

All this – navigating the aged care system, packages – has been horrendous. It's exhausting. If I didn't have 30 years working in the welfare sector, we could not have managed. Mum and Dad didn't understand. I took leave to look after Dad. Part of the reason I'm caring for Dad is because Mum can't. If my parents didn't have me, my Dad would either be dead or in a nursing home. That's a fact. (Participant 19)

I said I want someone to help me with the gardening so I could spend more time with my partner. To get Provider M to approve that was like pulling teeth. And that was something the council had provided. (Participant 9)

It was like pulling teeth. I would constantly be phoning and emailing Provider B. It was a fight to get basic chores done. (Participant 3)

One participant described "going to war" with providers. Another described "the fights" as constant.

I've heard of providers literally going to war with care recipients when they ask: "Can I have x. Can I have y?" (Participant 3)

We had a fantastic gardener for 12 months. But then they sent another gardener. I phoned and said: "Never send that person again." These are the fights that are constant. (Participant 9)

A participant described her interactions with the provider as "stressful".

It's really stressful. It is traumatic and frustrating. I want to wring their necks... I don't want to be angry all the time that we can't get the things we need. It blows me away how ridiculous it is when the government is trying to help but the provider won't help. It's like they sit in a gold office chair in front of a gold desk with a gold phone and do nothing. That's how it feels to me. (Participant 21)

Unsuitable providers

Some participants were concerned that the government was giving home care package licences to companies with no expertise in the delivery of aged care services (e.g. insurance companies).

Provider M doesn't know how to provide aged care services. They are a bloody insurance company. They see it as an opportunity to make some money – but they don't know how to do aged care. I recently wrote an email to the CEO. I was shocked by his ignorance about how his company treats its clients. I said: "If you treat educated well-connected people this way, how on earth do you treat those who are unable to protect themselves?" (Participant 9)

The current provider seems just interested in making money. It's a business. For sure. (Participant 1)

Participants were also concerned that some providers accepted too many clients without hiring enough staff. They were unable to deliver the services that participants expected.

Providers should only take on the number of clients they can properly manage. Provider M has far too many clients and far too few case managers and support workers. It was simply not possible for them to deliver services we expected in a Level 4 home care package. Their failure to deliver services has resulted in my partner moving into an aged care home (Participant 9)

Provider P didn't have enough staff. They used an agency. There were several weeks when they didn't send someone to help me shower. They said they couldn't find staff. (Participant 12)

Several participants expressed concern that their provider may be "rorting" the system. They worried about the impact this may have on an older person.

My concern is for the government. How do they make sure that providers don't behave illegally by rorting? That does worry me. I am concerned that the agent isn't honest. What would happen if they didn't pay the cleaner? There is a possibility of a confrontation with the older person. (Participant 7)

Company takeovers

Some participants described a local provider being taken over by a large national company. They ended up with a provider they did not choose.

I started with a company but it has changed names. This is one thing that pisses me off a bit – they all keep changing names. I haven't changed providers but they were taken over by another company 12 months ago. They are now nationwide. If I have to phone after hours, Queensland answers the phone. (Participant 1)

You could start with an honourable company. But it gets taken over by a dishonourable company. I started with the council. I am now dealing with a large company. I did not choose this. (Participant 7)

Giving feedback to providers

Participants were disappointed by the manner in which some providers responded to their feedback.

My support lass has gone on holidays. They sent a new lass who was as thorough as the other girl is not as thorough. I mentioned this to the case manager. I said: "Could I change to the new lass?" But the answer was "no". (Participant 7)

Twelve months ago, the case manager came here with Provider M's CEO. The CEO wanted to meet some consumers. The case manager encouraged us to tell him all the bad things that had happened. She had sympathy that we had been duded all the way along. He was here for a couple of hours. I told him about the bad culture (you could tell there was no cohesion in the organisation). He seemed genuinely interested. So I thought: "Hang on. Things are going to improve." But nothing ever improved. It's gone from bad to worse. People keep leaving – they can't hold on to their staff. (Participant 9)

Contracting an external provider

Some participants requested the services of a specific professional. They were surprised they were asked to pay a "brokering fee" to establish a contract – particularly when the service was provided by a government agency.

My mother's package is in surplus. So I asked for some dementia counselling support with Dementia Australia though Mum's package. Provider JJ agreed but said they would need to contract Dementia Australia. This would cost \$500 to establish a

contract. Once I told them Dementia Australia is a government organisation, they changed their mind. But it shows how they are looking for every cent. (Participant 37)

We had a great private gardener. We wanted her to continue as our gardener. It took four months for this to happen. They charged a set-up fee of \$350 for the brokering. (Participant 9)

I suggested Mum see a physiotherapist but because they are not on Provider JJ's books as a contractor, they would charge Mum's package \$500 to establish a contract with the physiotherapist. (Participant 37)

Some participants used external services. They believed this should be a financial arrangement between providers and the external service. They felt the external service should not contact the client about late payments.

The day care is \$70 per day. They sometimes email me to say they have not been paid. However, this is a contractual agreement between the provider and the day care. They should be emailing the provider not the client. (Participant 22)

Provider profits

Participants commented on the “big chunk of money” some providers take from the home care package. Several participants described the taxpayer as being “ripped off”.

The provider gets paid very well. They take a big chunk out of the money every month. Big chunk. And if my case manager has to do something else, like ring up the supplier for the stockings, that's another charge. (Participant 1)

I once asked Provider A how four hours of domestic assistance had cost me over \$544.40. It was because they charge \$136.10 per hour on public holidays. But that does not go to the worker. I phoned around and most agencies charge from \$85 to around \$99 for public holidays. My service is usually on Mondays so now I go without rather than give them this obscene amount. (Participant 17)

When I saw the hourly charges, they are very high. Are they allowed to charge this much? (Participant 13)

Several participants did not object to providers making profits when they provided a good service. However, one person was at her “wits' end” with the lack of quality services her partner received.

It wasn't fair on my partner and it wasn't fair on me. Meanwhile, Provider M is sitting back there raking in all this money. But everything we got was due to my persistence and determination. But it wears you down. Last year, I was at my wits' end. I told them: “I need more support.” I didn't have anyone as a backup. I was so stressed out. And not knowing where to go for help. (Participant 9)

Another participant questioned whether her mother and the taxpayer were getting value for money.

Sometimes I think I should do Mum's shower myself. Mum pays a \$10 per day fee (\$300 a month) and we get 15 hours support per week. The provider gets around \$4,600 a month and that buys us 15 hours support. That doesn't seem right. (Participant 25)

Consumer directed care

Several participants questioned why home care packages were described as consumer directed care when the consumer did not direct it.

They tell me that I direct the package. But they don't let me use our own gardener. It had to be their gardener. They use Jims Gardening. We had Jims Gardening once and I wasn't happy. So we pay our gardener out of our own pocket. (Participant 1)

It was a fiasco from the beginning that it was a consumer directed care package. It was not consumer directed care – absolutely not. It has always felt like a service-directed package – and these are the restrictions and you just have to fit in with that. It has been the bane of my life from the word go. (Participant 9)

Participants who had received in-home care for many years said the new system gave the 'consumer' more control than in the past. However, they did not have full control over how their home care package was spent.

We've had a package for about 15 years. We're finding consumer directed care better because we have more control over things but it is still not enough. I still have to deal with the Provider X who is still in control. I still have to ask them what I'm entitled to use the money for. (Participant 21)

I didn't have any say in how the funds [in my home care package] were spent. They don't want to let you know very much. They don't sit down with you and explain what you're entitled to. They don't spell it out to you. A Public Guardian showed me a list of things I'm entitled to. But it was all airy-fairy stuff. You don't know if you're entitled to a printer cartridge because you keep printing off all these bills... My neighbour told me I could get vitamins. I've been with Provider A for over three years and I didn't know this. (Participant 17)

Although I had about \$12,000 in my package, I found it hard to get anything other than the shopping, cleaning and a taxi. Then suddenly the case manager was trying to get me to spend everything. I checked whether you lose your balance at the end of the year. You don't. (Participant 11)

Home Care Agreement

Some participants signed the Home Care Agreement without reading it or without understanding what they were signing. A participant said she "trusted" the provider.

I read the contract – but at that stage I didn't have enough knowledge about average hourly rates for care. I didn't know what else was out there. I signed a contract. With the little I knew about the industry at the time, the fees and charges seemed pretty good. It looked like a good deal. But as I learnt more, I realised it so wasn't a good deal. (Participant 3)

Who is going to sit down and read all this stuff? I just want some help. Not all the mumbo jumbo. (Participant 21)

I just signed the contract without reading through it. I trusted them. I found out later they had an exit fee of \$500. I also found the fees were very high. I agreed to it all – so there was nothing much I could do about it. (Participant 35)

Length of contract

Several participants described the Home Care Agreement as "too long and complicated".

I can't even remember the contract – it was a mile long. Mostly looking after their tail – not much about what they are going to do for you. (Participant 1)

When I got the Home Care Agreement, it was very long (29 pages). I asked some questions. They said: "Don't worry it's all fine. There is nothing here to worry about." They showed me the fees. It didn't mean anything to me. All I wanted was a good service. We had chosen the provider because we wanted the carers to be Jewish. They didn't tell me the carers would be from an agency. Maybe it was written somewhere in the contract. (Participant 16)

Some participants wanted a hard copy of the Home Care Agreement.

They prefer to send the contract via email. Mum wanted a hard copy. Who could read 40 pages online? (Participant 13)

Clarity

Some participants found the language of the contract “legalistic”.

I'd prefer the home care agreement to be written in clearer English. It contained information about rights and responsibilities of the provider and clients, the financial arrangement, exit fees, notice to be given. The contractual agreement didn't contain any details about how it was going to be managed. So when we signed it, we didn't have in front of us a written agreement about what they were going to do for us. (Participant 15)

Fees

Although all home care providers are now required to publish their existing pricing information on the My Aged Care Service Finder, several participants described the contract as having insufficient information about the fees.

You can't negotiate the fees in the home care agreement. This is not right. Also, the agreement should have the hourly rate, and the loading for public holidays. (Participant 16)

Home Care Package entitlements

Participants described their home care package entitlements in terms of hours of personal support, transport and reimbursements for items they had purchased. Several described providers' policies around hours of support and reimbursements as being “unclear”.

Hours of support

Participants wanted to know how many hours of support they would receive with their home care package. Staff at My Aged Care were unable to answer this question because each provider charges different rates for support workers.

In the beginning I used to ask: “How many hours am I entitled to each month?” No one could answer me. That's because of fees and charges but I was too ill to sort it out. My Aged Care were hopeless in explaining it. They gave me some convoluted answer that did not make a scrap of sense when I got off the phone (Participant 17)

We could never understand the money. It was always: “How many hours of service will that give you?” (Participant 13)

Participants on a Level 2 package described receiving personal/domestic support for approximately three to four hours per week.

Mum's on a Level 2 while waiting for a Level 4. The provider is getting \$18,000 per year. They are giving Mum three hours support a week. (Participant 26)

Participants on Level 4 described receiving a different number of hours of personal/domestic support per week – ranging from seven hours to around 25 hours for those who self-manage their home care package.

Mum is on a Level 4. In total, we get seven hours per week. We get a support worker for respite (five and a half) and domestic (one and a half). We also get podiatry once every six weeks. We occasionally need a registered nurse visit – whenever Mum goes to a home for respite, she comes home with a pressure sore. (Participant 30)

On Level 4 with the Cognitive and Dementia Supplement, Mum will get \$58,000. Provider BB has told us that will buy her 12 hours of personal care per week. I said: “You're kidding.” If the government gave me \$58,000, I could employ someone full time to live in our home to give us a hand. (Participant 26)

For participants who did not self-manage their home care package, the average number of hours of personal/domestic support on the different levels of home care packages were:

- 2 hours per week on Level 1 package;
- 3 hours per week on a Level 2 package;
- 8 hours per week on a Level 3 package; and
- 14 hours per week on a Level 4 package.

Several participants were “furious” when they compared these hours with the funding the government provided annually for their care and support (Table 1). They described far too much money that was intended to support older people at home went “into providers' pockets”.

Reimbursements

Several participants were unclear about the government's reimbursement policies.

Do you know what you can claim? I don't. The new provider told me about dental. The previous provider had not told us dental could be claimed from the package. (Participant 16)

My agency didn't tell me what could be reimbursed. They bought me a new bed but won't pay for a doona and sheets. Yet they allowed me to buy a new stove. So it gets confusing. To be fair the government has not made this easy as it has so many grey areas. My neighbour's provider told her "if it will keep you in your home" it passes the test. (Participant 17)

Nobody told me we could get reimbursed for equipment. I purchased Dad's wheelchair myself. It wasn't until later that I asked if we could be reimbursed. Now I don't rely on the provider for purchasing equipment. I find it myself and then ask for reimbursement. (Participant 19)

Participants described the lack of guidelines about what items you can buy with your package.

People are not being given guidelines that tell you what you can and can't have from your home care package. The interesting thing is what you can't have is pretty much very clear – you can't get a gambling or footy membership. But under the guidelines of what you can have it is quite grey. (Participant 3)

Participants expected case managers to tell them what they could purchase with their home care package. They were disappointed when this did not happen.

I didn't know there was a government reimbursement for continence products. I expected the Provider X to tell me these things. But they didn't. So things like that fall through the cracks. (Participant 35)

I had an accumulation of money in my package. I didn't know I could spend it on equipment. (Participant 13)

Mum burnt the stovetop. I asked if she could get a new one with some of the surplus in her package. I received no reply. (Participant 37)

Some participants described the reimbursement policies as "ad hoc". Some providers reimburse items that other providers do not.

It's not clear what I can spend the package on. I bought a van to transport my husband. The package can be used to repair the hoist but not mechanical repairs on the van. That is so stupid. If the van doesn't work, he doesn't go anywhere. Another example is when our fridge died. Some of my husband's drugs have to be stored in the fridge. I asked if we could get a new fridge (\$700) with the package – Provider X said "no" because I also use the fridge. A friend is with a different provider - they got a new fridge, cordless phone and a new TV. (Participant 21)

Financial statements

Government-funded providers of home care packages are required to provide a transparent account of how money in the package is being spent. However, there is no requirement that these financial statements be easy to understand.

Difficult to understand

A common complaint about home care packages was that the monthly financial statements were "difficult to understand". A participant said: "The statement is in code."

We didn't understand the statement. Nobody explained. We asked the case manager to explain. She couldn't understand it either. Our granddaughters who are studying at university couldn't even understand. It was very confusing. (Participant 12)

Nothing much to do with my package or accounts has ever been explained to me. We were very confused about the invoice. My husband is an intelligent man - particularly with finance. He found all this overwhelming. He had to sort it all out himself. We could never make head or tail of the statement. You need to sit there for a few long hours to work out all the costs. (Participant 17)

Even participants with business and accountancy experience found the financial statements "bamboozling".

We couldn't understand the invoicing. I phoned the regional manager to say I could not understand the invoices – I've been trying to understand them for two years. The invoices didn't match the hours the support workers came. How do they work that out? I've had a business and I know how to do accounts. These invoices are crap. (Participant 25)

Participants said they should not need a university degree to understand their monthly statements.

I shouldn't have to be a qualified accountant to manage my Mum's aged care package. I shouldn't need that knowledge... Month after month my Mum's invoices would be incorrect. There was a specific agency (Provider E) that would phone to say the carer could not make it. I would reply: "That's fine, but please don't invoice my Mum." Sure enough, the invoice would come with this included. Luckily I was dating this and putting it in my calendar – "Carer didn't turn up on Sunday." Who else would be this detailed? They were also putting extra meals into the invoice that Mum never had. When Mum was in hospital, Provider B had "meal delivery" on the statement. Mum could not possibly have been having meals when she was in hospital. Anomaly after anomaly after anomaly. I think there are genuine mistakes and also greed. If you throw dementia into the mix, what hope do recipients have of being able to interpret their invoice? (3)

Participants described older people, particularly those with dementia, having difficulties understanding the monthly financial statements.

How could my husband have managed on his own? How could he handle all these invoices that come in? I feel so sorry for so many of these people. (Participant 16)

Some participants described not understanding the statements as causing recipients and their families "stress".

Mum does all her own finances. These statements have caused her so much distress. (Participant 13)

Mistakes

Several participants noticed financial anomalies on their statements. A common anomaly was being charged for services they had not used.

I was getting all these crazy statements from Provider E. Last year they charged me for services when I was in hospital. My son has power of attorney. When I showed it to him, he was annoyed. I got in touch with them and complained. They rectified it. But what if I didn't have my brain working? How many get duped? It's the government paying these packages. And I am so grateful for it. I don't like to think they are being ripped off by a company charging for things the people didn't get. (Participant 18)

They were charging quite a lot of money per kilometre to take my partner out. They used their phone to determine kilometres. They logged on at the start of their journey to our home, and would then take my partner to the supermarket to shop and afterwards come home. I was being charged for 30 kilometres even though the supermarket was only a couple of kilometres away. I phoned to complain. They agreed it was not right but they never put the money back in. I followed this up a few times but I gave up out of sheer exasperation. (Participant 9)

I just wrote a complaint letter to Provider E because there were inconsistencies on the statements. In our last statement, Dad had over \$2,000 listed as "Income Adjustment". What does that mean? They also double charged us for some services. They said it had been fixed, but it's not clear to me on the statement. (Participant 19)

I arranged some extra support after Mum was discharged from hospital. I then cancelled it but they kept charging for it. They claimed I had not cancelled it. I sent the case manager the two emails. But I didn't have the energy to fight. I just gave up. Mum has so much in surplus that I didn't worry about it. (Participant 37)

At the beginning Provider M charged \$450 for a health and safety check. It was never done. Right from the word go, it's always felt as though they can charge for this and that – irrespective of whether they do it. I had so many arguments with these young case managers: "You can't charge for something that you haven't done." (Participant 9)

One participant was fortunate to notice a provider withdrawing money from her bank account that the provider was not entitled to withdraw.

After I left Provider E, I noticed they were taking money out of my account. I had lots of phone calls with Provider E's accountant in Melbourne. What would have happened if I hadn't noticed? (Participant 18)

Delayed statements

Some participants were concerned about the lack of real-time invoices.

My biggest beef is the lag time with the statements. They come about six weeks after the end of the month. Too long. I got a phone call that Mum had overspent her package. I had no idea. On our last account, they whacked on a \$6,400 fee for pending services. When Provider S contract out this work to Provider L, there's a paperwork lag. This is July and they have services dating back to February that haven't been taken out of the package. They have taken away our gardening services and cut the support workers to nine hours per week on a Level 4. I'm furious about this. (Participant 14)

Complaints about statements

A participant lodged a complaint with the Aged Care Complaints Commissioner about a provider charging her for services she had not used. She subsequently decided not to make a formal complaint.

I reported Provider E's accounting system to the complaints. It was wrong that they took money for services I didn't use. There was a very nice man there. He wanted me to follow it up. He told me there were several complaints about Provider E. He said: "You're not the only ones who has complained about them." It is shift but I let it go. (Participant 18)

Fees

Several participants stated it was reasonable for a provider to charge about 35 per cent in case management and administration fees to deliver a good service.

The provider I ended up with charges around 35 per cent of the package. I wouldn't mind paying this if they provided a good service. But Provider Y does not provide this. (Participant 22)

Participant 24's daughter worked in the home care space - helping people find suitable providers. She shared her professional views of providers' fees. She also shared her experiences of finding suitable providers for her clients.

Providers have got superannuation, workers compensation, public liability and professional indemnity - looking at wages plus 15 per cent. You've got to give the agency something. So my view is about 20 per cent. So if they are charging any more than 35 per cent, I query it. Good quality carers would be earning \$30-\$35 per hour plus their

on-costs. \$55 per hour is not unreasonable. I've moved so many clients from faith-based providers to private providers because they were being gouged. For a Level 4 package they should be getting between 18-22 hours per week. This one client was getting around 10 hours. Provider I was sub-contracting to seven different providers. So each day, she had a different carer working with a different agency. (Participant 24)

Participants agreed that providers were entitled to a percentage of the home care package for costs and profit. However, when a provider took a large percentage of the home care package funds, the recipient did not receive the support they needed - and the support the government intended them to receive.

The agency is entitled to a percentage - but it's not a specified percentage. The agency could take a large percentage and the older person may not be getting help the government intends. (Participant 7)

They charge \$110 per hour to have someone with Mum on a Saturday while I go to work. So that's \$440. It's ridiculous. I earn \$100. I accept Provider S has to make a profit - and they have payroll, insurance and running costs. But they shouldn't be charging double for their services. (Participant 14)

Several participants were shocked when they calculated the percentage of their package spent on case management and administration fees. Some were charged more than 50 per cent of their home care package.

A woman went through my Mum's contract with me and said: "Do you realise your Mum's provider is taking 53 per cent of the package?" I was shocked, particularly because I had chosen a not-for-profit provider... I calculated that when the Level 4 package came in, they were going to be getting \$26,000 per year out of my Mum's package. Given that Mum was going to need care twice per day (14 sessions per week), I calculated that with their case management and administration fees, the package would be in debt. And that is just from care costs. And that package is supposed to cover minor home renovations - everything. (Participant 3)

I am currently getting nine hours of personal support on a Level 4 home care package. The package is mostly spent on fees. (Participant 14)

About half of Mum's package is taken out in fees (Appendix 5, Example 4). That's before Mum gets any services. And then Provider G charges high

rates for the services: \$51 per hour on weekdays and \$81 for a shower on weekends. The carers are with Mum for half an hour but they charge the full hour. (Participant 13)

Several participants said they were happy to pay case management fees if the case manager provided a worthwhile service.

They were taking over 50 per cent of my husband's package for case management and administration. I actually don't know what the case manager did apart from managing the funds and paying the bills. If I sent her out of pocket, she would send it to admin... I wouldn't have minded paying case management fees if they provided a good service. (Participant 16)

They were charging us hours per week of case management at \$91 per hour. But we don't get anything like that. I never saw the case manager. And I hardly ever spoke to her. I imagine some of the work is due to Provider S contracting out care work to Provider L. But at the most it would be one hour per month. (Participant 14)

Participants said it was wrong to be charged a fixed cost for case management irrespective of how much case management they used.

I didn't realise that case management was in the contract as a fixed four hours per month – no matter whether you used 10 minutes or four hours, you were charged \$96 per hour for four hours... I used to think I didn't have a right to phone the case manager. I used to timidly phone – and think I should not take up much of their time. Until I realised that Mum was paying \$400 per month for it. (Participant 3)

The invoice indicates that Provider L continues to charge \$623.65 per month for case management irrespective of whether any case management services were used. (Participant 14)

A participant felt lower level packages might not require much case management.

A Level 2 package is about \$1,200 per month. You cannot afford to lose \$400 on case management fees and then on top of that another 23 per cent administration fee. Nor would you even need that much case management on Level 2. You get shopping, a bit of cleaning – you certainly don't need \$400 worth of case management. (Participant 3)

Some participants questioned why they were charged case management fees when they received no case management.

It's how it is delivered that is the problem – and all the fees they charge. My husband doesn't use any personal services, so why does he pay for a case manager? (Participant 21)

I found out that Mum's package was being deducted by \$400 per month for case management. So they are supposed to be doing all the work and yet I'm doing all the work. (Participant 3)

How do they work out the administration fees and the case management fees? I've had the same case manager for three years. She doesn't visit often, only when necessary. I haven't needed to contact her for a long time. Yet every month, I'm charged \$400 for case management. (Participant 5)

I hate to think of the old people sitting alone in their homes too scared to phone anyone because it will cost them a bomb. (Participant 25)

A participant had no case manager allocated for 18 months. Yet they were charged \$603.30 per month for case management. This participant was also charged \$673.20 per month for administration (Appendix 5, Example 1).

Right from the beginning, I had my back up because I knew enough about packages to know the provider was creaming off a great deal in terms of management monthly fees and so on. And I never felt that we were getting any case management at all. There was an 18-month period when we did not even have a case manager allocated to us. We seriously had no case manager for 18 months. Yet they still charged us for case management. (Participant 9)

Fees for support workers

Participants were also alarmed at the disparity between what they paid the provider for support workers and what the support workers said they were paid. In some cases, the support workers told participants they were paid below the award rate.

The provider gets the funding from the government. They hand some of it out to Mum and keep the rest. They take a substantial amount of the package in fees. They also charge us twice or even three times what they pay the carers. (Participant 23)

Costs for equipment and supplies

Participants expressed concern about the amount charged for equipment and supplies. Some participants questioned whether providers received a “kickback”.

I asked for a new mattress. The case manager suggested I get an occupational therapist to assess my home. I said OK. She hadn't told me it would cost \$250. The OT wrote a five-page letter with all these recommendations. And the case manager then wanted me to order all this stuff I didn't need. All I wanted was a new mattress but she wanted me to purchase a new bed that cost \$4,000. She was pushing me to buy it. I did but I don't like it. It was not the right bed for me. I've turned off all the gadgets – so it's just a flat bed. All I wanted was a bloody mattress. There was nothing wrong with old bed. I concluded that someone must have got a kickback. (Participant 11)

I've used most of the package for home modifications and some equipment. That is what my husband really needed. I told the care manager my husband was having trouble in shower. It took her about a month to send an OT to assess the house. She made a lot of suggestions. They then got quotes for equipment. The quote for the chair was \$2,700. I could get the same chair from the same company for about \$600 cheaper – but the supplier inflates price because it's on a package. The suppliers know the providers will pay for it so they inflate the price. There is lots of this nonsense going on. (Participant 16)

I am concerned about the costs for items like the walker and wheelchair. It's hard to know if the providers are taking a cut. We don't know the arrangement the equipment supplier has with the providers. It's the same with physiotherapists and occupational therapists who come into the home. You'd like to think things are above board. But I just don't know. (Participant 5)

Questioning fees

Participants wondered whether costs were inflated because home care packages were subsidised by the government.

We got gardening support – but I noticed we were being charged more than double what a gardener normally charges. As soon as you mention it's an aged care package, sub-contractors (e.g. gardeners) inflate their costs. Also, we were not able to continue with our gardener friend. And that was important to us – for social reasons. (Participant 15)

Some participants said they did not have the energy to question the fees.

When you get elderly and have some sort of terminal illness like I have, it's just too overwhelming to get involved in questioning the fees. I am just trying to survive day to day. (Participant 5)

Staff

Administration

Several participants described people who answer phones in the office as “unhelpful”.

The people who answer the phones are just not well educated about the services. (Participant 27)

I phoned and reception put me through to the case manager's voicemail. She didn't phone me back. I later found out she was on leave. But the receptionist didn't tell me this. (Participant 33)

Somelarge providers have a centralised administration. Several participants said this made communication difficult for the older person and their family.

There have been so many small things. They changed over to a centralised system for answering the phone. There are always issues getting through to them. And then it takes time for the person to get back to you. There has been mistake after mistake after mistake. If you ask for an extra hour and give plenty of notice. And then it doesn't happen. Or someone doesn't turn up because the scheduling wasn't done properly. If anything gets a little bit out of the ordinary, it doesn't work smoothly at all. I can't leave Mum on her own. So if no one turns up, I can't go out. It is tearing-your-hair-out-stuff for me. I don't know how vulnerable people communicate well with them. (Participant 30)

To speak to the case manager, I have to ring a 1300 number. Then a person in the head office looks up my husband's name on the computer and asks me what I want. Head office then phones the local office and asks the question. Head office then phones me back. It's ridiculous. Much better for me to email unless it's urgent. I keep a copy of my email and their reply. (Participant 21)

A participant described administrative problems when ordering supplies.

But we seem to find lots of roadblocks. The office gives me the pip. For instance, I am incontinent and wear pads. I use different ones for night and day. If I ring up to order the pads, they say: “Yes we'll order them today.” And sometimes they are quite quick off the mark and they arrive. And other times they don't. On one occasion, we ordered some pads and they sent the wrong ones. So I phoned and pointed out the mistake. And then they sent a different lot of wrong ones. It took a third phone call before they got it right. (Participant 1)

Case manager

Some participants became aware they had a case manager when they saw the fees on their financial statement.

I didn't know what the case manager did. I became aware I had a case manager when I noticed a \$270 core advisory fee each month on the statement. I thought: What's that? (Participant 13)

Role

Participants expressed confusion about the role of the case manager.

I went to a carers' meeting once where people didn't know what was the role of a case manager. I was quite shocked at their level of knowledge. It showed me how deep this confusion runs – it runs down to the most basic. (Participant 3)

I want to know what a case manager does? Given the fees, I thought a case manager would touch base once a month to see what's happening. I also thought the personal carers would report back to the case manager monthly on the state of the client. I never heard from the case manager unless I contacted her. And she was very difficult to contact. (Participant 16)

A participant described a case manager's role as “putting out fires”.

They spend their time putting out fires. That is obviously a priority. But she hasn't spent time with me to explain things with me. I've had to work things out for myself. (Participant 35)

Several participants who were the primary carer of the older person described themselves as the “real case manager”.

When I asked the case manager: “What is your role? What do you do different to me?” She replied: “I assist with the budget. I find services for you.” But I found my own services. She couldn't articulate the difference between what she does and what I was doing. (Participant 19)

I don't know why I get charged case management because I do almost everything myself. I plan everything. (Participant 30)

Expertise

Some participants questioned the expertise of some case managers.

The expertise, skills and knowledge of case managers is questionable. (Participant 19)

Contact

Several participants said they had rarely met their case manager. A participant explained that this was a problem when a recipient's health deteriorated. She was concerned how the case manager would know to arrange an assessment for a higher-level home care package.

I had to insist that the case manager organise another assessment for my Mum. The Level 2 package was not meeting her needs. If the case manager had been competent, she would have recognised this without me having to insist. What are we paying our case management fees for? It seems obvious that older people are going to deteriorate over time. They should not just deliver a Level 2 package and then keep it at Level 2 until the family brings it to the providers' attention that Level 2 is not enough. (Participant 36)

Several participants said they had difficulty contacting their case manager.

A new case manager started about a year ago. I am still waiting to meet him so we can update my husband's care plan. I have spent the past few months sending emails reminding them that it has not been updated since June 2016. They do not reply. (Participant 21)

I'm on the phone to them all the time. I phoned them three times yesterday because she didn't call me back and it was important. I then wrote an email. (Participant 26)

My carer told me the biggest complaint is that the case managers don't respond. The phone doesn't answer. You leave a message and it takes them days to get back to you. (Participant 17)

One participant waited six weeks for the case manager to respond. The receptionist failed to tell her the case manager was on holidays.

A couple of times I phoned reception who transferred me to the case manager. But no one answered the phone. I was later told this case manager was on holidays for a month. I had to wait until she came back. (Participant 12)

A participant described why she did not phone the case manager.

I was told the mainstream provider charged \$90 when you phoned the case manager. You wouldn't want to be charged that ridiculous amount. So you wouldn't phone. You'd go without. (Participant 41)

Some participants decided to put "everything in writing". Even then, some case managers took a long time to reply.

I sent an email to the case manager in desperation about all the different support workers going into Mum's home. Everything was going really wrong. It took six days for the case manager to reply. (Participant 35)

Communication

Some participants described communication with their case manager as "unsatisfactory".

I received minimal case management. And it wasn't satisfactory. When I phoned with queries, she was abrupt. She would always refer me to her manager. She wasn't informative. (Participant 19)

I make one call a month at the most. And they hardly ever contact me. And they certainly take out a nice old swipe. (Participant 27)

Some participants found it difficult to get information from the case manager about their entitlements.

I always have to drag information out of them about what we can and can't have. One recent example: I found out by accident Mum could have got taxi vouchers through the package. The case manager was very defensive. I asked if we could have them when I take Mum to the doctor. She ended up sending me four. When Mum ran out she said: "I can't keep just handing them out." But we are entitled to get them through the package. (Participant 30)

A participant was frustrated when the case manager did not explain the provider's policies.

Once a carer arrived when Mum was on the floor. They are not allowed to help her up. You only find out about these rules after it happens. It's not explained. Most people would help someone up. They wanted to call an ambulance. I didn't let them. My brother came instead. We have now learnt that if they want to call an ambulance, the family can't override – and Mum can't override them. It's their duty of care. (Participant 13)

Participants described poor handovers between case managers. They also described poor communication between case managers within different services.

The case manager texted to say he was going on holidays for six weeks. He said the replacement case manager would arrange a physiotherapist. I heard nothing. (Participant 22)

We've asked for the provider to phone a family member, not Dad. But they didn't pass this information on to the people coming to assess Dad's incontinence. They phoned Dad directly to arrange a continence assessment. I get the sense that there are lots of different groups involved but they don't share the relevant information. (Participant 39)

High turnover

A participant described the high turnover of case managers. She questioned the reasons so many case managers resigned.

The mainstream provider's case manager never came to my home. I was hardly ever able to even talk to them on the phone. If I phoned, I was told: "She's no longer here." They all left – and they never told you that the person was no longer your case manager. Nor introduce you to a new one. Why is there such a high turnover? What's behind that? (Participant 41)

Difficult to understand

Participants, particularly those with hearing impairments, found it difficult to understand case managers who spoke with strong accents.

She had a strong accent that I found hard to understand on the phone. She thought I was an idiot. She was condescending. I didn't like to contact her. I preferred to just leave a message with the receptionist. (Participant 13)

The new case manager was not easy to deal with. She was hard to understand – strong accent. She didn't seem relationship driven. She was operational – and I found that annoying. I've had lots of problems (Participant 35)

Authoritarian manner

Some participants said their case managers were poor listeners, thought they knew what was best and would tell them what to do.

My case manager thinks she knows best. She thinks I don't know what I need. I told them I wanted a desk chair but not one with arms – so it would fit under the desk. I was told: "No you can't have that, you've got to have the one specified by the OT." They say it's consumer directed care – but that's not how I was being treated. They were telling me what I could have, what I should do and when. (Participant 11)

I was 63 and my partner was 61 – younger than their other clients. They were used to telling older people what to do. They tried to tell us what to do. Of course, I got my back up. I didn't like their attitude at all. (Participant 9)

Inexperienced

Some participants had case managers who were inexperienced.

The first two case managers were 20-somethings who knew nothing about dementia – even less about early onset dementia. They also knew nothing about coming into a household of our age group. (Participant 9)

Lack of continuity

Participants said it was difficult forming relationships with case managers because some did not remain in the job for very long.

We got a new case manager who only lasted two weeks. And then I got another, then another and another one. I never have continuity... The staff changes are phenomenal. All the case managers leave. (Participant 17)

There have been three case managers in the last year. There was no case manager between December and April. They still charged. (Participant 14)

Too busy

Some case managers were too busy to provide the support required. Participants suggested this was because their caseloads were very high.

The case manager had so many people on her books – and she couldn't give us the time we needed. (Participant 9)

Case manager caseloads are very high, some as high as 100 and so they are unable to provide a quality service to clients. (Participant 19)

Support Workers

Participants did not want strangers working in their home.

Growing up, we were told not to let strangers into our homes. Now older people are being told to trust these strangers who come into our homes. (Participant 36)

Unsuitable

Several participants suggested providers needed to be more selective about the people they employ as support workers.

They just employ ordinary people. I am not able to choose who comes... I've had some terrible ones – one was an IV drug user but I didn't know. She looked like she was going to drop dead. She was grey. What would I do if I had no husband and they were sending me this crap? (Participant 17)

They just didn't have the right people. I had several mini meltdowns, and then I had a major meltdown. I had to get more help. (Participant 9)

I once had a carer who told me she didn't like showering people. And I thought: "Bloody hell, what are you doing here then?" (Participant 1)

The support worker was hopeless. She didn't come across as very caring or compassionate. Why do people like that work in aged care? (Participant 35)

Participants were concerned about the lack of strict selection criteria when employing support workers. They said this meant providers had to keep a close eye on the support workers.

With Provider M, they know where staff are at all times. They are followed with GPS. They clock on and off with their phones. There is something about being watched and checked – it undermines relationships. With the charitable organisation that we used to have before the package, there was a level of trust with their staff. (Participant 9)

When participants found a good support worker, they would request that person return to their home. However, this was not always possible.

When we find a good carer who has a rapport with Mum, it's a struggle to get her back again. I had to keep phoning and asking. I've also found when I compliment a carer, I never saw her again. I suspect they don't want clients and workers becoming too attached. (Participant 30)

High turnover

Some providers were constantly understaffed. These providers also had a high turnover of support workers.

Provider M was always understaffed. If someone phoned in sick, they would send any Tom, Dick or Harry. Their staff turnover was also very high – churning different people through. It was extraordinary. Support workers would come and you wouldn't see them again. Last year, my partner had five different people in the first five months of the year – new person coming and going... I would get so sick of new people coming in to our home. So no wonder we were not able to spend our package because I did not want strangers coming into our house. With the local council, we'd had the same support workers for several years. (Participant 9)

Several participants complained about the number of different support workers who were sent to work in their home.

Recently, we've had about 40 different support workers. Mum became very stressed by all these different people coming into her home. (Participant 35)

My parents were both on a Level 4 package until Mum moved into a nursing home. They were initially very resistant to having people come into the home. At the beginning, Mum threw people out. One of the things that didn't help was the inconsistency of people. (Participant 40)

The inconsistency in staff is a real problem. It's unmanageable with dementia. The consistency is critical. With one agency, there was a constant turnover. It took six months of emailing and phoning to get a roster. (Participant 3)

Provider I is a big company. I had different people coming to my home. Someone came on Monday, a different person Wednesday and another person on Friday. I told the case manager I wanted to stick with one person. I don't have to explain everything – the mop is here, the detergent is here, the brush is here. If I had the same person, they would know what to do without me having to explain every time. I finish my shower, and then have breakfast. She replied: "Yes, of course." But it never happened. (Participant 4)

Participants were upset when a stranger turned up at their door saying they were the support worker. A participant said this made him feel physically unsafe. Another participant was afraid of theft.

They used to send different people. Someone would knock on my door and I would say: "Who are you?" They would tell me they had been sent to help me shower. I would reply: "I can't accept you." No one phoned me to tell me anything about it. I needed to know who was coming into my home. I used to get very upset. One day a man turned up at my door. I asked: "Who are you?" He replied: "I'm the cleaner." I asked: "Who sent you?" He was agency. I said: "I don't know you. I don't want you in my home." I don't feel safe like that. I don't know his name, where he comes from. He could attack me. Who knows? I can't defend myself. I said to the case manager: "You have to stop this. It can't go on like that. I need to find someone who can take care of me." (Participant 4)

Provider AA promised the world but they were all over the shop. I ended up going off at the case manager because they kept sending different people every week. And they were never on time. I insisted on someone who knows us – and knows Mum. I can't keep having all these strangers in my house. I may as well be doing it myself because I had to keep explaining Mum's needs. (Participant 25)

It's important that support workers form relationships. You can't have strangers going into people's homes. Knowing that I have vulnerable parents on their own – you hear stories of people going in and robbing them blind and god knows what else. (Participant 40)

Although participants made it clear to the case manager they wanted support workers to be consistent, the high turnover of support workers remained a problem.

We were clear the staff coming to our home had to be consistent – so my partner could get to know them and vice versa. Nonetheless we were sent a whole ream of people. My partner refused some of them. (Participant 15)

I've told them numerous times: "If you can't send the girls we've approved to care for Mum, don't send anyone." These new girls stress Mum and cause more stress for my wife and me. With Mum's dementia, I don't want a different girl coming every day. It confuses Mum. Provider BB stuff it up. They keep sending new girls. (Participant 26)

Mum had short half-hour visits. They were different people all the time. She had 14 visits a week with around 10 different people. (Participant 23)

Participants suggested the problem is that some providers do not employ enough support workers. Agency staff were used to fulfill commitments.

There is a different person each day. They often change. It seems to me they don't have enough carers – not enough staff. Because when they can't fill the roster, they use an agency. (Participant 1)

Unreliable

Several participants said they never knew what time the support person would arrive at their home.

I never know when they are turning up. I knew when they were supposed to turn up. But one day I went to Mum's place at 3.30pm. Someone was in the kitchen and microwave was on. I asked what they were doing here. "Dinner. I came early." Fancy giving someone dinner at 3.30pm. It's wrong – and made me realise this type of thing is happening all the time. It's not fair because lots of people – with or without dementia – have trouble sleeping. And so they are up at 1am – and my Mum has no access to a stove – so she is going to be hungry if you feed her at 3.30pm. (Participant 3)

Participants said it was important to not only know who was coming, but also when. They were dissatisfied when support workers did not arrive on time or, in some cases, did not arrive at all.

Provider I was never on time. They were always phoning me to say they couldn't send someone today. Or they said they were coming at 10am and they would phone to say 11am. One day recently, I was still waiting at 1pm for a shower. I phoned the office and said: "What has happened? I need a shower." They told me they were short of staff and would send someone new from an agency. (Participant 4)

A carer was supposed to come at 7am but no one came. The carer who was rostered on was sick. Someone came at 10am. I was at work so I had no idea. When the carer arrived Mum was distressed – upset, hungry. I began to think Mum couldn't live alone if the service was not reliable. It was a difficult decision – she loves her neighbours, we are in the next street. Her geriatrician felt she needed proper care in an aged care home. (Participant 23)

A participant described feeling frustrated when a support worker did not turn up despite making the booking in advance for a special occasion.

I had asked Provider Q to have someone here at 1pm because I had an appointment. I had made the booking a long time in advance. The day came and the person never arrived. After half an hour, I phoned. The office people told me he should be there. And they phoned back to say they had made a mistake. On another occasion, I had cancelled but they forgot to tell him and he arrived. (Participant 16)

Communication

Participants expressed frustration when they were unable to communicate directly with their support worker.

The biggest frustration for me is that agencies don't want you to have contact with their staff/carers... Why are the agencies blocking family carers and professional carers from getting hold of each other? If I want the carer to get Mum milk, I have to phone the case manager and leave a message just to ask the evening carer to get some milk. (Participant 3)

The communication doesn't exist. It's hopeless. We had to phone a Melbourne number if we had to tell them we would not be home tomorrow so we don't need someone to come. Melbourne people would then phone local people. It was just hopeless. (Participant 9)

Having to go through a bureaucratic system to get a message to my carer is a stumbling block for me. If I want to say: "I don't need [Name] this week because I have a meeting somewhere," I can't say to [Name] – well I do say it anyway. But it has to go through the system. (Participant 41)

Participants also found it frustrating when they did not know the roster in advance.

I don't know who is coming tomorrow – but I have to trust that they will be OK. (Participant 1)

A participant was upset when the case manager did not inform her about a new support worker. Another participant said it was inappropriate to send "anyone".

They sent a woman who couldn't speak English. Mum was sitting in her chair. She cleaned but didn't give Mum anything to eat or drink. I would never have left Mum alone if I had known it would be a new person. Nobody told me. I think it is incompetence. (Participant 14)

If the regular workers were not available, they would send anyone in without telling me in advance. They learnt after a few discussions with me that this is not appropriate. (Participant 40)

Frequent staff changes made communication difficult.

I wasn't happy with the program because there was no connection. Staff changed so often. And you were never told who the new worker was. I would phone for something and I would be told: "No, she's not here any longer. Maybe you should speak with so-and-so." I just wasn't happy with it. Also she didn't try to match me with an Indigenous carer. That is an issue. (Participant 41)

Qualifications and experience

Many participants did not know whether the support workers were qualified.

How do you know if the carer is qualified? Are they nurses? Would they know what to do in a crisis. Do they have first aid or CPR? They once sent a support worker who was a student. I went out when he was here and told him not to let anyone into the apartment. He did and it caused a problem. (Participant 16)

Some participants were shocked to find that not all support workers were qualified. Provider O, for example, required only a police check.

Most care providers in an area advertise for staff with Certificate 3 or in the process of doing it. Little did I know that Provider O took anybody. Staff did not need to have any qualifications or experience. They literally employed anyone. They just needed a police check. They got staff from Centrelink - unemployed people who were told they had to get a job in aged care. These people didn't want to be there. (Participant 15)

Participants were concerned that inexperienced support workers might not know what they were doing.

A few have been quite inexperienced. They are tentative when they give me a shower. I'm quite sure one was still a schoolgirl – she didn't really know what she was doing. (Participant 13)

Training

Some support workers were insufficiently trained. Participants described new support workers as “thrown in the deep end”.

I actually asked a carer one evening whether she had any training in dementia. Nope. Are you kidding me? University of Tasmania MOOC is free. There is no excuse for not having any training... You'd think a company as large as Provider G would have properly trained staff. (Participant 3)

It is unacceptable that staff are not trained and they don't offer them any training. All the training has to be done out of hours under their own steam. Provider M needs to provide training about situations that their staff are going to face. (Participant 9)

New staff were supposed to have two weeks buddying with experienced staff, but often they get none. They got thrown in the deep end. They sent staff who lacked experience and knowledge. They had no initiative – because they were so new. (Participant 15)

Some support workers had not been trained how to safely use equipment such as a hoist. This put pressure on families to train the support worker.

I don't feel the carers are adequately trained. I had to teach them how to use the hoist. They didn't know how to do it. (Participant 19)

I had to keep telling them what to do. They didn't even know how to use the hoist. It is easier for me just to do it myself. (Participant 21)

Participants were annoyed when support workers without any experience came to their home. They were particularly concerned when support workers had not received any dementia training.

A few times, they have sent someone who is very young and inexperienced. My Mum is too high level. They need to train her before they send her out to someone who is Level 4 like my Mum. I end up having to show them what to do. That has been another struggle. (Participant 30)

Provider K has sent me a lass who is only 20 years old. She is training in occupational therapy. I don't think she has ever cleaned a house in her life. My eyesight seems better than hers. I see all

the dust. I see the rim in the bath. When she cleans the bathroom bench, she doesn't move things. She cleans around them. When she cleans the kitchen floor, she doesn't move the kitchen stools. The other day, she left a puddle of water on the floor. I could easily have slipped. (Participant 7)

All the support workers with Provider M seemed to be casual – and they were very young. They knew nothing about dementia. (Participant 9)

Competency

A participant was disappointed when a carer failed to call an ambulance when she was very sick.

I was very sick recently. My carer came to see me on Monday morning, but I don't recall her visit. I must have been very sick. I'm disappointed she didn't call an ambulance. Later that day, my friend called an ambulance and I was in hospital for a week. I phoned the case manager to ask why the carer didn't phone the ambulance. The carer had reported that I wasn't well. But she didn't do anything. (Participant 33)

Another participant reported a support worker being unable to complete her tasks in a reasonable time. As a result, the older person was not able to go on her scheduled outing. The daughter expressed alarm that the support worker left her mother home alone.

On one occasion, Mum missed her outing because the support worker could not get her dressed and breakfast ready for her outing. They then left her alone at home. This could have been a disaster. (Participant 35)

Manner

A participant described an episode of transphobia.

I had one woman come to my home, and she didn't speak. When she finished, I asked her whether she knew who I am. She replied: “Yes, I know who you are. I just don't approve of it.” So she didn't come again. That's the only issue I've had with transphobia. (Participant 11)

Another participant described a support worker making a decision without consulting her. Her daughter questioned whether the support worker's behaviour was ageist.

One woman was cleaning. She made it clear she didn't like cleaning. Two days later, two big parcels arrive – a mop and bucket. She had gone back to

the office and told them my cleaning materials were not adequate. The cost came out of my package. And I had no idea. Surely I should have a choice of the type of mop used in my home. (Participant 13)

Remuneration

Participants said the support workers were underpaid. Several participants described support workers being paid below award wages. They also noted the difference between what the support workers were being paid and what the participants were being charged.

People working in sector are underpaid. Our carer has a Certificate IV and gets \$27.17 per hour (the award). Provider E charges \$48 per hour. So that's where they make some money along with their administration/case management fee. (Participant 20)

The care workers at Provider O were being paid about \$22 per hour. We were being charged \$65 an hour. That's base rates – not overnights, weekends or public holidays. (Participant 15)

Gender

Several participants described preferring support workers to be female. They felt the case manager should have known their preference and not sent a male support worker.

Once a male turned up, and Dad would not let him in. Dad is obviously more comfortable with women. (Participant 39)

Travel

Participants noted the long distances some support workers travelled between client visits.

Some of the carers come all the way from Frankston. This is why they are often late. And their next client is in Frankston. It is not very efficient. (Participant 13)

I felt for the staff as well. They would ask whether we needed staff for half an hour. I said: "No, that's not fair on them." Provider N wouldn't let anyone come here for less than two hours. I think that's reasonable. Out of respect for the worker, they are driving from somewhere to our place. It needs to be worth their time. I think Provider N has always been the benchmark for me in terms of comparing with Provider M. (Participant 9)

A participant excused the support workers for being late due to the distances they travelled between jobs.

They are sometimes late. But the traffic is murder. They send them from here to Richmond – and expect them to get there in 10 minutes. It is impossible. So they are late. The other day, they sent a lass from Bulleen across to me. They gave her 15 minutes' travel time. (Participant 8)

Stress

Some participants described the support workers as "stressed out". One participant suggested staff receive training in meditation. Another suggested dementia training. They felt additional training might help reduce stress levels.

A lot of the carers are very stressed out. The agencies don't give a damn about them. They're not interested in helping their staff. I suggested to the state manager they could send out a CD for meditation for carers. "Oh fabulous idea" – but nothing gets done. (Participant 17)

Providers don't realise that by having dementia training you are bringing your own staff's stress levels down. For me, dementia is extremely stressful to deal with. By not training staff, you are contributing to workforce stress level and burnout. (Participant 3)

Time spent with care recipient

A participant questioned the amount of time support workers were spending with older people.

I'd be on the phone to Mum and hear the doorbell ring. I'd phone back 10 minutes later and say "Hi Mum. Is [Name] still there?" She would reply: "No, he has gone." They were paid for a 30- and 45-minute session. There is no way to confirm that the staff are in the home providing that care for the allocated time. For many isolated people, that 30-45 minutes is the only human contact they have all day. So to be ripping them off like that and just zipping in and out in 10 minutes – which is what they were doing – is terrible. (Participant 3)

Sub-contracting support workers

Several participants described providers hiring support workers from another provider. These providers either did not employ their own staff or employed an insufficient number of staff.

It is totally misleading for Provider Q to use another provider for carers. I came to Provider Q so that the carers would be from the same religious

group. But they are not. Provider Q is just the middle person providing no service. If I had gone directly to Provider R it would have been cheaper. (Participant 16)

Provider S gets carers from Provider C. Provider S doesn't have enough staff. The communication between agencies is terrible. If Mum has any problems, I phone the case manager at Provider S, who then phones the case manager at Provider C, who then informs the carer. It's very hard to change rosters. I can't speak directly to the carer. (Participant 14)

Agency staff

Some participants said they “stumbled upon” good agency staff. However, their case manager told them it was more expensive to hire agency staff. Other participants were dissatisfied when the provider sent agency staff.

I once stumbled upon a good agency person. I asked if I could keep him as a regular. But they said: “Agency are more expensive.” They told me he would cost \$140 per hour. (Participant 4)

If someone is sick, you have to take whoever. The problem with that is they don't know my mother, they don't where anything is in the house. I don't want some stranger working around the house, rooting through my cupboards. They often don't even tell me someone else is coming. It's wrong. They should have sent even an email or text or something to say: “Someone else is coming. Is that OK? Or do you want to change your booking?” (Participant 14)

A participant said support workers sourced from other providers were not flexible.

Provider S is not flexible – probably because they get their support workers from Provider L. (Participant 14)

Lack of respect

Some participants described support workers treating them disrespectfully.

Some of the workers treat me like a child... They don't always listen to me. They treat me like I'm a patient. They take control. (Participant 13)

A few weeks ago, when the lass came in I said: “I'm not getting out of bed.” So she tried all sorts of ways to coerce me. But I insisted. I just wanted to stay in bed. (Participant 1)

There was a few hundred dollars missing. I couldn't say anything. With dementia it would have been Mum's word against the support worker's. (Participant 37)

Culturally and linguistically diverse

Some participants chose the provider specifically because they assumed the provider would provide support workers who could speak their language and/or share their culture or religion. They were disappointed when they discovered this was not the case.

It seemed sensible to choose one that suited our religion. I thought they would understand our religion and culture. I didn't know Provider Q does not employ carers. All their carers are sourced from another provider. They are taking over half the package in fees but not providing the service I expected... We had a family bar mitzvah in the synagogue. Men sit downstairs and women sit upstairs. I called the rostering people six weeks in advance. I wasn't sure how my husband would be on the day – but I arranged for a male carer to come with us, because I could not sit with him. They arranged for a young man from the Philippines. I needed someone who was Jewish. I was very unhappy. (Participant 16)

Mum preferred Greek-speaking support workers. As Mum's dementia has worsened, she has forgotten a lot of English. I chose this provider because they have Greek-speaking staff. Yet they sent Mum new support workers – none of whom spoke Greek. (Participant 35)

Although the following quote may be perceived as offensive, several participants expressed a preference for “Anglo” support workers.

Some care workers from different cultures don't understand our slang – they may not understand what my parents are saying. Dad is deaf and found their accents very difficult to understand. It was very important to get Anglo care workers. (Participant 40)

Food handling

Some participants were concerned about the level of training support workers received in food preparation. They questioned whether food handling in the home was regulated.

There is no regulation on food handling for people who come into the home. (Participant 29)

Cleaning

In many instances, the same support worker who provided personal care also cleaned the house. Some participants indicated they would have preferred a professional cleaner. Others suggested the support workers needed more time to clean.

I'd like proper cleaners. These women don't nearly do what I'd do. But I am not terribly assertive. When she comes out to say she is finished, I say "Good, thank you." And then I go into the bathroom and I see the cobwebs. I don't like to be picky. (Participant 1)

They are restricted in what they can do. They can't move furniture. A professional cleaner would do a better job. (Participant 13)

[The support workers] never have time to do a decent clean. They are in a rush to get to the next job. Also, they are restricted in what they can do. (Participant 17)

Daily fee and means tested contribution

A provider was entitled to charge a daily fee for a home care package. As of September 2018, the daily fee was \$146.02 per person per fortnight. Participants described several instances when providers did not charge this fee. However, it was not clear how providers chose who, and who not, to charge.

They said it was government recommended fees of \$10 per day - \$260 per month. My mum was on a full pension. The case manager told us they had some clients who were not paying anything at all. How is that fair? It is a big chunk out of her pension. (Participant 35)

Participants were concerned about being charged a daily basic care fee for seven days when they received care on only one or two days per week.

Dad was approved for a Level 2. Once he was means tested, we were charged \$20 per day. Our contribution was \$20 a day for every day of the year - irrespective of how many days per week we used the service. But that didn't all come through until we were three months into the package... Prior to the package, I was paying the carer \$25 an hour for seven hours per week. But on a Level 2 package we only got four hours. It worked out that Level 2 was not financially viable - so we stopped it. (Participant 20)

Unspent package

As of 30 June 2017, providers who submitted their financial reports to the Department reported unspent funds of around \$329 million (Aged Care Funding Authority, 2018). This equates to holding average unspent funds per 'consumer' of \$4,613, an increase of 26 per cent from the previous year.

Participants described several reasons for having a large surplus in their package. One participant described her mother preferring her family over professionals to provide the support.

Mum is in a retirement village. Within a radius of about six kilometres is me, my brother, my son, and my daughter. We have a large surplus in our account because of the level of support Mum gets from family. (Participant 37)

Several participants described being unable to spend their home care package because the provider did not supply the required services.

My partner couldn't spend her package because the provider did not provide services that we needed. It's morally wrong for Provider M to offer packages if they don't have the staff to give you the services to help you stay at home together. (Participant 9)

Some participants described not using the services because they were unhappy with the quality of the services delivered.

We have a Level 4 but I cancelled the personal services because they were useless. I couldn't wait around until 2pm for my husband to have a shower. I also used to have a carer come in for some respite. But I need to be able to trust the person - especially when my husband is hoist lifted. The last one we had sat outside smoking and on her phone - leaving my husband alone inside. I also had a carer steal. So I don't use them. Our closing balance is \$13,400 - because we are not spending it on services. (Participant 21)

When we first signed up with Provider M, they gave us a list of their services - but a lot of these services were not of any interest... We just didn't fit in with how they wanted things to be. (Participant 9)

We realised what is currently around does not suit us at all. Our early onset dementia group is aware that we will have to create what we need ourselves. (Participant 15)

A participant had more than \$30,000 surplus in her account. She was told she was not using enough of her package. Another who had \$20,000 in her account said the provider was going to change her package from Level 4 to Level 3.

Our balance is simply because they haven't had the staff to deliver the service. We had over \$30,000 unspent in our account. We would have spent it if they provided a service we could use. The regional manager came back one day – she said I was not using enough of the package. I said: "You give me decent staff and I will use it." She replied: "If you don't use it, we will give it to someone who will." I really flew off the handle. "How dare you say that? I am not the problem here. You're the problem. The organisation is the problem. You're not providing me with what I want and when I want it and how I want it... We've been trying to spend some money out of the package before my partner goes into residential care. Well, stuff you. You haven't looked after us for four years. You have to be prepared to compensate my partner for that." (Participant 9)

Provider O threatened to cut us back from a Level 4 to a Level 3 package "to share the money around to those who really need it". Bullying. Illegal. It still makes my blood boil, just thinking about it. (P 15)

Several participants were saving their money for a later date when they would require equipment or house renovations.

We had saved some money in our package for a rainy day. The house will need some modifications to be more accessible. These savings created further conflict with Provider O. This time last year, we had nearly \$20,000. It has gone down to about \$5,000. I suspect this may be financial fraud. (Participant 15)

A participant was saving the package because she anticipated her father would not be able to access a Level 4 home care package when it was required.

Level 3 is meeting his needs right now. In fact, we are not utilising the whole package. I'm accumulating on purpose because one expects if you're on Level 3 you are going to progress to Level 4. But the system doesn't allow for that. When you know things have deteriorated there are still huge hurdles to jump. You have to be reassessed by ACAS, you've got to be made high priority, you have to wait for someone to die or go into care. Only then do you get the next level package and can increase your hours. I'm accumulating on purpose because my father is now 95, his deterioration is significant but he is still

holding himself together – just. This is a downfall of this system. (Participant 20)

Some participants had a temporary surplus because they used services from another provider. The surplus in their account was due to delays in the primary provider receiving the secondary provider's invoice.

The only problem now is Provider E is very slow sending their invoices to my new provider. Currently I have a large surplus because they haven't received invoices for the services I have used. (Participant 18)

Some participants expressed concern about the unspent money being taken back by the government.

I've heard rumours that the government is considering taking some of that back, to be seen to be injecting funds into more home care packages. (Participant 15)

I heard on the grapevine that a certain large care provider is telling their clients on packages they need to spend their package money or the government is going to take it off them and give it to the drought farmers. (Participant 21)

Complaints and advocacy

Complaints

Some participants made complaints directly to My Aged Care. Others contacted the Aged Care Complaints Commissioner. There was some confusion about whether the Aged Care Complaints Commissioner dealt with home care. When one participant contacted the commissioner, she reported being told the Aged Care Complaints Commissioner only deals with residential aged care. This was incorrect.

I used the complaints through My Aged Care. I spoke to someone on the phone and they wrote it all down. I asked to speak to someone, but was not allowed. I never heard anything back. (Participant 19)

I've found the Complaints' Commissioner useless. Not supportive at all. They just wanted to close the case without it being resolved. They were not prepared to put anything in writing to me. (Participant 35)

A participant relied on the Public Guardian to advocate on her behalf.

I had to get the Public Guardian on to them a couple of times. It was terrible. (Participant 17)

Moving into residential aged care prematurely

Although 22 participants were approved for a Level 4 home care package, five had been assigned a lower package. One participant approved for a Level 4 package had not yet been assigned a home care package.

Dad is still on the wait list. I think he will die before his funding comes through. (Participant 24)

Some participants could not manage to remain at home on a lower home care package. Their families were forced to consider residential aged care.

Mum was approved for a Level 4 package two years ago. She was given Level 2. It was not enough. I was exhausted. So Mum went into respite. She had four falls in the first few days. I don't understand how she fell. She could walk with me to the local shops. She didn't even use a walking stick. She broke her hip and now can't walk at all. It is now not possible for me to look after her at home. (Participant 6)

Mum was not ready for residential aged care. She was fully mobile, hadn't had any falls or anything else, but the system was going to put her there because we were still waiting for the Level 4. And she couldn't survive at home on Level 2. If the Level 4 package had not been assigned, Mum would have been another statistic in residential aged care ahead of time. (Participant 3)

Ideas for improving in-home care

Participants made some practical suggestions about how the quality of in-home care could be improved. A number of these are being funded through the *More Choice for a Longer Life* budget measures.

In some cases the suggestion had already been implemented (e.g. interpreters). The fact that participants were unaware of interpreters suggests further communication about the National Translating and Interpreting Service may be warranted.

Participants' suggestions are discussed under the following headings:

- Make aged care system easier to navigate
- Legislative changes
- Improving My Aged Care
 - Better information
 - Website
- Reducing the queue
- Providers
 - Licences
 - Accountability
- Choosing a provider
- Schedule of fees
- Financial statements
 - Clarity
 - Explanations
 - Real-time statements
- Person-centred care
 - Culturally sensitive
- Case manager
- Support worker
 - Recruitment and training
 - Empathy

- Consistency
- Matching workers with clients
- Information about outsourcing
- Mentoring system
- Roster
- Support for carers
- Purchasing private services
- Private health insurance
- Peer support
- Connecting care recipients
- Respite
- Advocacy

Make aged care system easier to navigate

Carers of older people are experiencing grief at the same time as they are trying to navigate a complex system. In some cases, it was “*all too much*”. Participants said they would have benefited from assistance to navigate the system.

You can't be expected to do it on your own when you first start out. You need some guidance.
(Participant 28)

Legislative changes

A participant suggested legislation to ensure providers only charged a certain percentage in case management and administration fees.

It is open to abuse. More so because they are working with a group in society who are not able to monitor what is happening to them. An older person like my forgetful friend may not even know to ask the question. I don't know what you do about it. Somehow they need legislation that locks the providers in to a certain percentage. No lower than, no higher than... The providers can then decide whether they can run a business on those margins.
(Participant 7)

Another participant recommended more government regulation.

It is not a very regulated service – there appear to be no client-centred frameworks, structures or adequate guidelines – they are different with each provider. A more consistent approach is needed. (Participant 19)

Improving My Aged Care

A participant suggested a “complete overhaul” of My Aged Care.

I think this service needs a complete overhaul, with more qualified and trained staff who can offer families and clients more support and advice. (Participant 19)

Better information

To make genuine choices, participants said they required more information.

We need more publicly available information that encourages people to be able to make those choices. Consumer directed care is ridiculous if the choices aren't real. (Participant 15)

Participants also wanted more reliable information. They suggested staff at My Aged Care should be better informed. My Aged Care should be a “one-stop-shop” for information and advice.

We need one place where we can pick up the phone and find an answer to almost everything within aged care, including the legislation, parts of the Act – all of that stuff. You have to be prepared to make 20 phone calls. I have been – and that is the reason I know what I do (Participant 3)

Website

Several participants were aware that the government had recently funded improvements to the My Aged Care website. They suggested the search engine that helps people find providers in their local area should be refined.

We went to the My Aged Care search engine and put in our postcode. It brought up hundreds of providers, many from miles away. I believe some of the money being thrown at the web page is to address this problem. The search function has to be more refined. (Participant 15)

They also suggested the My Aged Care website should provide more detail about the different providers.

We need to be able to search for providers and see their reports – have they met standards, what is going on if they haven't? We also need to be able to see the basic costs – and for what. How do you know if you are getting value for money? (Participant 15)

A participant suggested testing the website with ‘consumers’.

They need to field-test the website with those of us who use it. (Participant 11)

Reducing the queue

Participants suggested the government should increase funding so more home care packages can be released.

It is horrible for many people in queue. If they have been assessed as needing a Level 4, they need it now. Not in a year or two. And the government has all these ads on TV. It's ridiculous. They should have released a lot of packages instead. (Participant 27)

Participants also suggested certain groups should be given priority in the queue.

People who are on pensions or don't have any family support need to be pushed up the queue. (Participant 24)

Providers

Licences

To become a provider of home care packages, an application is submitted to the Commonwealth Department of Health. The department reviews suitability as per criteria stipulated in the *Aged Care Act 1997*. However, participants suggested the government restrict licences to only those companies that can demonstrate expertise in aged care. Only providers that employ qualified staff and deliver ongoing training should be given licences.

They need to give licences to providers who know about aged care not just companies that are interested in taking government money. (Participant 25)

Accountability

Participants suggested providers needed to be transparent, accountable and financially audited.

There has to be accountability and transparency. You have to show that you have trained people, that you have an understanding of the area – and it's up to the Commonwealth Government to set the standards in both residential and home care

that organisations have to sign up to. Why is an insurance company given a licence to deliver home care packages? (Participant 9)

It all depends on the integrity of the provider. There certainly needs to be a provision for more auditing. (Participant 5)

When we look at inefficiencies, and not having enough money in aged care, if they were to audit this entire industry with these invoices and everything else, there would be millions of dollars in either incorrect charges or unscrupulous charges that are going on to these invoices. (Participant 3)

Why didn't they include an audit when they set up My Aged Care? It just seems common sense – so government knows how providers are spending taxpayers' money... I just can't understand the government. It makes them look so weak when they don't have a built-in system where every provider is audited so many times a year. I just can't believe it. (Participant 5)

A participant suggested what providers paid their staff should be published.

Make the providers financially accountable. All salaries and fees must be published. And also made accountable for their duty of care. (Participant 29)

Several participants would prefer the government to give the home care package directly to the recipient so the family could employ professionals.

There are too many hands in the funding pie... It would work better if Mum received the funding directly and I hired the support workers. Mum would get more hours. Two hours a day is simply not enough for a person with dementia on a Level 4 package. (Participant 25)

My ultimate cry is: "Can't we please get the packages directly?" (Participant 15)

Choosing a provider

A participant suggested an innovative way to ensure recipients of home care packages chose a reputable provider.

How does an elderly person who has not had any experience with this system choose a provider who is going to do the right thing by them and the government? I was introduced to provider J by my GP. I wonder if it would help if the agent had to be introduced or recommended by the person's GP.

Verified by the GP – so the older person knows they are honourable. And keeps on being honourable. (Participant 7)

Several participants would have preferred the government to give them a provider rather than require them to choose their own.

When the home care package was assigned, I immediately received phone calls from Providers M and O and others. They wanted me to sign papers. It was overwhelming. I was told later that I had to make the decision. I would have preferred to just be given a provider. So much was going on. My husband was very sick. It was hard to think about all this. (Participant 31)

Schedule of fees

Participants suggested it should be mandatory to receive a schedule of fees before older people signed the Home Care Agreement.

Before you sign up for these packages, you should be sent a document with an average cost for the fees – like my private neurologist. She sent me a list of all her fees before my first appointment. We need the government to provide us with a schedule of fees. We need a schedule that everyone understands. For example, how do I know the charge for my walker was reasonable? Or the hourly rate the company charges? (Participant 5)

Home care providers must publish their existing pricing information on My Aged Care by 30 November 2018. This requirement was legislated in August 2018. However, on 22 January 2019, Provider B had not published its pricing information (Appendix 5, Example 6). A participant suggested there should be some penalty pricing information on My Aged Care.

What is the penalty for not publishing fees? Easy solution, their profile is removed from MAC!! (Participant 3)

Financial statements

Participants suggested improvements to the financial statements, which included improving clarity and providing explanations and real-time statements.

Clarity

The financial statements should be clear.

When we receive our invoice, we should know exactly what is going on. When they say “total expenditure”, is that for the month? \$1,344.50. That seems a lot for the three hours help that I get. (Participant 5)

Explanations

Participants suggested the case manager explain the monthly statement to those who had trouble understanding it.

Many women my age did not do the family's finances. We haven't even got the language to check the statements. It's not a criticism, it's a fact of life. (Participant 7)

Real-time statements

Participants described a need for real-time access to statements.

They should provide real-time accounting so we can know the balance of our accounts. (Participant 14)

Person-centred care

Participants said listening to older people and their families – understanding their needs and matching them with compatible support workers – was an essential component of delivering person-centred care.

Overall, the idea of a package is a great idea and absolutely necessary. But there has to be a lot more professionalism. They have to take into account the family they are supporting. There has to be a culture at the top of person-centred care and listening to what clients want. (Participant 9)

The service is very administratively driven with less focus on the client. Costing and budget is a priority to providers. A more personal approach is required. This could be achieved with more realistic caseloads and recruitment of more staff. (Participant 19)

Culturally sensitive

A participant suggested a more culturally sensitive approach was needed. Although a national interpreting service is available, she also suggested there was a need for more interpreters. As stated earlier, this may indicate a need to further promote the Translating and Interpreting Service.

The language barrier inhibits quality of care and service provision and I think this needs to be incorporated in the clients' individual care plans and the system as a whole. More interpreters are required and need to be offered more readily. This is very hit and miss. Cultural training for case managers and personal carers is needed on a regular basis. (Participant 19)

Case managers

Participants described what makes a good case manager.

A good case manager has an understanding of disabilities – in our case dementia, specifically younger onset dementia. A case manager needs to be a good listener. They don't come in with pre-set ideas of what it is that we may want or need but ask what you want/need. They then set about making sure that this happens. (Participant 9)

Participants suggested recipients of home care packages should be given information about a case manager's role.

When you sign up with a provider, you need to be given a list of what the case manager is going to do. They need to be very clear about what the case manager does. (Participant 16)

Participants also suggested providers give them a clear explanation about the different types of case management.

The different tiers of case management need to be clearly outlined. They are currently very ambiguous. There is no clear role differentiation provided between self-managed, partnership and fully managed. The agency needs to discuss differences with their clients and provide advice about which one to choose. (Participant 19)

Some participants suggested case managers should receive specific training in consumer directed care.

They need better training of case managers so they understand customer directed care. (Participant 11)

Support workers

Recruitment and training

Participants recommended more targeted recruitment and better training of support workers.

Regular training for staff needs to be incorporated. Also more targeted recruitment is required. (Participant 19)

Although participants praised some online training courses (e.g. The University of Tasmania's Massive Open Online Course), face-to-face training was described as much better than online training.

An Indigenous elder suggested cross-cultural training.

It is important to train non-Aboriginal staff to be culturally aware. To make them find out what mission we come from, what country we come from, what tribe. So we can talk about our history. (Participant 41)

Empathy

Participants said that support workers needed to be empathetic.

Hopefully people who work in people's homes have a degree of empathy. The biggest challenge we have is most people have never known anyone with Alzheimer's. So they don't know what it's like. They don't understand how long it may take to help someone bathe and get into bed – only to have them get up again. It's not a job for young people who have had no exposure to age or illness. (Participant 7)

You have to be a kind, caring person. You can't just breeze into someone's home. (Participant 28)

Consistency

As much as possible, providers should provide the same support worker.

I need the same person so I don't have to explain everything each time. I need someone who understands what I need. (Participant 4)

Matching workers with clients

Several participants suggested in-home care would be improved if support workers were “matched” with the recipient.

I have said to them so many times: “I want you to match Mum with someone. Mum loves AFL footy, barracks for Hawthorn, loves to play cards, Scrabble and was an art teacher and artist. Surely you can do some sort of matching.”

When you're in a special group, you'd think they might consider sending us someone from our community. It was not necessary to send gay workers. But if there are members of staff who are gay, you'd think the case manager might ask us if we'd like to meet a worker who is a member of the LGBTI community. We were never asked. (Participant 9)

Information about outsourcing

Participants suggested providers should be transparent about how they source their support workers. Do they employ them? Or do they use an agency?

You need to know about support workers – do they work for the company or are they contracted from elsewhere. (Participant 16)

Mentoring system

Support workers would benefit from a mentoring system.

A new worker would benefit from going around with an experienced worker for a good deal of time. (30)

Roster

Participants wanted to know in advance who would be working in their home.

I would like to have a weekly roster. I'd like to know who is coming every day before they arrive. I'd also like regular carers. (Participant 1)

Some participants suggested local people should be responsible for preparing the weekly roster.

They needed to have local people rostering because they know the clients. Clients have to be matched with workers. (Participant 9)

Support for carers

A participant suggested full-time family carers needed additional support.

I believe that more support for full-time carers is required in order to ensure continuous and consistency of care in the home. This can be in the form of regular respite in the home, counselling, or other offers of support as the carers needs. This should be provided as additional funds and not from the current funded packages. (Participant 19)

Purchasing private services

A participant suggested families needed to be prepared to pay for private services.

This is where families really need to put their hand in their pocket. It doesn't cost an arm and a leg to pay someone to check on Mum or Dad a couple of hours three times a week. (Participant 24)

Some participants suggested all those who could afford to pay for in-home support should do so rather than depend on “welfare”. Others felt they had paid taxes all their working lives and were entitled to access a “public service”.

If I had money, I wouldn't have bothered. I'd just pay for it. But I can't afford it. (Participant 14)

Some people think people who can afford to pay for their own care should. I agree in a way. But Dad has paid his taxes all his life. (Participant 24)

I told my partner she had paid her taxes all her life and we could get some services for free. (Participant 15)

A participant predicted that future generations would not receive government support in their old age.

The younger generation with their superannuation will hopefully not be so dependent on the government's social service. My children don't anticipate they will need to use the government for support. But I didn't anticipate that I would live to my 80s. (Participant 7)

Private health insurance

Some participants suggested an older person's health insurance scheme should contribute to the costs of in-home care.

Mum's had private health insurance for years. Why aren't the private health funds covering some of this care? (Participant 25)

Peer support

A participant indicated a need for peer support. She suggested those who had cared for an elderly person in the home could be employed as peer support workers.

When an elderly person moves from a home care package to an aged care home or dies, family who have been the primary carer lose the carer's pension. People who have cared for a family member on a package could be employed as peer support for those of us who are currently in the system. (Participant 35)

Connecting care recipients

A participant suggested finding a way to connect care recipients. He suggested this might help to overcome his perception of the providers' “divide and conquer mentality”.

The providers know we're all old and isolated in our own homes to a large extent. The divide and conquer mentality. If we could all get together somehow, we may understand how we are being exploited for their profit. (Participant 5)

Respite

There is widespread acknowledgment that family and others who care for older people in the home need a break from their caring duties. However, rather than place their parent/partner in an aged care home for respite, some participants suggested it would be better to have support workers stay with the older person at home. If this was not possible (due to the expense), they suggested support workers visit their parent/partner in the aged care home. Some providers allowed this while others did not.

I'd like someone to come to our home to stay with my husband for a week. They can do it but I'd need a lot of money to be accumulated. (Participant 28)

It would be valuable if one of the care workers could visit Mum for an hour a day when she is in respite – to check on her, give her a glass of water. She always comes home dehydrated – urine very smelly or left in soiled pads. A lot of things. I've asked Provider X if we could get this as part of the package. I've asked for that and have been told they don't do that. I am not sure if it's because of insurance. I am not sure if another provider would be able to do that. It would be most valuable – it would revolutionise our lives if we knew that was something we could have. (Participant 30)

Advocacy

A participant suggested an advocacy service to help people navigate the different home care services.

An advocacy service is definitely required to assist in navigating the aged care service as well as consultation and advice – perhaps it can be incorporated in My Aged Care or as a stand-alone service... Dad's case managers didn't do that. No one phones to check in – what are your issues this week/month? What do you think needs improvement? No one does that. (Participant 19)

Conclusion

The Commonwealth Home Support Programme and home care packages have been designed to help older Australians remain in their own homes for as long as they can and wish to do so. These programs delay the need for older people to move into an aged care home.

As part of the 2017-18 Federal Budget, the Federal Government committed to extend funding arrangements for the Commonwealth Home Support Programme to 30 June 2020. After that, who knows? Given such uncertainty, the conclusion focuses solely on home care packages.

The analysis of the data identified factors that are important to older people. These factors include:

- Access to a competently staffed My Aged Care information line/web page to provide accurate and consistent information and advice;
- A clear explanation of providers' services including their fees;
- Publication of providers' fees and charges on the My Aged Care website;
- Clear information about entitlements and reimbursements;
- Information on sub-contracted services, including rates and any additional charges;
- A home care agreement that is easy to understand;
- Reasonable fees for case management and administration;
- Reasonable charges for support workers;
- Support workers who are paid the award rate or above;
- Reasonable costs for equipment and home modifications;
- Reasonable charges for gardeners and other maintenance personnel;
- Clear financial statements that accurately reflect the services provided;
- Person-centred care delivered by a local provider;

- Support workers who are suitably trained², competent, trustworthy, punctual and empathetic;
- Knowledge about the qualifications and experience of staff;
- An option to choose support workers;
- Consistent support workers who work at regular and set times (e.g. 9am rather than sometime between 9am and 11am);
- Flexibility with times and changing needs;
- Access to service provision "on the spot" (i.e. same day) when a situation changes (e.g. transport to a doctor's appointment);
- Sufficient time allocated for support workers to undertake tasks required;
- Direct communication permitted between recipient and support workers for easier co-ordination;
- A weekly roster of support workers supplied in advance;
- Case managers who are experienced, qualified and easy to contact;
- Consistent use of mutually agreed means of communication with case managers (e.g. emails, messages, home phone or mobile);
- Information about how many older people case managers are overseeing;
- Forward-thinking case managers who seek to improve care and offer suggestions if new services become available;
- Regular mandatory visits by case managers to include health/welfare checks, face-to-face conversations and updates with the older person.
- Better-trained office staff (e.g. how to talk respectfully to older people, including older people with dementia);

2 Some suggested a mandated level of training be introduced for all support workers. Others suggested support workers without formal qualifications were sometimes better than qualified support workers.

- Options for different degrees of case management support/self-management;
- Involvement of family/advocates when issues arise;
- Ongoing professional development, including dementia training, for all staff;
- Access to affordable social activities inside and outside the home;
- Provision of information from case managers on other community resources (e.g. local services, volunteer groups etc.)
- Feedback from older people and their family/advocates welcomed by providers; and
- An effective complaints process.

On 30 June 2018, there were 869 approved home care providers. In this research, only 36 of these providers are represented. Fifteen were described as a “*good provider*”. A “*good provider*” delivered a high quality service and charged reasonable fees and fair hourly rates for support workers.

Findings from this study suggest that some providers need to be more transparent and accountable. Providers also require regular financial audits. In this study, there were large differences among providers in both case management and administration fees and also hourly rates for support workers. How can these differences be justified? Some suggest it is a result of the market-based system that has been established explicitly to create competition, innovation and choice for the ‘consumer’.

Questions must also be asked about unspent funds. How many older people are not spending their allocated home care package due to the poor quality of the services being provided? Or are they saving funds for a significant purchase (e.g. home modification).

Although an application to be a home care provider is submitted to the Commonwealth Department of Health to review suitability as per the criteria stipulated in the *Aged Care Act 1997*, participants described companies with limited or no expertise in the delivery of aged care services being given licences (e.g. insurance companies). It is not surprising that a company that specialises in insurance would deliver unsatisfactory aged care service. It is, however, surprising how many large established aged care providers were criticised for delivering an

unsatisfactory service. The most common complaints were an insufficient number of staff and unqualified, inexperienced and untrained support workers.

Finally, participants described the negative impact of the policy of full cost recovery. In some cases, it prevented older people on higher-level home care packages from enjoying an active social life in their communities. Social isolation among older people is emerging as one of the major issues facing the industrialised world because of the adverse impact it can have on health and wellbeing (Cotterell et al., 2018; Landeiro et al., 2017; Commissioner for Senior Victorians, 2016; Aged and Community Services Australia, 2015; Pate, 2014).

When an older person transitions from the Commonwealth Home Support Programme and/or lower level home care package to a higher-level home care package, the cost of a bus trip or participation in an activity such as the Men’s Shed significantly increases. This limits an older person’s participation in local activities.

Participants also described the policy of full cost recovery as having a negative impact on people with chronic clinical needs who require daily nursing and/or allied health care. They are currently advised not to accept high-level packages due to the increased cost of delivering these health services.

Participants had high expectations for the services that would be provided by a home care package. Many participants described being disappointed. Those with the best outcomes had family and community support. Without this additional support, they acknowledged they would not have been able to remain at home.

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Appendix 1: Invitation letter

Date

Name

Address

Dear [Name]

I am writing to invite you to take part in a research project called “Consumer views of aged care in-home support services”. Your contact details were obtained from Community Health at Peninsula Health.

You have been invited because you receive a Home Care Package. Dr Sarah Russell (Research Fellow, Peninsula Health) would like to hear what's good about the Home Care Package you receive and what you think would make it better. We are inviting you on Sarah's behalf.

The Participant Information Sheet enclosed tells you about the research project. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. You may want to talk about it with a relative, friend or local health worker before deciding whether to take part. All information will be confidential. Sarah will have no access to your personal files.

Please contact Sarah if you have questions or want more information. Sarah's phone number is 9489 5604 or mobile 0435 268 357. My email is sarahrussell@comcen.com.au

Yours sincerely,

Iain Edwards
Community Health

Appendix 2: Flyer



Would you like to participate in a research project?

Do you receive in-home care?

My name is Dr Sarah Russell. I am the Principal Researcher at Research Matters and a Research Fellow at Peninsula Health.

I would like to talk with people who have been approved for a Home Care Package, irrespective of whether this package has been assigned.

- * Are you getting the support you need?
- * Do you have suggestions to improve the program?

I would like to come to your home to talk with you in person, or talk with you on the phone. Our conversation will take about 30-45 minutes. You are welcome to have a family member or friend with you.

If you would like to take part in this useful project please contact me before 30 October 2018 so I can send you further information.

My phone number is 03 9489 5604 or mobile 0435 268 357.
My email is sarahrussell@comcen.com.au

Your name will be kept confidential and no identifying information about you will be used.

The Commonwealth Department of Health has funded this project. The ethical aspects of this research project have been approved by Peninsula Health's Human Research Ethics Committee.

T: 03 9489 5604 (B) or 0435 268 357 (M)
E: sarahrussell@comcen.com.au
www.research-matters.com.au
www.agedcarematters.net.au

Appendix 3: Participant Information Sheet / Consent Form



Participant Information Sheet/Consent Form

Title	Consumer views of aged care in-home support services
Principal Investigator	Dr Sarah Russell
Associate Investigator(s)	Professor Velandai Srikanth, Dr Kristy Siostrom, Mr Iain Edwards

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called Consumer views of aged care in-home support services. You have been invited because you have been approved for a Home Care Package. Your contact details were obtained Community Health at Peninsula Health.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The aim of the study is to investigate firsthand experiences of in-home care for older people who have a Home Care Package or use Commonwealth Home Support Program. We want to know what is working well, and what is not working well. We also want to hear your suggestions about how home care services can be improved. This information will help Home Care Packages and Commonwealth Home Support Program to better meet people's needs.

3 What does participation in this research involve?

If you decide to take part in our study, you will be asked to participate in a face-to-face interview in your own home. The interview will last about 30-45 minutes. The interview will take place at a time that suits you.



During this interview, you will be asked to talk about your experiences of home care. With your consent, the interview will be tape-recorded so that we can ensure what you say is recorded accurately.

You will be asked to reflect on both positive and negative aspects of home care. What do you like about home care? What don't you like? How could things be done better?

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way. There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

There will be 40 people participating in this study.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Peninsula Health.

6 What are the possible benefits of taking part?

We cannot guarantee that you will personally benefit from this research; however, a potential benefit is you will be contributing to research that may help to improve the future delivery of Home Care Packages and Commonwealth Home Support Program.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the principal researcher becoming unwell.



10 What happens when the research project ends?

A copy of the final report will be mailed to you in January 2019.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collect and use will be the transcript from the recorded interview.

Any information obtained in connection with this research project that can identify you will remain confidential and be securely stored. Your contact details will only be kept with your permission so we can send you a copy of the final report about the project.

Your information will only be used for the purpose of this research project. The data you provide will be permanently de-identified; this means that it will not be possible for the researcher to match recorded interviews to particular individuals.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, you will be referred to by a pseudonym.

In accordance with relevant Australian and/or Victorian State privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact: Ms Lee-Anne Clavarino from the Research Office at Peninsula Health. Ms Clavarino's contact details are: Phone 9784 2679 or Email: LClavarino@phcn.vic.gov.au

13 Who is organising and funding the research?

This project has been funded by a grant from the Commonwealth Department of Health. The researcher is independent. She has no affiliation with the government or any provider of home care services.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Peninsula Health.



This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

If you would like further information, please do not hesitate to contact Dr Russell by phone or email.

Research contact person

Name	Dr Sarah Russell
Position	Principal Researcher
Telephone	9489 5604 or 0435 268 357
Email	sarahrussell@comcen.com.au

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Peninsula Health
HREC Executive Officer	[Name]
Telephone	[HREC Executive Officer Phone number]
Email	[HREC Executive Officer Email address]

Local HREC Office contact

Name	Ms Lee-Anne Clavarino
Position	Manager, Office of Research
Telephone	9784 2679
Email	LClavarino@phcn.vic.gov.au

Appendix 4: Interview Schedule

1. What made you realise you needed support in the home?
 - Did someone suggest you may be eligible (e.g. family, friends, GP or other health care professional?)
2. Tell me how you went about getting the services you needed?
 - Did you do it yourself? Did others help you (e.g. family, friends, GP or other health care professional?)
 - Tell me about your experiences with myagedcare?
 - Information
 - How did you get? (e.g. phone, internet)
 - Was it helpful?)
 - Screening questions (e.g. relevant?)
3. Tell me about your assessment
 - What prompted you to have an assessment? Who instigated it?
 - Did you have services in mind?
 - Did you want a HCP or CHSP?
 - How long did you have to wait for the assessment?
 - Were questions asked during the assessment
 - Relevant to you and your situation?
 - Repetitive (e.g. did you have to re-tell the story you told at screening)?
4. Do you have any comments about the approval letter? (e.g. Did you understand what you were required to do?)
5. Tell me about your experiences whilst you waited to receive your package?
 - What is your understanding of the queue? How long have you been on it?
 - Did you need support during this period? Who provided the support you needed?
 - What services did you receive while you were waiting for your package?
 - Did you receive a lower level package/CSHP?
6. What type of services are you receiving while you wait for your package?

Question 7 only for those who are using CHSP (while waiting for HCP)

7. Tell me about your experiences of CHSP.
 - Are you receiving the help you need?
 - Do these services meet your needs?

(Question 8 only for those who have transitioned from CHSP to HCPs)

8. What was it like to move from CHSP to HCP?
 - Tell me about the transition?
 - What differences have you noticed between the 2 different programs

9. How did you go about identifying and choosing your provider?

- What support did you receive from family or others to choose a provider?
- Was information you needed to easily available?
 - Overwhelmed by choice? Feel pressured by any service provider?
- Were the costs explained to you?
 - Did you understand how much you would be required to contribute to your services?
 - Did you ask how much your service provider would access from your package?

10. Tell me about your experiences with your chosen provider.

- Your views about your Home Care Agreement
 - Do you understand what the provider is contracted to do?
- Your understanding of the monthly statement/fees.
 - Was the statement explained to you?
- Communication with provider (e.g. understanding what you're entitled to, what you need to do?)
- Tell me about your relationship with your case manager
 - Continuity?
 - Do you feel you can contact them if something is going wrong?
 - How do you contact them? (phone, email?)
 - Answer their phone?
 - Is the response timely?
 - How often does the case manager visit your home?
 - How did you go about choosing and planning actual services with your case manager?
 - Are the services meeting your needs?
 - Did you feel that you had a say in how the funds in your package were directed?
 - Did you have enough money in your package to get everything you need?
 - Are there any services that you need but can't afford?

Question 10 only for CALD participants

11. How did you go about finding a case manager that spoke your language and understood your cultural needs?

For those who did not find a case manager that spoke their language

- Do you have difficulty communicating with your provider and case manager?

12. Tell me about staff who come to your home:

- How did you choose them?
- Same people?
- Skills/qualifications/experience/competency?

- Do you make decisions about:
 - Time the staff come?
 - How long they stay with you?
 - What staff do when they are in your home?
 - Flexibility (can you change arrangements according to your needs?)
 - Are staff reliable (arrive on time? Inform you if late/sick?)
- Tell me how staff show their respect towards your particular needs/circumstances.
 - Do you feel staff listen to your needs?

13. How has your quality of life changed since commencing your HCP?

- Confidence living at home
- Relationships with family and friends

Question 13 and 14 only for those who are dissatisfied with provider

14. Do you intend to change providers?

- What is the process for changing your providers

Question 14 only for those who changed providers

15. Tell me about the process of changing providers

- How did it go? (i.e. was it straightforward or complex)
- Did you understand the exit fees?

16. What is the best thing about the HCP?

- What are your suggestions for how HCP could be improved?

Example 3:

Participant 22 receives a Level 2 home care package. Provider Y takes 35 per cent of a Level 2 home care package in case management and administration fees.

from 01-August-2018 to 31-August-2018			
		Debit	Credit
Opening Balance at 1/08/2018			\$2,328.92
Income			
Subsidy - Government Subsidy			\$1,277.82
Total Income			\$1,277.82
Expenditure			
Administration costs			
Administration costs - Administration Fee		\$191.58	
Core advisory & case management services			
Core advisory & case management services - Case Management Fee		\$255.44	
Service and Support	Total Hours/Quantity		
Visit: Transport	5.00	\$240.00	
Total Expenditure		\$687.02	
Closing Balance at 31/08/2018			\$2,919.72

Example 4:

Participant 13 receives a Level 2 home care package. A personal support worker helps her to shower 3 mornings a week and once a fortnight the support worker also cleans. Provider G takes 41 per cent of her Level 2 home care package in case management and administration fees.

Monthly funds for my care			
Government Funding		\$1,277.82	
Customer Contribution		\$53.13	
Total Funds available this month			\$1,330.95
Fixed Costs			
Administration Fee		\$250.00	
Core Advisory Fee		\$270.00	
Total Fixed Costs			-\$520.00
Services			
Cleaning 60 minutes	(7.5 hours)	\$382.50	
Personal Care	(9 hours)	\$459.00	
Personal Care 30 minutes	(4 hours)	\$324.00	
Miscellaneous - Mop & Bucket		\$79.16	
Total Services			-\$1,244.66

Example 5: Provider A's hourly rates.

Duration Time/Day	Home Care Services									
	Low Needs Care Support with housework, companionship		Standard Care		Complex Care Support from higher skilled staff		Nursing Services Enrolled Nurse (EN) and Registered Nurse (RN)			
	30 mins	Hourly	30 mins	Hourly	30 mins	Hourly	EN 30 mins	EN Hourly	RN 30 mins	RN Hourly
Weekday	\$37.20	\$57.20	\$39.20	\$60.30	\$39.90	\$61.40	\$49.70	\$76.50	\$70.70	\$108.70
Weeknight	\$41.10	\$63.20	\$43.20	\$66.50	\$44.00	\$67.70	\$54.90	\$84.40	\$78.00	\$120.00
Saturday	\$43.40	\$66.80	\$45.70	\$70.30	\$46.60	\$71.60	\$58.00	\$89.30	\$82.50	\$126.90
Sunday	\$55.40	\$85.30	\$58.40	\$89.80	\$59.50	\$91.40	\$74.10	\$114.00	\$105.30	\$162.00
Public Holiday	\$82.50	\$126.90	\$86.90	\$133.60	\$88.50	\$136.10	\$110.30	\$169.70	\$156.80	\$241.20


Example 6: Provider KK charged \$607.56 in case management and administration fees (51.6 percent of a Level 2 package) to supply an outing valued at \$130.22.

General Funds	
Balance carried forward from previous month	\$0.00
Package Income	
Government Funding	\$1,177.83
Client Contribution	\$219.34
Total Income	\$1,397.17
Package Expenditure	
Administration Fee	\$258.75
Case Management	\$348.81
Service and Support Provision	\$130.22
Total Expenditure	\$737.78
Balance carried forward to next month	\$659.39
Pending Charges	\$0.00
Net Available Balance	\$659.39
Net Available Balance is estimated taking into account pending charges.	

Appendix 6: My Aged Care Service Finder

Appendix 6: My Aged Care Service Finder


At the time of publication (March 2019), Provider B had not published its fees on the My Aged Care website.

 There are no notices of non-compliance or sanctions for this service

Overview

Services

Costs

Average percentage of package available
for services 

Maximum exit amount  \$500

Provider pricing 

Provider website

Average surcharge for evenings

Average surcharge for weekends

Average surcharge for public holidays

Average surcharge for 24/7 care (incl.
overnight stays)

Older People Living Well with In-Home Support



Sarah Russell
March 2019

Appendix 3

1. What is your role?

- ☐ Manager
- ☐ Registered Nurse
- ☐ Enrolled Nurse
- ☐ Personal Care Attendant/Assistant in Nursing
- ☐ Leisure Activities Staff
- ☐ Receptionist
- ☐ Food services
- ☐ Cleaning
- ☐ Laundry
- ☐ Maintenance
- ☐ Other (please specify)

2. What do you like about your work in an aged care home?

3. What don't you like about your work in an aged care home?

4. If you could change 3 things to improve residents' quality of life in an aged care home, what would you change?

5. What type of aged care home do you work in?

- ☐ Not-for-profit
- ☐ For-profit
- ☐ Government owned
- ☐ Don't know
- ☐ Other (please specify)

6. What is your first language?

- ☐ English
- ☐ Other (please specify)

7. How many hours a fortnight do you work?

8. How many residents live in the aged care home where you currently work?

9. Is the Manager a registered nurse?

- ☐ Yes
- ☐ No
- ☐ Don't know

10. Does the aged care home employ a clinical care manager?

- ☐ Yes
- ☐ No
- ☐ Don't know

11. Does the aged care home where you work have a registered nurse on site each shift?

- ☐ Yes
- ☐ No

12. Not including manager and clinical care manager, how many registered nurses work on the following shifts:

Morning

Afternoon

Night

13. Would you recommend this aged care home to your parents?

Definitely yes

Probably yes

Maybe

Probably no

Definitely no

☐☐☐☐☐

14. Are there any additional comments that you would like to make?

Thank you for taking the time to share your ideas. The findings will be published on Aged Care Matter's web page.

www.agedcarematters.net.au

An aged care facility in crisis

Consumer action
to improve
standards of care



Sarah Russell

An aged care facility in crisis: Consumer action to improve standards of care

Research report

September 2012

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I am grateful to the residents, relatives and staff of the aged care facility who spoke openly about their experiences. I am also grateful to the owner of the aged care facility for taking these grievances seriously and responding appropriately. Thanks to Simon Kneebone for illustrating the 'tidal wave' of older people who will soon be entering the aged care sector."



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Introduction

Relatives of residents at a private Aged Care Facility (ACF)¹ in Melbourne, Australia met twice in August 2012. The aim of these meetings was to discuss their concerns about the poor quality of care at the facility caring for their mother and/or father. During these meetings, allegations of poor management, theft, negligence, incompetence, illicit drugs, bullying, racial vilification, and damage to property were made. All grievances were reported to the owner of the ACF, and the more serious grievances were also reported to the Australian Government Department of Health and Ageing's Aged Care Complaints Scheme and Elders' Rights Victoria.

This report describes the relatives' grievances, and provides evidence of poor care, including breaches of current legislation in relation to treatment of both residents and staff. The report also includes numerous examples of poor care.

In addition to their grievances, relatives made suggestions to the owner about how standards of care 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 report concludes with the outcomes that were achieved by this 'consumer action'.

ACF had once been a well managed aged care facility, with extremely high standards of care provided for residents. However, a recent lack of leadership and poor teamwork had created low morale among staff - and this low morale had a negative impact on the general standards of care. In addition, there were also many systemic issues that impacted on the quality of care. Relatives believed that ACF's policies and procedures needed to be reviewed.

Despite relative's concerns about the current standards of care, ACF has many wonderful and dedicated nurses, carers, kitchen staff, reception staff and activities staff. With good leadership, ACF could once again be one of the best aged care facilities in Melbourne.

¹ The Aged Care Facility is not named. It is referred to as ACF.

Background

The resident's handbook states that the facility aims "to promote, foster and maintain the highest possible level of care, service and accommodation. Our staff are trained to demonstrate the philosophy in their dealings with each resident and their relatives, representatives and visitors". It also states that the vision of the facility is "to be one of the highest quality with innovative services that are responsive to the changing requirements of residents and their families ". Specifically, the aims are to:

- Provide the highest standard of residential care and services in a manner that serves the best interest of the residents
- Uphold privacy and dignity of the individual
- Conduct affairs with integrity and honesty, rendering services on a high ethical level
- Provide an appropriate level of care to residents on the basis of need regardless of gender, race, nationality, religion or belief
- Treat residents with respect, dignity, confidentiality, warmth and friendship"

Some of the objectives listed in the handbook are:

- Foster a safe and pleasant work environment for staff, promote and support ongoing education
- Ensure living conditions and surroundings are pleasant, comfortable and safe, allowing residents a feeling of homeliness and security with maximum independence
- Encouraging involvement of residents, their relatives, friends and staff in the management of the facility.

Relatives believe that ACF is currently failing to meet its aims and objectives, as outlined in the Residents' Handbook
--

Method

Ethics

All participants (relatives, staff and residents) gave written consent for their stories to be included in this Research Report.

In the interests of confidentiality, people who have shared information have been identified by number rather than by name (e.g. Relative 4, Carer 2). In addition, staff named in an alleged incident have been identified by role (e.g. RN, carer) and number. The names of all residents have been removed. The name of the aged care facility has also been changed to a generic Aged Care Facility (ACF).

Recruitment

Relatives who attended the meetings, or were an apology for the meetings, were asked to contribute examples of poor care at the facility. Some staff and residents also volunteered examples of poor work practices.

Sample

30 relatives, 9 residents and 10 staff, including 3 staff members who no longer work at ACF, participated in this study.

Data collection

On Tuesday 31st July 2012, six relatives met to discuss issues of care at ACF. Notes were taken at this meeting. These relatives were concerned about the safety of their mother/father.

After the initial meeting, 15 relatives met on August 6th 2012 to discuss their grievances and to suggest a 'way forward'. Notes were also taken at this meeting.

On 9th August 2012, a list of grievances were given to the owner of the facility (Appendix 1).

Since 9th August 2012, relatives, staff and residents have continued to share incidents with researcher either verbally or by email. These incidents support allegations of poor standards of care, and in some cases, negligence and abuse. Several of the more serious allegations have been reported to the Department of Health and Ageing. In addition, numerous incidents have been reported to both the facility (via continuous improvement forms) and/or emailed to the owner of the facility.

Data analysis

The data was analysed using thematic analysis. This method of analysis is a qualitative research method that is used to generate common themes. The data were organised into a system of categories.

Strengths and limitations of the research

A limitation of the study is that participants volunteered themselves for the research. Self-selected samples may be biased toward people with strong opinions, either positive or negative. Another limitation of the study is that participants were specifically asked to provide examples of poor care. Although there are undoubtedly many examples of good care at this facility, data describing examples of good care were not collected as part of this research project.

Findings

Relatives, residents and staff have made these allegations of:

- Negligence
- Incompetence
- Staff not telling the truth
- Theft
- Drug taking
- Bullying
- Racial vilification
- Damage to property

1. Medical Negligence

1.1 Competency of staff

- Some staff demonstrate a lack of responsibility and accountability
- Some staff do not know procedures, and have therefore not carried them out
- Medical issues are not noticed by some staff
- Many carers have insufficient training (sometimes as little as a 3 week course) to work competently with older people with health issues such as dementia and incontinence
- RN 2 is incompetent (many examples of her incompetency are provided throughout report)

Examples:

On 3rd August, my niece found Dad in bed at 11.45am saying he was feeling unwell. His breakfast, and morning tea were on his table untouched - no-one seemed aware or concerned. A nurse was called who took Dad's blood pressure which was recorded as 199/92. I don't understand the figures but believe this is high. Upon my arrival approximately 15 mins later, I requested Dad's blood pressure be retested. The second reading was a lot lower. The nurse commented that the equipment was known to be faulty. Why was faulty equipment being used? How was she to know whether the reading was/was not accurate and/or if it was an indicator that something serious may be in the offing (e.g. a forerunner to a stroke). The nurse seemed completely unconcerned/unaware about Dad's complaint that i) he was feeling unwell, ii) that he was in bed and it was almost noon, iii) had eaten neither breakfast nor morning tea and iv) the high blood pressure reading. No effort was made to take a second reading with a machine in working order. (Relative 5)

[RN 2] described my mother's prolapsed uterus as haemorrhoids...I can diagnose my mother better than the nurses. (Relative 6)

[RN 2] phoned me to inform me that my mother had had a stroke and needed to go to hospital. I came immediately to ACF and assessed mum had not had a stroke but a reaction to new medication that had been administered earlier by [RN 2]. (Relative 7)

My mother had a small ulcer on her heel. Despite requests that mum wears slippers (i.e. not shoes) until the ulcer healed, carers continued to put shoes on mum. The ulcer deteriorated to the extent that the tendon was visible and mum needed to be taken to a vascular surgeon...Mum now has a daily dressing to the ulcer. Due to skin irritation around the ulcer, the dressing should be secured with a crepe bandage, not sticky tape. On numerous occasions, I have found the dressing is secured with sticky tape. On numerous occasions, I ask for a dressing pack to do the dressing myself (Relative 7)

I repeatedly asked carers not to place mum near front door – it unsettles her and makes her want to leave the facility. I frequently find her sitting in chair by fireplace facing front door. (Relative 8)

Private carer found mum lying on toilet floor. No one had responded to the buzzer (Relative 8)

My mother became hospitalized last Monday (6 August). When I saw my mother on Monday morning, she was asleep. I returned around 6 pm just as my mother's GP telephoned me to express her concerns about my mother's medical condition as she was extremely dehydrated. The GP was of the opinion that the dehydration should have been obvious to ACF nursing staff and it should have been addressed but as it was not. The GP's strong advice was that my mother should be hospitalized and stabilized. My mother was transported to a hospital by an ambulance. It is interesting to note that during my mother's absence from ACF, a total of 11 days, I did not receive a single telephone call from anyone at ACF to enquire about my mothers progress and well being. (Relative 12)

Suggestions:

1. Staff receive regular professional development
2. Only RNs who have completed a graduate year to be employed at ACF.

1.2 Medication errors

Many relatives have reported incidents in which a medication error occurred. Types of errors include:

- Resident with dementia not being supervised to take medication – untaken medication found in these residents' rooms
- A discrepancy between medication in webster pack and what is recorded on medication chart
- Resident given another resident's medication
- Resident given the wrong medication

Examples:

On multiple occasions, my father's tablets are not administered and I have found tablets in my father's room. I have brought these to the attention of staff and on one occasion enclosed the tablets in a complaint form (being unable to find staff), and placed it in the complaint box with my details and date and requested an explanation - no response was received...The lack of proper administration of the medication could lead to serious medical consequences for the person not receiving it; another resident could potentially ingest it (particularly as many residents suffer from dementia); or even a visiting child swallow it. (Relative 5)

[RN 2] gave my mother medication that had been ceased. This was due to poor communication between GP, pharmacy and ACF. I documented the incident in a letter to ACF. I copied the letter to her GP who apologised for his error. (Relative 7)

RN 2 gave me the wrong cardiac drug this morning. My ankles have swollen up like balloons. (Resident 1)

There have been a number of incidents where my mother (who has dementia) was put in charge of the administration of her medication resulting in her not taking the medications at all. On another occasion it was discovered that a medical patch that she is to receive daily was not applied resulting in serious physical discomfort being experienced and a locum was called to attend mother. By chance my mother's GP turned up unexpectedly and when she learned of my mothers discomfort, proceeded to examine her to find that the cause of my mothers condition was that the patch was not administered. This incident was discussed with Manager as well as [RN 3]. (Relative 12)

2. Health and Safety of residents

2.1 Response to buzzers

It often takes a long time for carers/nurses to respond to a resident's buzzer.

Example:

At 3.15 on 3rd August, I arrived to find my Dad at the reception desk (he had come down from his room) looking very distressed because he had been trying to buzz a carer for ages, not sure how long, and no-one was coming. The receptionist came over to try to help and said sorry but it's handover time and carers are busy with that. My Mum had been unwell and didn't go down to lunch, but after a sleep wanted to get up and get dressed. Dad needed help to do that and she was giving him a hard time about helping her. He's 97 and can't help her. I calmed him down and went to their room to find my Mum sitting on the ottoman in her undies and bra waiting for someone to come. I dressed her myself and at about 3.30 a carer came to answer the call. Does this mean no carers are available at handover time? (Relative 3)

Suggestions:

Management should:

- Determine a reasonable time to expect a nurse/carers to respond to an emergency call.
- Develop a policy to ensure that staff respond to buzzers within these times.
- Inform residents and relatives about how long they may be expected to wait until they receive a response after pressing the buzzer.

2.2 Condition of rooms

Residents' bedrooms are often not cleaned adequately. Evidence of this includes debris on floor, and bins not emptied regularly. The downstairs toilet is sometimes putrid (with bin overflowing with used paper towels).

Examples:

Recently, there were no bath towels in mum's bathroom – mum had to use paper towels to dry her hands. After several nights with no towels, I told the receptionist – and since then, there have been towels. (Relative 7)

Bathroom with urine stains on floor and walls, faeces/blood on towels, mould in grout. Very strong urine smell in bathroom, indicating it had not been cleaned for some time. Urine on floors would be carried through facility on the bottom of shoes. Carpet in rooms dirty. (Relative 5)

My mother often removes her wound dressing overnight. The soiled dressing often remains on the floor for several days (unless I pick it up and place in bin). (Resident 7)

On occasion, no soap in the bathroom when I have gone to shower Dad. (Resident 5)

The room needs more thorough cleaning. It is only cleaned superficially. (Relative 1)



Picture: Photo of residents' toilet on ground floor on Saturday 18th August 2012

Suggestions:

All rooms should be cleaned regularly and properly.

2.3 Phone contact after hours

The phone is answered promptly on weekdays between 9am-5pm, and the receptionist is courteous and extremely helpful. However, after hours, the phone is often not answered.

Examples:

It is almost impossible to make contact with staff members on duty during the evening shift. There have been numerous occasions when I telephoned the facility and waited for someone to respond with the phone disconnecting automatically after ringing continually for up to 10 minutes when I would dial again and again repeatedly for up to 50 minutes with no success. On one occasion I wanted to alert a staff member of my mother telling me over the phone that she was not feeling well. On another occasion I was returning with my mother from a hospital to facility and I telephoned to alert the staff of our return and that the entrance door should be unlocked. Unfortunately, again the telephone was not responded to. (Resident 12)

I rang ACF on at 10am on Saturday 18th August and asked to speak with [resident's name removed]. RN 2 said that I could not talk with mum. She told me that care coordinator had told RN 2 that residents must have their own mobile phones. I told her that we have tried mum with a mobile phone but that Mum could not remember how to use a mobile. Mum likes to speak with a member of her family every day - and I cannot drive over to ACF every day. Two of her sons are not living in Melbourne – one in Wodonga and one in Cortona, Italy. They like to phone mum regularly...I appreciate that RNs need to keep the phone line free for incoming calls. However, it seems unrealistic to expect someone who is 88 and with a degree of dementia to learn how to use a mobile phone. I felt that this decision demonstrated an uncaring approach to the care of those older people who do not know how to use a mobile phone and, due to their dementia, cannot learn a new skill. I later learnt that RN 2 had lied about the care coordinator telling staff that residents must have mobile phones. I cannot understand why RN 2 persists in telling relatives lies². (Relative 7)

Suggestion:

1. A policy to ensure phone is answered out of hours. In those instances when it is not possible to answer phone (because nurses/carers are busy), an answering machine is used to record messages. The answering machine must then be checked regularly.

² Other examples of RN 2 giving relatives information that is not true are provided in Section 5.8

2. ACF has a dedicated phone line for relatives to call residents, and an operational cordless phone so the phone can be taken to the resident when a relative phones to speak with the resident.

2.4 Occupational health and safety issues

A relative noticed an overflowing rubbish bin of clinical waste in the basement car park.



Picture taken on Saturday 19th August 2012

3. Elder neglect and abuse

3.1 Behaviour of staff towards residents

There have been several incidents in which relatives have witnessed staff speaking rudely to residents, or in an abrupt manner. There are also examples of residents being treated roughly, and examples of staff ignoring residents' requests for assistance.

Examples:

I heard dismissive, discourteous conduct directed at residents not only by carers but also by one senior nurse as well. (Relative 12)

Several residents, including my mum, refuse to receive personal care from [Carer 1]. Mum tells me she has seen him be very rough with residents – She told me that she has seen [Carer 1] pick a resident up and carry her. (Relative 7)

When I was leaving one night, I heard [Carer 3] shout at a resident after the resident asked to be taken to bed. [Carer 3] told resident that it was time for her meal break. (Relative 7)

I told [RN 2] that [resident's name removed] was short of breath and wanted to see a doctor. [RN 2] replied: "[resident's name removed] is always asking to see a doctor". [RN 2] said that she was too busy to come to [resident's name removed] room to assess her breathlessness. (Relative 7)

On Sunday, 15th July, my mother asked the PCA not to be so rough when doing up the buttons on her blouse. [Carer 4] response was that mum was fussy and different and that no-one liked her. When my sister arrived later [Carer 2] and [Carer 4] ran up to her stating that mum was confused and thought that no-one liked her and that it is not true. (Relative 3)

My mother stated that when assisted in the shower and she complained that the soap was in her eyes the PCA took hold of the shower head and sprayed down mum's face. She has commented that the PCA's can be rough and in a hurry, even showering her in cold water. (Relative 3)

I telephoned my mother one morning and found her extremely agitated as a result of a staff member being pushy, impatient and highly disrespectful with her. In the course of my mother talking to me she used the expression "socking" repeatedly, in reference to the conduct of the carer (this being in a foreign English accent) who started imitating my mother by saying "socking" which I overheard. I asked my mother to hand the telephone receiver to the carer concerned, I established her identity and requested the carer to leave my mother's unit and said that I will deal with the situation personally. I promptly drove to ACF and requested the offending carer to join me in my mothers unit and suggested to her that if she finds my mother unhelpful or uncooperative, instead of being pushy, which generates the wrong reaction and upsets her (as well as the Staff)the carer should telephone me, as I am contactable 24/7 and I will resolve whatever the problem. I suggested that maybe mimicking a 93 years old Alzheimer resident is disrespectful, unacceptable and in my opinion shameful and indicates a fundamental ignorance of how to deal with a vulnerable elderly person with dementia. This incident took place on a weekend, consequently I was only able to alert Manager of what happened on Monday. Manager agreed with me that the behavior of the staff member was unacceptable and responded by saying that she was about to step into a staff meeting and that she would endorse my comments to the carer concerned. (Relative 12)

I have had a number of telephone calls from my mother from time to time, being upset at the manner she was spoken to usually by young and on many occasions, recently employed carers. If it was suggested that due to her diagnosed medical condition her information might be regarded as unreliable. It is an interesting fact and a manifestation of her medical condition that when she becomes angry, she is lucid and becomes able to relate accurately what has taken place. (Relative 12)

Suggestion:

Relatives should document incidents when they witness staff talking rudely to residents. Any incidents of bullying and abuse of a resident should be reported to the aged care complaints scheme.

3.2 Theft

There have been many incidents of residents' missing money and valuables, though many of these incidents have not been reported to either the police or ACF. Residents are often unsure about whether or not they have misplaced the money (or valuable item). There are also incidents of missing chocolate and sweets (that carers insist that the resident has eaten). There are also reports of carers behaving suspiciously.

Examples:

Money (\$50 note) stolen from mum's purse between 1pm Tuesday 22 May and 9am Wednesday the next day when she went to the hairdresser. An incident report was filled out so the management would be aware that there is a problem. (Relative 3)

Named Hip Protectors ordered from Western Australia disappeared between bedtime and shower. Critical for her safety. After 4 days of questioning by me, Manager produced another pair ordered for another resident... 3 pairs of prescription stockings disappeared... New clothing hung in wardrobe on a Sunday night in June. Missing by Monday. CCC and Laundry alerted. Search conducted for a week. Made it clear that I was calling police and clothes reappeared in her room. (Relative 8)

On 17th November 2011, my grandson accompanied me to the ATM at the Commonwealth bank to withdraw \$700 to cover my Xmas shopping for my family. My grandson used the ATM while I stayed in the car. My grandson came back to the car and counted the money in front of me. I gave him \$50 and he handed me the remaining \$650 which I immediately placed in my handbag. My grandson then drove me back to ACF, and he accompanied me to my room. On entering the room, I noticed that the room had been cleaned and the large cushions on the couch were not in place. I was very tired and I may have placed the handbag on the couch, but I doubt it – my normal routine is to place my handbag in my wardrobe. The next day, when I looked in my handbag the money was not there though the receipt for the withdrawal was in my handbag. I told my children and they were shocked. My son, daughter and I searched my room (including under cushions on couch). They questioned whether I had locked my door, but I could not remember. I was very embarrassed because I thought I may have misplaced it so I did not make a formal complaint at the time to ACF but senior nursing staff were

notified. My family did not contact the police. I am drawing management's attention to the missing \$650 now because I have been told there have been other thefts at ACF. (Resident 1)³

One evening recently, I was not feeling well – so I did not go downstairs to the dining room for my dinner. I stayed resting in my bedroom and then went into the bathroom to freshen up. I heard a cuffuffle in my lounge room and wondered what was going on. The next moment I saw a long male arm around the bathroom door. I was frightened because I did not expect anyone to be in my room. It was Carer 1. I said to Carer 1: "What is the trouble?". He told me that he was looking for [residents name removed] – he thought she may have come into my room. However, it was dinner time – and later I thought: "Wouldn't [residents name removed] be in the dining room?". It all seemed very suspicious. (Resident 1)

My wife used to always wear her wedding ring, and also a bracelet and necklace. All solid gold. They were stolen. (Resident 2)

A small issue, but never the less indicative of poor management - A private carer who visits my mother every Saturday told me that on Sat Aug 11th when they were giving out afternoon tea, there was not enough to go around for the residents and then she saw the staff eating the same food. (Relative 14)

I often see RN 2 taking food from residents' meal trays. She even takes those little butters and jams from the breakfast trays. (Carer 6)

I had \$250 in my wallet. Before I took the kids out to dinner one Friday night, Carer 1 was in my room with me. When I got to the restaurant, I realised I did not have my wallet with me. When I got back to my room, the wallet was missing. When I next saw Carer 1, I said to him: "I take you to the police or you bring the wallet to me in 5 minutes". Carer 1 said he had been looking for me because he found the wallet on the stairs. He told me that he had put the wallet in ACF's safe. He brought the wallet straight back and gave it to me. (Resident 2)

A resident's ATM card was taken and \$9,000 withdrawn without authorisation. We all think we know who took it, but there is never any substantial proof. I reckon they sold the card so there will be no proof that they stole it. They are very clever. (Carer 10)

A new resident had \$800 stolen on Saturday night (15th September). Carer 1, Carer 3 and I spent ages looking everywhere in his room, but could not find the missing money. We called the police but by the time I went off duty they had not arrived. (Carer 9)

I can't understand why Carer 1 is still employed here. Shouldn't management have sacked him after so many complaints about him? Or at least put him on paid leave while they investigated all these complaints? (Carer 11)

³ Complaint form submitted 21st August 2012

I am frightened of Carer 1 and the manager. I think they are robbing us.
(Resident 4)

I came into my room and Carer 1 was looking through my drawers. When I asked him what he was doing he told me he was looking for chocolates. Afterwards, Carer 1 and Carer 3 came in and now I feel very confused about what I saw. I did not make a complaint because I cannot be sure. (Resident 5)

Mum had some money stolen recently. It wasn't much – about \$50. It didn't seem worth contacting the police. I haven't put in an incident report – but I should. (Relative 14)

Suggestions:

1. All reports of theft should be made to the police.
2. Carers should be reminded that they are not to eat resident's chocolates without it being offered to them.

3.3 Not escorting residents to their rooms

There is a lack of care when escorting residents back to rooms after meals. Residents with dementia have been witnessed being put in lifts without being accompanied by a carer – these residents become distressed because they exit the lift and cannot find their room.

Examples:

[Carer 1] put a resident in lift with other residents. He did not accompany her. The resident was very distressed when she got out of the lift – she said that she “felt unsafe”. (Relative 13)

[Carer 5] told a resident to exit lift and turn left. [Carer 5] did not accompany the resident out of the lift. Resident did not know where he should go. (Relative 7)

Suggestion:

A policy that carers must accompany residents with dementia to and from their rooms.

3.4 Unable to find a carer to assist a resident

Sometimes it is difficult to find a carer to assist a resident.

On Saturday 18th August, I found [resident's name removed] in the 2nd floor corridor crying and asking for my help. She told me she was afraid. I could not find Carer 1 (who was working on the 2nd floor). I asked the resident whether she would like to come down with me to the TV room where I and 5

other residents were watching a movie. She accompanied me downstairs. An hour or so later, Carer 1 came into the TV room saying that he had been looking for [resident's name removed]. The resident said she was scared of Carer 1 and did not want to go with him. She lay on couch and pretended to be asleep. Carer 1 left the TV room, and I organised for resident to be taken back to her room. (Relative 7)

I have complained constantly about lack of staff in main sitting room (Relative 8)

On several occasions, I have seen Carer 1 sitting in his car during his shift (Relative 8)

3.5 Residents' wandering

There have been incidents in which residents wander into the basement car park without the knowledge of staff.

Notwithstanding the existence of two monitoring gadgets installed in her unit Mum managed to get to the basement on a number of occasions where she has been found to be distressed and disoriented. On one occasion it was a relative of a resident who happened to be in the basement and escorted my mother to her floor. (Relative 12)

I found [resident's name removed] in the car park at 8.30pm. She was very distressed. (Relative 11)

4. Personal Care

4.1 Toileting

There has been an increase in the incidence of residents wetting themselves because carers are not taking residents to the toilet (unless the residents ask to be taken to the toilet). Some residents with dementia need to be reminded to go to toilet – and taken regularly. There are also some residents who do not have a sufficient amount of toilet paper in their rooms.

Example:

Mum is often extremely distressed when I arrive as there is no one to reassure her or take her to the toilet. She is often very dirty with food all over her clothes and despite my constant requests for more frequent hair washing she often has dirty hair. She gets very agitated and walks around for long periods without a break. She needs someone to sit her down and reassure her regularly but there isn't anyone around... On a brighter note , [Staff 1] and [Staff 2] are a godsend and I am grateful for their kindness and assistance to mum. Without them I don't think I could cope. (Relative 1)

When I arrived yesterday, I took mum immediately to the bathroom (which has become routine because the carers no longer take mum to the bathroom regularly). Unfortunately mum did not make the toilet in time - this is the

second time this week alone that mum has wet her pants. Not surprisingly, mum is humiliated by these incidents. (Relative 7)

Inadequate toileting 3 consecutive days in July. First time we did not make it in time and mum had to be washed and changed. She cried with humiliation. (Relative 8)

Mum did not have access to sufficient amount of toilet paper – staff told us they did not have access to storage facility, and were unable to get her any more toilet paper. (Relative 6)

I was at ACF on Saturday night (18th August) watching a movie with mum and some other residents. I noticed [resident's name removed] in the corridor in her nightie with her hand between her legs holding crotch, looking very distressed because she could not find a carer to help her. The resident told me that she had no toilet paper. I too could not find a carer, so I ran up to mum's room and got [resident's name removed] a roll of toilet paper. It seems to me that ACF should provide enough toilet paper for all residents - and some residents (for whatever reason) require more toilet paper than others. It must be humiliating to roam corridors looking for toilet paper. (Relative 7)

Suggestion:

1. Carers should regularly ask residents with dementia whether they would like to be taken to the toilet.
2. A sufficient amount of toilet paper should be provided for each resident.

4.2 Hygiene issues

- Some residents are coming to meals in a dishevelled state – wearing dirty clothes, without having had their hair brushed, and without wearing any lipstick.
- One resident's relative is concerned because the resident is not being showered, and his clothes are extremely dirty and smelly.
- Poor supervision - of daily showering/hygiene

Examples:

"She needs more supervision eating so that she is not always covered in food stains." (Relative 1)

Sunday 29th July, I arrived at ACF in the late afternoon. My Dad informed me my Mum didn't have any pullups at all in her room and she dressed herself using normal undies. He had asked carers but they still hadn't given them to him. She is high care and they are supposed to provide them. (Relative 3)

The showering has been an issue for some time and various members of the family have lodged independent complaints and been witnesses to exchanges between staff about this issue. On one past occasion when Dad had clearly not been washed for several days and had been wearing the

same clothes which were dirty and urine stained, the nurse on duty was called in. When the situation was pointed out she advised she had no time to bathe Dad, as it was almost afternoon tea time; it was not her job; and that she would pass it on to the change over staff. Only when I insisted, were arrangements made for staff to bathe Dad. When Dad emerged after being showered he was still wearing the same dirty clothes, he had not been changed. (Relative 5)

Mum often dressed in same clothes. Pants, shirt and cardigan. On one occasion 5 days in a row... Clothes often have food stains and should be in laundry basket... Clothes often hung up very carelessly or not at all. Thrown onto shelves... Hair often not washed. Last week hair not brushed for 5 days in a row... [An x-staff member] told me that she found [Carer 2] making mum's bed while mum sat naked waiting for assistance with dressing after her shower (Relative 8)

Suggestion:

A policy to ensure that residents are dressed in clean clothes, and assistance given (where required) to shower, brush teeth/hair and apply make-up.

4.3 Quality and selection of food

Meals are no longer to their former standard. Fresh fruit is no longer freely available to residents on dining room tables at meal times, as in the past. There was a recent incident of a resident's companion noticing that drinks had passed their expiry date.

Examples:

Two residents [names removed] requested in writing on their menu choice that they are not to be served tomato. When their meal arrived with tomato they asked for the tomato to be removed and reminded carer of their written request. The carer ignored them and replied that she would let the kitchen staff know. (Relative 8)

Fresh fruit no longer freely available to residents on dining room tables at tea times, as in the past. Meals no longer to past standard. Dad has for 2 ½ years not eaten the breakfasts provided. His request is for porridge, which is not that unreasonable, yet every day his breakfast is returned uneaten (save for the coffee) yet no-one seems to questions why. (Relative 5)

Many residents here are Jewish – and the kitchen gives them ham sandwiches!! (Relative 8)

Suggestions:

Residents should be given nutritional food, including fruit.

5. Staff issues

5.1 Staffing levels

There is an increase in the number of residents at ACF who are high-care. As a result, staff are busier – and often not able to provide an adequate standard of care to all residents. Although there may be sufficient number of staff on duty, some staff are not spending their time on duty doing their job. There is currently no supervision to ensure that carers are actually doing their job.

Examples:

I have often seen groups of staff often witnessed talking and smoking together in basement. Surely, they couldn't all be having their break at the same time... They have installed cameras to stop this – but staff have just found other spots in which to huddle (Relative 3)

I help my mother to bed most nights. When I leave the room, I put the TV on - tuned to Channel 2. Each day, mum leaves the room before breakfast, and does not return to the room until bedtime (since dad's death, she hates spending any time in the room without him). At bedtime, I often find the TV tuned to a different station – suggesting that someone (? Member of staff) has been in the room watching the TV. I made a complaint to management – the next night I noticed a laminated sign beside the TV. The sign said "STAFF PLEASE DO NOT CHANGE TELEVISION CHANNEL. TELEVISION SHOULD BE ON CHANNEL 2 AT ALL TIMES." This seemed inappropriate – almost like a reminder to staff to change the channel back after their 'rest' watching TV in mum's room so that I would not notice! A more appropriate response may have been a memo to staff that they are not to watch TV in residents' rooms and that any staff caught watching TV in a residents' room would be grounds for dismissal. (Relative 7)

On 21st August, I went into the 2nd floor lounge at 1.30pm to prepare the card table for my weekly game of bridge with 3 residents. A carer was asleep on couch. Assuming this carer was 'sleeping on the job', I took a photo. I later learnt that this carer was working a double shift – and the manager had suggested that the carer sleeps on couch on 2nd floor lounge. This was an inappropriate place to recommend that a carer sleep. Finding a carer asleep in a public area easy leads to assumptions such as those I made about carer. I have been told that the manager subsequently suggested the carer sleeps in hairdressing room – and locks the door! (Relative 7)



Picture: Carer sleeping on couch in 2nd floor lounge room

Suggestions:

1. Determine the best practice ratio for high-level to low-level care in an aged care facility such as ACF.
2. Ensure staffing levels are adequate to cope with number of high-care residents
3. Adequate supervision and training to ensure a high standard of care is provided to *all* residents.
4. Supervision of carers – to ensure they are doing their job (and not watching TV, talking on mobiles to friends/family ,smoking in basement or sleeping in public areas)

5.2 Resignation of staff

Under the new manager there have been numerous staff resignations. Notably, the resignation of two highly respected clinical care co-ordinators negatively impacted on the standard of care. There have also been resignations from 12 carers who relatives noted were competent, hardworking and kind to residents. Some relatives have been told that RN 1 and Carer 2 bullied these nurses and carers. Also, some carers told relatives that they had to resign because they were not given a sufficient number of shifts.

Example:

3 Senior Staff members told me that they could not work with Manager because of bullying and resigned. [Their resignations have] severely impacted on standard of care and staff morale. (Relative 8)

I spoke [to owner of the facility] about the regular loss of competent staff which is not only undesirable for the residents and their families but also to the facility. (Relative 12)

Suggestion:

The owner(s) should ensure that all staff who have resigned in the past 12 months are given a formal 'exit interview' to determine the reasons for their respective resignations. The staff interviewed should be assured of their anonymity and confidentiality.

5.3 Bullying behaviour

Relatives have witnessed incidents of staff being bullied by other staff. Several carers have told relatives of incidences in which they have been bullied, most often by Manager and Carer 3. Relatives have reported being bullied by Manager. At a recent bullying training session, Manager attended both sessions – making it difficult for staff to discuss incidents in which they felt bullied. There have also been allegations of damage done to personal property, such as a staff members car being keyed by Carer 3.

Example:

I met with Manager to discuss culture, staff morale and bullying and she shouted at me and called [staff member removed] in as a witness. To what?
(Relative 8)

Attempted to comfort a very distressed member of staff last week who begged me not to talk to her as Manager has spies everywhere and would report back that we were talking. (Relative 8)

The manager phoned my wife to report an incident in which mum was found to have "faeces in her vagina". Manager insisted that a carer speak to my wife on the phone and apologise for her personal care of the resident. The carer was very upset on the phone. My wife felt Manager's behaviour towards the carer was aggressive. (Relative 2)

Carer 3 was seen keying my new car. She is a nasty bully. We are all terrified of her and her husband (Carer 1). But RN 1 protects them both – RN 1 is godmother to their child. (Carer 8)

I am available to meet with [owner of facility] to tell him how poorly I was treated by Manager during my employment as Clinical Care Coordinator and my reasons for resigning. I have witnessed Manager show a lack of respect for members of staff. I have witnessed her bully and treat staff unfairly. (RN 5)

The following two statements concern a malicious rumour that was allegedly spread by manager and Carer 2.

On Monday 31st October 2011, I was working on ground floor at ACF. My break was at 11.30am but I had not had time to toilet [Name of resident removed] because the morning shift had been very busy. I had also promised [Name of resident removed] that I would change his bed sheets, but when I

went to do this, he was lying on his bed. I asked RN 5 if she could ask someone else to do these 2 tasks or I would do them after my lunch break. RN 5 asked Carer 2 to do these 2 tasks. Carer 2 became upset. Carer 2 went to see Manager to complain about me. I was having my lunch break when Manager came into the staff room. She screamed at me and asked me to come to her office immediately. I replied to Manager that I would come to her office after my lunch break. She screamed at me again, and told me to come immediately. I went to Manager's office and she spoke to me in a very rude manner, and very loudly. She told me that Carer 2 had complained that I had not toileted [Name of resident removed] nor changed [Name of resident removed]'s bed sheet. She told me that I do not do my job properly. I asked Manager to not scream at me. I also asked if I could speak with Carer 2. Manager took me to [Name of resident removed]'s room and paged Carer 2 to meet us in [Name of resident removed]'s room ([Name of resident removed] was not in her room at the time). I asked Manager if we could speak in her office rather than in a resident's room, but she insisted that we talk in [Name of resident removed]'s room. Carer 2 joined us in [Name of resident removed]'s room. Both Manager and Carer 2 spoke loudly and rudely to me, telling me that I am not doing my job properly. They also told me that I should stop working as Rachel's companion. They also told me that I am having an affair with RN 5, and that we had been seen out together having coffee. I denied the affair with RN 5, and told them that I was doing my job well. They told me that Head Office knows about my "affair". Manager threatened to phone RN 5's husband to tell him about my "affair" with his wife. Manager then went out of [Name of resident removed]'s room to page other carers to [Name of resident removed]'s room. Manager then told the carers that they should speak openly in front of me about their complaints of my work. Manager also threatened to reduce the number of my shifts. I felt intimidated, and I left the room. Manager went back to her office and paged all carers and nurses (except for me and RN 5) to come to her office at 12pm. RN 5 and I were the only ones on the floor during a busy time (when we bring residents to the dining room for lunch). Afterwards, one of the carers told me that Manager forced those in Manager's office to sign a complaint form about my work. I never saw this complaint. After this incident, I told RN 5 that Manager is making false allegations about us having a sexual relationship. On Wednesday 2nd November, I was not working at ACF. I received a phone call from RN 5's husband, [name of husband removed]. He told me that he had just received a telephone call from me. I told [name of husband removed] that I had not phoned him – and I explained that I did not know his phone number. [Name of husband removed] said that someone had phoned him saying that his name was Carer 6. This person (who was most definitely not me) had told [name of husband removed]: "I am having an affair with your wife, RN 5." This person told [name of husband removed] that I and RN 5 go out together after work at ACF. I explained to [name of husband removed] that I had previously told RN 5 that Manager and Carer 2 are making false allegations about our relationship. I told RN 5 that Manager had threatened to phone her husband and tell him about our "affair". [name of husband

removed] said that he would speak with RN 5, and that RN 5 would phone me back. During the course of the next few days, several staff told me that Manager had told them about my "affair" with RN 5. I felt too intimidated to talk with Manager about this. I was very stressed and had trouble sleeping. (Carer 6)

On Monday 31st October, Carer 6 told me that Manager had accused him of having an affair with me. I was shocked and disappointed. Nonetheless, I came to work at ACF as usual on Wednesday, 2nd of November. At approximately 1045am Wednesday, 2nd of November, I received a phone call from my husband [name of husband removed] Johnson. He asked me to go somewhere private so he could speak to me. He asked me "Are you having an affair with Carer 6?" I was in shock, and denied the affair. My husband told me that he had just received a phone call from "Carer 6". [name of husband removed] said: "Carer 6 just rang me and told me that you have been going out for coffee and you told him that we are getting divorce". I was in shock and felt sick in the stomach. My husband asked me for Carer 6's telephone number. My husband rang me back soon after speaking with Carer 6. He told me that Carer 6 had not rung him. My husband was furious. He asked me to give him the phone number of the Operations Manager, Leanne. My husband telephoned Leanne and informed her of the telephone call he had received from someone pretending to be Carer 6. My husband told me that Leanne was not at all sympathetic to the problem. Leanne told my husband that RN 5 had been seen with Carer 6 after working hours. Leanne was not interested in investigating who had pretended to be Carer 6 in the phone call to [name of husband removed], or why they had made this malicious phone call. I was extremely stressed and upset because I knew I had to go home to face a very difficult situation with my husband despite having done nothing wrong. I was outside ACF speaking to my husband on my mobile phone. I was in tears. Sitara, a PCA, saw me crying and she said to me: "I need to talk to you". Carer 7 told me: "Manager is telling staff that you and Carer 6 are having an affair. Manager said it openly to everyone in the staff room. Manager also told me and my husband that you and Carer 6 are having an affair". I was shocked. I asked Carer 7 to please put in writing what Manager had said in the staff room, and what Manager had told her and her husband (who also works at ACF). I suggested that she write a statutory declaration. Carer 7 initially agreed to do this, but later declined to write it. She told me that she was afraid that she and her husband could lose their jobs at ACF. I made an appointment to see my general practitioner, Simon Cooper, as soon as I left work that day. I explained to him the dreadful events of the day. I was crying and obviously extremely disappointed with the rumour that Manager had spread and the lack of support provided by senior management. I was unable to return to work for a couple of days because I was so stressed by the accusations. These accusations have caused me difficulties in my relationship with my husband, which I am still trying to cope with. I resigned from ACF because of Manager's lack of professionalism and

RN 3's lack of interest in investigating who made the malicious phone call to my husband. I am making this complaint now because I have heard that the owner of ACF has recently repeated this false allegation to a relative. My reputation has been tarnished by this malicious rumour. (RN 5)

Suggestions:

1. Review of ACF's organisational bullying policy is required. This policy would identify a diagram of what to do/where to go (e.g. Health Services union), including options where it involves manager/staff or manager/resident or staff/staff etc. Policy should include visible referral list for relatives, residents and staff to seek confidential advice e.g. Seniors rights; people's rights under the HREOC etc.
2. Any staff who has personal property damaged by another member of staff should report the incident to police.

5.4 Racial vilification

Specific staff members have been overheard referring to other staff using demeaning and offensive language, including racial slurs (e.g. "Korean cunt", "Chinese bitch", "Bloody Indian). Some employees are feeling so desperate about the workplace culture that they have taken phone recordings during meetings with the Manager.

Example

I was working as a companion to [resident's name removed] when I noticed that she was being given drinks that had passed their expiry date. I informed the RN in charge on Saturday. The RN said that she would discard the box. I told the RN that I felt an obligation, as [resident's name removed] companion, to inform the family which I did. On Monday, I was working as a carer at ACF when I noticed that the box of drinks had not been discarded. I asked the team leader why the box had not been discarded. She told me she had also noticed on Friday that the drinks had expired – and that she had informed Manager. She told me that Manager had said that it is OK to give [resident's name removed] the drinks for the next few months. The team leader gave [resident's name removed] the drink, even though it had expired. I said that I had told the family on Saturday in my capacity as [resident's name removed] companion. I suggested that the team leader should tell Manager that the family knows about the expired drinks. I went to the second floor and I overheard Manager and the team leader talking together about the expired drinks. Due to the fact that I have been feeling insecure about my ongoing employment at ACF, and aware that Manager speaks badly about me, I turned on the recording device on my phone so that I could have proof of the

way that Manager talks about me. I heard Manager refer to me as a “bloody Indian”. (Carer 6)

Carer 6 made a complaint with his union regarding the incident in which the manager referred to him as a “Bloody Indian”. RN 3 met with Carer 6 to discuss his complaint - a union representative was present during this meeting.

I am proud of myself that I stood up against wrong things. (Carer 6)

Suggestion:

Any staff member who is racially vilified should report incident to appropriate authorities (e.g HREOC, union)

5.5 Communication with staff

English is a second language for the manager and many of the carers/nurses. Relatives often feel their conversations with manager and some carers/nurses are not understood.

Example:

I am having great difficulty communicating with some of the nursing staff particularly [RN 2]. My mother has difficulty swallowing her tablets so the nurses have arranged for Mum's doctor to eliminate her panadol dose (which was about 6 per day). Consequently mum is in considerable discomfort which she cannot communicate well. The nurses seem unwilling to try a liquid alternative and continually argue with me saying that mum is not in much pain. This is a most distressing situation for me. I have lost confidence in the nursing staff. (Relative 1)

I have a lot of difficulties talking with RN 2. I often feel that she does not understand me. I tried to explain that mum often has sticky tape applied to her leg when her dressing is done, despite explicit instructions not to apply sticky tape to her excoriated leg. I became exasperated when it was clear that RN 2 did not understand what I was saying. (Relative 7)

Suggestion:

The facility provide compulsory ESL training for all staff.

5.6 Mobile phones

Staff are often seen talking/texting on mobile phones whilst on duty, some for extended periods of time.

Examples

I walked into mum's room and found a carer talking on her mobile phone in mum's room. Mum was in lounge room...I was talking with Carer 1 when his mobile phone rang. He took the call and spoke in a foreign language while I was standing beside him. Immediately after this phone call, Carer 1 left ACF. He told me that he was going to his car to get the charger for his mobile phone. He did not return to ACF for over 15 minutes. (Relative 7)

On Saturday 26/5 I visited my mother, when I passed through the lounge at 11.10am a staff member was talking on her mobile phone and when I left at 11.30am the same person was still on the phone by the piano. (Relative 3)

I have observed on many occasions young carers walking in front of a resident who would be relying on the use of a walker, with the carer pulling the walker at times faster than the comfort speed of the resident but the carer was unaware as the carer was conducting an obviously personal conversation on her mobile phone with her back towards the resident. No

ACF supervisor appears to be around to reprimand the carer for the irresponsible and potentially dangerous conduct... I told [owner of ACF of the inappropriate behaviour of many staff members, use of mobile phones for the conduct of personal conversations while pulling residents' walker at times faster than the comfort speed of the resident, but the carer was unaware as the carer was not facing the resident. (Relative 12)

Suggestion:

Staff are not permitted to use their mobile phones whilst on duty.

5.7 Night shift

There have been reports of:

- Staff sleeping during night shift.
- Buzzers not answered during night shift.
- Buzzers out of working order during night shift.
- Residents not being checked during night shift

Examples:

On 16 April my mother had surgery to her face and the night staff were asked to check mum regularly. She awoke before midnight and pressed the buzzer as she was in pain and the pillow was covered in blood. According to the medical records the staff came at 3.15am to find mum asleep. When she pressed the buzzer a second time after 5am the night shift found her covered in blood and had to change the sheets and pillow case as well as the dressing on her nose. The comment made by the night staff was that the place looked like an abattoir. (Relative 3)

I provided [owner of ACF with a number of specific examples where the staff's conduct towards my mother was unprofessional, discourteous and unacceptable. He agreed with my conclusions. I told him of an incident which occurred during the night when my mother was wondering in the corridors whilst male nurse who should have responded to the call generated by a mat attached to the call system was asleep. (Relative 12)

I complained [to owner of ACF about the difficulties of communicating with staff members during the night as some staff members do not respond to the ringing of the telephone. (Relative 12)

I have become aware of the fact that my mother got out of bed during one night, triggered the call system by stepping onto the mat next to her bed, connected to the call system. There is a second monitoring system installed in the living room which is meant to be activated upon my mother's retirement for the evening, which should have alerted the night staff of the fact that my mother left her unit. I understand that 2 staff members were on duty (as they are every night) The two staff members agreed between themselves as to

which of them was to respond to the first call from any of the residents with the other staff member responding to the next call. On this occasion, apparently the staff member who agreed to respond to the first call was asleep. It was only after some considerable delay when the second staff member realized that the first one failed to respond to the call, that the second staff member found my mother wondering around escorted her back to her unit and proceeded to look for his colleague who was found sound asleep in one of the communal lounges which was in darkness. (Relative 12)

Suggestion:

The ratio of staff to patients on night duty should be best practice (irrespective of current legislative requirements).

5.8 Incidents of staff not speaking the truth

There are reports of staff avoiding talking about issues with relatives and making excuses. Also, there have been several allegations made of RN 2 lying to relatives.

Examples:

On Saturday, Nov 12, 2011 Mum followed some visitors out of building. As they drove off they noticed her and ran back to ACF. No staff visible and mum was rescued by private carer. RN [RN 2] telephoned later and lied to me about incident. (Relative 8)

I was worried about a resident wandering at night and coming into my mother's room and sometimes trying to get into bed with her. [RN 2] told me that the resident is "locked in her room". However, the locks on doors are hotel locks that can be opened from the inside (but not from the outside). When this was pointed out to [RN 2], she replied that the staff can hear the "click of her door" when it is opened. I then checked - there is no "click" when door is opened from the inside. This lie was unnecessary, as was the lie that RN 2 told about my mother having been on antibiotics. It was so easy for me to check the medication chart to see that this was not correct. (Relative 7)

Suggestion:

Staff should be told by management that relatives are entitled to be told the truth, and that staff will be reprimanded for not talking honestly with relatives about issues of care.

6. Management issues

6.1 Response to complaints and suggestions

- Inadequate response to complaints, including incompetent written responses (See Appendix for an example)
- Some complaint letters are filed inappropriately.
- Suggestions for ways to improve ACF are not acted upon.

Examples:

Prior meetings have taken place with management, where procedures were to be implemented regarding showering and changes of clothes. These have not been adhered to. When repeated complaints were raised about hygiene issues, Management has countered with allegations of Dad molesting and assaulting staff. When asked for documentary evidence, what has finally been disclosed is that Dad had placed his hand on staff shoulder/arm? No copies of reports were provided despite requests. Serious allegations of sexual misconduct/assault/throwing a chair at a staff member were made, yet records fail to document/evidence same. Given Dad has serious balance problems, there is some doubt if he could even pick up a chair let alone throw it. (Relative 5)

The manager filed my letter in which I outlined several mistakes in a folder that contained minutes of staff meetings. I thought this letter should have been kept confidential given that it named the GP who contributed to the mistakes. All staff could access this folder and read the letter. The GP subsequently threatened me with defamation – but I had every right, as a daughter, to raise issues of concern with the Manager of the facility. It was her actions that shared this information with others (Relative 7)

After Comment and Improvement Form was submitted I received no formal reply from Manager (Relative 8)

I met with [RN 3] to discuss many issues including bullying of Laundry employee and resignations of Senior Staff. I do not feel she acted on any of the information I gave her, despite the fact that she took notes. (Relative 8)

I discussed the installation of a FOB system in the lift with Manager but I did not hear from manager of any progress. (Relative 12)

After submitting three incident reports, the manager came to talk with me in the lounge room where I was playing cards with my mother. She told me (in quite an aggressive tone) that incident reports about Carer 1 were being made because he is a big man. She told me that he could go to Fair Work Australia for harassment. I replied to the manager that the complaints about Carer 1 were being made because he did not do his job properly, not because of his size. The manager was very angry with me. A short time later, RN2 talked with me - also in lounge room in front of my mother. She too was angry. I told her that it was not professional to talk with me in front of my mother in the lounge room. It is very unfortunate that both the manager and RN 1 spoke to me in front of my mother. She now feels frightened. (Relative 7)

Suggestion:

A policy that all written complaints should receive a written response. Confidential letters should remain confidential.

6.2 Lack of teamwork

The carers, kitchen staff and activities staff are not working well as a team. This is evidenced by carers complaining about kitchen staff; activities staff complain about carers etc.

Suggestion:

Teamwork in a health service requires good leadership.

6.3 Inconsistency between formal records and verbal information

There is a discrepancy between what is recorded in care plans and what staff did (or said that they did).

Examples:

“A decision was made to give my mother her daily serapax at 4pm rather than with her dinner – to prevent her experiencing ‘sun-downers’. This change was documented in her care plan. However, I needed to remind [RN 2] and [RN 4] to do this”. (Relative 7)

8/7/2012: I arrived and Dad reeked of urine and BO. I had Dad take a shower. I called in the nurse on duty and when we re-entered Dad's bedroom where he had left his clothes, the odour was overpowering and offensive. I put in a complaint and asked to see the ACF records regarding Dad's showering. The nurse agreed that Dad had clearly not been showered for some time. ACF records showed he had not had a shower for 3 days (there have been incidents of even longer periods in earlier complaints lodged by me). A young female staff member approached and said the records were wrong, she insisted that she had showered him that day (Peter G. was a witness to this exchange). (Relative 5)

Physio requested mum be dressed in lace up shoes. In Care Plan. Consistently found wearing slip on shoes and on one occasion in slippers. (Relative 8)

6.4 Not keeping relatives informed

Several relatives are concerned that they are not being kept adequately informed. It was also noted that staff are now being asked to sign confidentiality agreements to ensure that staff do not speak to relatives about care issues.

Example:

After an incident with expired drinks, Manager called me into her office. Manager told me that the RNs had complained that I was interfering with [name of resident removed] treatment. She referred specifically to the expired drinks. She then told me that staff had complained about me. The staff had complained that I had told them they worked too slowly, and that I was rude to them. Manager also told me that I get too involved in the families. She told

me that I must never again tell families about anything. Manager said that I must come to her or CCC, not the families, if I have any problems. I explained that when I told the family about the expired drinks, I was working as [name of resident removed] companion (not a carer). I told her that I felt it was my duty to let the family know. Manager gave me a warning letter to sign. This warning letter stated that I had breached confidentiality, I am rude with staff, and I am interfering with medication. I refused to sign it. Manager insisted that I sign. I agreed to sign only next to the 'breached confidentiality' (because it was true - I had told the family about the expired drinks). I also agreed to maintain confidentiality in the future. (Carer 6)

Suggestion:

A policy of open disclosure should be introduced. A policy of open disclosure has been proven to be effective in reducing number of formal complaints in many health services.

6.5 Reactive not proactive treatment of residents

Situations that could have been prevented (by good care and supervision) are occurring because staff are not doing their job satisfactorily.

Example:

"Everything that is done for my mother is reactive and not pro active".
(Relative 2)

I found [resident's name removed] in the car park at 8.30pm. She was very distressed. I took her to her room and told a nurse. The nurse was not able to come to [resident's name removed] room. The resident became increasingly distressed. (Relative 11)

Outcomes

Manager 'retired from' ACF

On 24th August, the owner of ACF issued a memo to residents, relatives and staff. The Memo advised that the Manager of the facility would be retiring; however she would remain as manager until 26th October.

After receiving this memo, several relatives emailed the owner asking him to reconsider his decision to keep the Manager in her position for a further 2 months.

Thank you very much for sending me your memo and I am glad you have reached the first of many difficult decisions. I am however extremely concerned. In a Business environment it is absolutely unheard of for any employee who has committed, contributed to, or condoned a serious breach of workplace conditions to remain in that role for any period of time. Manager has been involved in numerous unethical activities and has failed in her duty as a Manager to support her team. Manager does not deserve the gracious exit she has been offered. She is not a fit Manager and with the two months you have granted her, could continue to inflict serious damage upon some already very fragile employees. This is a very unsatisfactory outcome and I ask that you reconsider your decision, removing Manager immediately and remunerating her accordingly. (Relative 8)

Thank you for the Memo and the very important decision to rid ACF of a person that has caused so much angst and unpleasantness in her tenure. She has together with her 2 cohorts Carer 1 and his wife created immense stress to our parents and the staff...Manager incredible ability to twist untruths into truths and her complete lack of respect for the residents who in most cases were defenceless, as well as their families who had to endure time after time unpleasant tirades from a person with little or no people skills. Manager has rid ACF of some wonderful people and staff of immense sensibility and ability as well as ruining people's lives and her leaving is a blessing for all. I am amazed that she has been given 2 more months to continue her trail of destruction and would urge you to reconsider this decision. I further urge you to seriously consider the tenure of the 2 people mentioned above. I for one will not be thanking Manager for anything except to be thankful that she will not be part of my daily visits to ACF. (Relative 2)

Thanks for sending me the memo. Replacing the manager will hopefully help to address many of the grievances of relatives. However, I am slightly concerned about how ACF will be managed between now and October 26th. I also wonder if you have considered having a relative and a resident on the committee to select a new manager? The practice of having 'consumer representation' on staff selection committees is increasingly common in health services. It has been a very successful strategy for ensuring both staff and consumers of the health service are happy with the new appointment. (Relative 7)

The Manager is responsible for the safe and appropriate, daily running of the facility, with final responsibility resting with you. That being the case, I repeat my concerns about the failure to immediately replace the Manager. Retirement of the current Manager in October, does not address the immediate ongoing issues and leaves the facility in no immediate better position than in the past. Although in due course, I look forward with anticipation to a positive change in leadership (that I hope filters right through to the most junior staff), it leaves an unsatisfactory situation in place for a further two months. If the situation has deteriorated to this level in the last week, while under Manager leadership, why is she left in a position of trust for a further two months? As I have not received any response from you, and this week alone there have been multiple serious medical negligence breaches (in relation to my father alone), and I am appalled at the suggestion that there is to be no change to the current management for some two months, I have copied my complaints to Aged Care Complaints Scheme, seeking their involvement. I would trust with your immediate intervention, matters can be resolved without further involving the Scheme. I anxiously await your response. (Relative 5)

Ongoing complaints

During the next few weeks, ACF was inundated with relatives documenting complaints. Some relatives also sent these complaints to the owner.

Yesterday (29/8/2012) I found medication (three tablets) in Dad's bedside table. A serious issue as: a) Dad is not receiving the prescribed medication, considered necessary to treat his medical condition; b) the extra tablets could have been ingested at a future time resulting in an overdose ie. a double dose being taken by Dad; c) medication could have been ingested by others (eg children who regularly visit or other residents – who suffer from dementia); and d) some hours later staff when following up on this with me, advised they had failed to ascertain the exact location of the tablets (they were asked to confirm that RN 3 had possession of the tablets) and simply advised they would refer the matter to the Manager. This incident is the latest of three incidents of medical negligence/malpractice in the last week alone. Despite lodging documents via the formal complaint system within the facility in relation to each incident, I have also been forwarding emails direct to you, as CEO, to keep you apprised of the serious nature of matters within [name of facility removed]. (Relative 5)

The increased number of complaints created a paradox at ACF - by trying to fix a low morale among staff, the relatives had created a low morale among staff. This was noted in an email to relatives.

I was leaving last night just when staff were leaving their "Team Building Training" - and chatted with a few staff (all who I consider to be "good eggs"). It seems our relatives' revolution is beginning to back fire - Our

complaints (about everything) are creating very low morale - particularly among the good staff. We have created a paradox - In trying to fix a low morale among staff, we relatives seem to have created a low morale among staff. Take the recent complaints about medications being left with residents with dementia. As a result of documenting these complaints, ALL residents (including those without dementia) must take their medication in front of the nurse. Residents who were once given their sleeping tablets during a medication round (to take when they wanted), no longer have the freedom to do this. This is causing a problem for those residents - who are very unhappy with the changes. A sensible manager would have agreed that residents with dementia need one policy regarding medication, and those without dementia another policy - but we are not working with a sensible manager. I am very impressed with some staff at ACF - and I think it is important to talk calmly with them when we are unhappy with things. I suggest that this may be a better strategy than documenting every complaint (or indeed shouting at staff as one relative did recently). What do you think? I am concerned that we may lose some of the good staff (who are sick to death of all this - just as we are). And our parents really need the good staff to stay. (Relative 7)

Staff changes

New managers

The manager left ACF on 12th October, and a new manager began. A new assistant manager had commenced a few months earlier.

In the absence of any welcome to the new managers having been organised by ACF, a relative suggested that it would be nice to have a welcome - so residents and relatives could meet the new managers (many relatives have still not had the opportunity to meet the assistant manager). Given the short notice, the relative sent around an email to relatives. However, the operations manager decided against relatives attending the welcome. She sent the following divisive memo to relatives. The memo was titled "Resident afternoon tea to meet our new facility manager".

As you may be aware, ACF is hosting an afternoon tea on Monday to welcome our new Facility Manager

We have become aware of an email sent by a relative of a resident inviting you to ACF for the afternoon tea. We did not authorise the email and became aware of it only after it was sent.

The afternoon tea has been arranged by ACF for residents only. Given the logistics and staffing requirements of putting on such an event, we are not able to host residents' relatives as well.

Please be aware that we consider that it is not appropriate for relatives to purport to correspond on behalf of ACF. The proper course is to direct all enquiries to the Facility Manager who will assist you accordingly.

[The new facility manager] is looking forward to meeting relatives over the course of the coming weeks.

Other staff changes

In addition to the manager leaving the ACF, Carer 2 took extended sick leave and then resigned. Her husband, Carer 1, remained employed until July 2013, despite numerous complaints about his behaviour toward residents. Several relatives had requested that he not provide any care for their parent.

I spoke with owner who told me that I should not talk with Carer 1 – the owner described him as “dangerous”. I asked owner to explain why he was still employed given all the accusations that had been made about his behaviour. I was told that current legislation made it difficult to sack employees...In July 2013, the manager asked me to document why I did not want Carer 1 to provide any care for my mother. A few weeks later, he was gone – though we were not told whether he resigned or was sacked. Although we were all glad he was gone, I hope he was sacked so that it goes on his employment record. This man and his wife should not be working with older people. (Relative7).

I was told that there have been no reports of theft since he left (Relative 8).

Staff speaking only English

The new Assistant Manager circulated a memo instructing staff to speak only English when on duty. This memo was in response to the increasing number of carers who speak Indian as their first language. The Memo was titled “Speaking in foreign languages”

There have been further complaints from residents and family members regarding carers speaking in languages other than English during work hours.

A written warning will now be given to anybody found speaking any other language other than English during working hours, this excludes breaks.

I am disappointed that this issue has had to be readdressed again and hope that by imposing a penalty, the behaviour will cease.

Thank you for your cooperation.

Response to grievances

The owner never replied formally to the list of grievances. However improvements in standards of care demonstrated that the grievances had been taken seriously.

We became tired of sending emails to owner and operations manager that did not receive any reply. In my mind, not replying was a 'power game' and showed a lack of courtesy. (Relative 7)

Six months after the new manager was employed, Relatives 7, 8 and 12 requested a meeting with the manager and assistant manager. At this meeting, the manager and assistant manager responded to each grievance. In addition, relatives requested increased co-operation between relatives and staff.

When my mother was admitted to ACF, the operations manager told my sister and I that we should visit mum only once a month. We are aghast. We chose ACF because we both live nearby – and we wanted to pop in to see mum most days. (Relative 15)

Relatives wanted to work in partnership with staff. We did not want to feel as though it was "us" and "them". (Relative 7)

Appendix 1: Document given to owner of facility

9th August 2012

Dear [owner's name removed]

On Tuesday 31st July, some relatives met to discuss issues of care at [name of facility removed]. These relatives were concerned about the safety of their mother/father. Although I am not personally worried about the safety of my mother, I was shocked and saddened to hear these relatives relate incidents that had recently occurred at [name of facility removed].

Since this meeting, I have talked with relatives, staff and residents. I have documented everything that I have heard. I have also received numerous documents from relatives to support these allegations of poor standards of care, and in some cases, negligence and abuse. I understand that several of the more serious allegations have been reported to the Department of Health and Ageing.

I am an experienced qualitative researcher with expertise in action research. I and my team often undertake research for health services, including services experiencing difficulties in service delivery due to low staff morale. I used this expertise to undertake 'research' and prepare a 30-page document (in a very short time). This document includes data (names, dates, incident etc) and my analysis of why the deterioration in quality of care has occurred at ACF. In this document, I also suggest some solutions to the current 'crisis'. However, I have been advised that the document is defamatory because it includes names of staff and allegations of misconduct. Consequently, I am unable to give you a copy of this document.

In summary, I found evidence of several breaches of current legislation in relation to treatment of both residents and staff, and also numerous examples of poor management. Most importantly, my 'research' found data to support the termination of three employees – one registered nurse and two carers.

This matter requires your full attention. I recommend you initiate an *urgent* independent investigation or consultation. (If I can collect so much information in just over a week, by simply talking with relatives, staff and residents, an experienced investigator could do the same).

Despite concerns about the current standards of care, there are some wonderful and dedicated nurses, carers, kitchen staff, reception staff and activities staff working at [name of facility removed]. I am very grateful for care and kindness these staff show daily to my mother (and father before his death).

I believe that [name of facility removed] can be a wonderful facility that provides services to older people that enhance their dignity and well-being.

Your sincerely
Dr Sarah Russell

Summary

The document that I have been advised not to give you reports on issues that were discussed at two formal meetings. It also contains information that was given to me after these meetings by relatives (in person or via phone, email and text), some staff (in person or via phone, and text) and some residents (in person).

By drawing these issues to your attention, and by providing evidence in the way of examples, I hope that there will be improvements in standards of care at [name of facility removed].

The relatives who attended the Relatives Meeting (6th August, 2012) unanimously supported a vote of no confidence in the Manager. This report also provides some evidence to support one carer's involvement in theft, negligence and drug taking. (I have been told that there were similar allegations at his previous place of employment). The report also provides some evidence to indicate that another carer has been involved in bullying, racial vilification, negligence and damage to property.

The report also offers my suggestions about how standards of care could be improved. It would not be necessary for me (and other relatives) to make these suggestions if [name of facility removed] was managed well.

Unlike the 'pie in the sky' suggestions that consumers commonly make for all health services, I and other relatives have made some practical suggestions about how the current standards of care could immediately be improved.

Grievances

Some grievances discussed below are not unique to ACF (e.g. staff ratios, insufficient training of carers, carers from CALD backgrounds). Other grievances are specific to ACF.

1. Medical Negligence

1.1 Competency of staff

- Many carers have insufficient training (sometimes as little as a 3 week course) to work competently with older people with health issues such as dementia and incontinence.
- Some RNs are incompetent.
- Staff demonstrate a lack of responsibility and accountability
- Staff advising they did not know of procedures, therefore have not carried them out
- Medical issues are not noticed by staff

Suggestion:

1. [Name of company] provide a policy and procedure manual that all staff must follow.
2. [Name of company] provide regular professional development in areas such as:
 - Education about the different types of dementia,
 - Strategies for caring for people with dementia
 - Incontinence training
 - Wound care

1.2 Medication errors

Many relatives have reported incidents of a medication error. Types of errors include:

- Resident not being supervised to take medication – untaken medication found in residents' rooms
- A discrepancy between medication in webster pack and what is recorded on medication chart
- Resident given another resident's medication

2. Health and Safety of residents

2.1. Response to buzzers

It often takes a long time for carers/nurses to respond to a resident's buzzer.

Suggestions:

Management should:

- Determine a reasonable time to expect a nurse/carers to respond to an emergency call.
- Develop a policy to ensure that staff respond to buzzers within these times.
- Inform residents and relatives about how long they may be expected to wait until they receive a response after pressing the buzzer.

2.2 Condition of rooms

Residents' bedrooms are often not cleaned adequately. Evidence of this include debris on floor, and bins not emptied regularly. The downstairs toilet is sometimes putrid (with bin overflowing with used paper towels). The repairs/carpet cleaning are taking a long time to be done.

Suggestions:

Rooms should be cleaned regularly and properly.

2.3 Phone contact after hours

The phone is answered promptly on weekdays between 9am-5pm, and Jenny, the receptionist is courteous and extremely helpful. However, after hours, the phone is often not answered.

Suggestion:

A policy to ensure phone is answered out of hours. In those instances when it is not possible to answer phone (because nurses/carers are busy), an answering machine is used to record messages. The answering machine must then be checked regularly.

2.4 Theft

There have been multiple reports of residents' missing money and valuables. There are also incidents of missing chocolate and sweets (that carers insist that the resident has eaten).

Suggestion:

1. All reports of theft should be made to the police.
2. Staff should be reminded that they are not to eat resident's chocolates without it being offered to them.

3. Elder neglect and abuse

3.1. Behaviour of staff towards residents

There has been a number of incidents in which relatives have witnessed staff speaking rudely to residents, or in an abrupt manner. There are also examples of residents being treated roughly, and examples of staff ignoring residents' requests for assistance.

Suggestion:

Relatives should document incidents when they witness staff talking rudely to residents. Any incidents of bullying and abuse of a resident should be reported to the aged care complaints scheme.

3.2 Not escorting residents to their rooms

There is a lack of care when carers escort residents back to rooms after meals. Residents with dementia have been witnessed being put in lifts without being accompanied by a carer – these residents become distressed because they exit the lift and cannot find their room.

Suggestion:

A policy that carers must accompany residents with dementia to and from their rooms.

4. Personal Care

4.1 Toileting

There has been an increase in the incidence of residents wetting themselves because carers are not taking residents to the toilet (unless the residents ask to be taken to the toilet). Some residents with dementia need to be reminded to go to toilet – and taken regularly.

Suggestion:

Carers should regularly ask residents with dementia whether they would like to be taken to the toilet.

4.2. Hygiene issues

Some residents are coming to meals in a dishevelled state – wearing dirty clothes, without having had their hair brushed, and without wearing any lipstick. One resident's relative is concerned because the resident is not being showered, and his clothes are extremely dirty and smelly. This suggests there is poor supervision of daily showering/hygiene.

Suggestion:

A policy to ensure that residents are dressed in clean clothes, and assistance given (where required) to shower, brush teeth/hair and apply make-up.

4.3 Quality and selection of food

Fresh fruit is no longer freely available to residents on dining room tables at meal times, as in the past. Meals are no longer as nutritious or tasty as they used to be. There was a recent incident of a companion noticing that drinks given to a resident had passed their expiry date.

Suggestions:

- Residents should be given nutritional food, including fruit.
- It is unacceptable to give residents food/drink that has expired.

5. Staff issues

5.1. Staffing levels

- There is an increase in the number of residents at ACF who are high-care. As a result, staff are busier – and often not able to provide an adequate standard of care to all residents.
- Visitors have difficulty finding carers when residents request assistance from visitors
- There may be sufficient number of staff on duty – but some staff are not spending their time on duty doing their job.

Suggestions:

- Determine the best practice ratio for high-level to low-level care in an aged care facility such as ACF.
- Ensure staffing levels are adequate to cope with number of high-care residents
- Adequate supervision and training to ensure a high standard of care is provided to *all* residents.
- Supervision of carers – to ensure they are doing their job and not watching TV in a resident's room (when resident is in lounge), talking on mobiles to friends/family and smoking in basement.

5.2 Resignation of staff

Recently, there have been resignations of three senior nursing staff, Agus, Vicki and Fabiola, and over 10 carers, including Janet, Tricia, Rong, Sitara, Kawal, Manjit, Mani, Veronica, Virginia, Rupinder, Sian, and Heidi. These staff were competent, hardworking, dedicated and kind to residents. These resignations have had significant negative impacts on the standards of care.

Some relatives have been told that some of these staff resigned because they were bullied by other members of staff. Also, some of these carers told relatives that they had to resign because they were not given a sufficient number of shifts.

Suggestion:

The owner(s) should ensure that all staff who have resigned in the past 6 months are given a formal 'exit interview' to determine the reasons for their respective resignations. The staff interviewed should be assured of their anonymity and confidentiality.

5.3 Bullying behaviour

- Relatives have witnessed incidents of staff being bullied by other staff.
- Several carers have told relatives of incidences in which they have been bullied
- Relatives have reported being bullied by staff

- At a recent bullying training session, manager attended both sessions – making it difficult for staff to discuss any incidents in which they may have felt bullied by the manager.
- Incidents of damage done to personal property

Suggestions:

- Review of organisational bullying policy is required at ACF. This policy would identify a diagram of what to do/where to go (e.g. Health Services union), including options where it involves manager/staff or manager/resident or staff/staff etc. Policy should include visible referral list for relatives, residents and staff to see confidential advice e.g. Seniors rights; people's rights under the HREOC etc.
- Any staff who has personal property damaged should report incident to police.

5.4. Racial vilification

Specific staff members have been overheard referring to other staff using demeaning and offensive language, including racial slurs.

Suggestion:

Any staff member who is racially vilified should report incident to appropriate authorities (e.g HREOC, union)

5.5 Communication with staff

English is a second language for the manager and many of the carers/nurses. Relatives often feel their conversations with manager and some carers/nurses are not well understood.

Suggestion:

[Name of company] provide compulsory ESL training for all staff.

5.6. Mobile phones

Staff are often seen talking/texting on mobile phones whilst on duty, sometimes for extended periods of time.

Suggestion:

Staff are not permitted to use their mobile phones whilst on duty.

5.7 Night shift

There have been reports of:

- staff sleeping during night shift.
- buzzers not answered during night shift.
- buzzers out of working order during night shift.
- residents not been checked during night shift

Suggestion:

The ratio of staff to patients on night duty should be best practice (irrespective of current legislative requirements) – see recent coroners report in NSW

5.8 Incidents of staff not speaking the truth

There have been numerous incidents in which the staff have lied to relatives. There are also reports of staff avoiding talking about issues with relatives and making excuses.

Suggestion:

Staff should be told by management that they will not be reprimanded for talking honestly with relatives about issues of care.

6. Management issues

6.1. Response to complaints

- Inadequate response to complaints, including incompetent written responses (see Appendix 4 for examples)
- Some complaint letters are filed inappropriately.
- Suggestions for ways to improve ACF are not acted upon.

Suggestion:

A policy that all written complaints should receive a written response. Confidential letters should remain confidential.

6.2 Lack of teamwork

The carers, kitchen staff and activities staff are not working well as a team. This is evidenced by carers complaining about kitchen staff; activities staff complain about carers etc.

Suggestion: Teamwork in a health service requires good leadership.

6.3 Not keeping relatives informed

Several relatives are concerned that they are not kept adequately informed. It was also noted that staff are now being asked to sign confidentiality agreements to ensure that they do not speak to relatives about care issues.

Suggestion:

A policy of open disclosure should be introduced.

A policy of open disclosure has been proven to be effective in reducing number of formal complaints in many health services.

6.4 Reactive not proactive treatment of residents

Situations that could have been prevented (by good care and supervision) are occurring because staff are not doing their job satisfactorily.

6.5 Inconsistency between formal records and verbal information

There is a discrepancy between what is recorded in care plans and what staff say did (or said that they did).

Appendix 2: Example of response to formal complaint

Email Sent: Sunday, 29 April 2012

Hello RN 3,

It is with regret that I inform you that [resident's name removed] broke her right hip on Anzac Day 25th April.

She was operated on on Thursday evening and is currently in hospital recovering.

I requested of RN 6 to establish how and when my mother fell and I have been receiving conflicting and answers that are confusing to say the least especially in light of the medical staff and other reports I have received.

According to RN 6 there is no record of my mother falling on that day in her records and there is also conflicting versions of my mothers movements that day.

I was phoned at 3.45 on the Wednesday to inform me that my mother needed oxygen as her blood pressure was low. When I arrived at 4pm she was in her bed and pale but her blood pressure was normal.

I was not informed at any stage that my mother could not walk but informed that she had trouble walking from her chair to her bed some 2 meters as result of low blood pressure, which my mother has never had in the past.

It was only the next morning that RN 6 phoned me to inform me she was concerned about [resident's name removed] and suspected a fracture. She sent her to emergency at 8.30 am.

In light of the above I would like you to instigate a full internal enquiry into the circumstances surrounding this incident as a matter of urgency .

I specifically want a movement timeline and a full report from the facility as to the people that were with my mother during that day. from the morning of the 25th April until the morning of the 26th April .

As you can imagine I am most concerned about this lack of information and await this report as soon as possible.

Email Sent: Monday, 30 April 2012

I am sorry to hear of [resident's name removed] fall [relative's name removed]. I will investigate and get back to you as soon as possible.

Outcome

No investigation and no factual investigation to both falls.

Appendix 5: Opinion Pieces

The following opinion pieces are available at www.agedcarematters.net

1. We need a complete rethink on aged care *Herald Sun* 23 January 2019
2. Google Translator Did Not Help Me Understand The Aged Care Workforce Strategy Taskforce Report HelloCare 6 December 2018
3. Rethinking The Staff-Quality Relationship In Aged Care Homes HelloCare 1 October 2018
4. 'I'd rather die': the horror stories of aged care don't tell the whole story *The Guardian* 16 September 2018
5. Has government by media replaced consideration of evidence in aged care? *The Guardian* 18 September 2018
6. 'Robbed of precious time': chemical restraints and aged care *The Guardian* 14 September 2018
7. To Ratio Or Not To Ratio *HelloCare* 4 June 2018
8. Better aged-care begins with more registered nurses in homes *ABC Online Opinion* 3 June 2018
9. The aged care crisis can be traced back to Howard's Aged Care Act. We need a new act *The Guardian* 20 April 2018
10. Aged Care Quality And Safety Commission: Shifting The Deckchairs On The Titanic *HelloCare* 19 April 2018
11. Turning away from evidence and data in aged care *Croakey* 9 February 2018
12. So many inquiries: so little action *HelloCare* 9 February 2018
13. Reports of poor standards in aged care are just the tip of the iceberg *The Guardian* 31 October 2017
14. Aged care reforms: who really benefits *Croakey* 4 October 2016
15. Here is why we need nurse-resident ratios in aged care homes *The Conversation*, 13 September 2016
16. Profiteering: the disgrace infecting aged care homes *The Sunday Age* 29 May 2016
17. Reverse the aged care cuts? *On Line Opinion* 5 July 2016
18. There is something very wrong with our aged care system *The Medical Republic* 2 June 2016
19. Optimising aged care funding *On Line Opinion* 30 May 2016
20. We're ignoring the needs of our ageing population *The Age* 18 April 2016
21. The Aged Care Gravy Train *The Age, Forum* 9 January 2016

Appendix 6: Inquiries and reviews

Table 1: Inquiries into aged care since 2005

Date	Inquiry Title
2018	Inquiry into the Quality of Care in Residential Aged Care Facilities
2017	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
2016 / 2017	Future of Australia's aged care sector workforce
2016 / 2017	Productivity Commission - Human Services
2016 / 2017	A public inquiry into the increased application of competition, contestability and informed user choice to human services.
2016 / 2017	Australian Law Reform Commission - Elder Abuse
2015	Registered nurses in New South Wales nursing homes
2015	Elder abuse in New South Wales
2015	Inquiry into End of Life Choices
2013 / 2014	Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)
2010 / 2011	Productivity Commission - Caring for Older Australians
2008	Inquiry into Aged Care Amendment (2008 Measures No. 2) Bill 2008
2006 / 2007	Inquiry into older people and the law
2007	Inquiry into Aged Care Amendment (Security and Protection) Bill 2007
2004 / 2005	Senate Inquiry into aged care: Quality and equity in aged care

Table 2: Government reviews of aged care since 2005

Date	Review
2017	Review of National Aged Care Quality Regulatory Processes
2017	Internal review: Australian Aged Care Quality Agency
2017	Oakden Older Persons Mental Health Service Review
2017	Single Aged Care Quality Framework: Options for assessing performance against aged care quality standards
2016	Aged Care Legislated Review
2015	Increasing Choice in Home Care - Stage 1 - Discussion Paper
2015	Review of Commonwealth Aged Care Advocacy Services
2013/2014	Consultation on the Quality Agency Quality Reporting Programme
2009/2011	Review of the Aged Care Complaints investigation Scheme
2009	Review of the Residential Aged Care Accreditation Process
2005	Elder Abuse Prevention Project

Dr Sarah Russell
Aged Care Matters
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8 November 2017

Dear Ms Carnell and Professor Paterson

We have not met. By way of introduction, I am a public health qualitative researcher who values evidence-based policies. I stumbled into aged care advocacy after writing several opinion pieces for The Age. I have recently published a research report "Living Well in an Aged Care Home" that is available on the Aged Care Matters' website.

I read your Review Of National Aged Care Quality Regulatory Processes with interest and support many of the recommendations.

I was pleased when I read on Page 61: "Historically, there has been a significant lack of publicly available data and policy-relevant evidence on residential aged care. This has limited the scope for comprehensive and independent assessment of the system". I am therefore surprised that, two weeks after its release, the submissions to your review have not been made public.

In the interests of transparency, it is imperative that 321 submissions (i.e. the respondents who agreed for their submission to be published) are made public so that the primary data can be read/analysed. Researchers like myself need access to the primary data – to confirm/refute conclusions you both drew from the submissions.

In terms of the methodology of your review, I have some critical feedback.

1. Sample

There were 436 submissions. Yet only 11.6% of these submissions were referred to in the report: 30 in the body of the report and 21 in Appendix C. Is there a reason so few submissions were referred to in the final report?

2. Qualitative analysis

When reporting examples (i.e. quotes) from the data, it is important to be clear about who is speaking. There are many examples throughout the review when it was not clear who was speaking – aged care worker, relative/carer or provider.

I am sure your thematic analysis of participants' views was rigorous. However I was surprised you quoted from specific submissions numerous times (e.g. COTA, 6 times; Alzheimer's Australia, 7 times) while other organisations known for their critical perspective of the aged care system (e.g. Aged Care Crisis, Elder Watch, CPSA, and the state/federal nursing unions) were quoted much less.

In addition, 159 aged care workers made submissions (36% of the sample). Yet you only included a few aged care workers in the report. You quoted one particular aged care worker 5 times – including using the same quote twice.

3. Unsubstantiated claims

I appreciate the document is a review not an academic thesis. Nonetheless, I noticed several unsubstantiated claims. For example, you claimed: "Evidence suggests that the residential aged care system as a whole is one of relatively high-quality care?" (p 38) without providing any evidence to support this claim. Do you know the proportion of aged care homes that provide high standards or care?

Clearly passing accreditation is not an indicator of high standards of care. In addition to Oakden, there have been several recent allegations of poor standards of care – e.g. Tricare (Queensland), Opal Raymond Terrace Gardens (NSW) and Opal Lakeview (Victoria). Like Oakden, these aged care homes were all accredited by the Quality Agency.

Despite these criticisms, I welcome your review. I was particularly pleased to see that one of the key priorities in your proposed reforms is to acknowledge and reward providers that consistently provide high-quality care. A proactive approach is often more successful in improving quality than a reactive/punitive approach.

I was surprised that Ken Wyatt announced 'unannounced visits' as though they are a new initiative. In your review, you note that during the 2015-16 financial year, the Quality Agency undertook 2,866 unannounced visits.

It would be a new initiative, however, if all reports from unannounced visits were on the public record. I am sure members of the public would appreciate the transparency. I strongly disagree with members of ACSC who expressed caution about releasing unpublished reports from the Quality Agency. The minutes of the May 2017 meeting claim "these reports were more technical and, without explanation, may not provide useful information for consumers or their families". This remark patronises those of us who seek pertinent information about specific aged care homes.

I agree that the current accreditation system is currently a tick-a-box exercise with regulators only checking processes and policies. For the past 12 years, aged care advocates have bemoaned the lack of government action after the 2005 Senate Inquiry. This Inquiry concluded the standards and outcomes were too generalised to effectively measure care outcomes.


I agree that assessors must be trained to consider *and measure* the quality of care being delivered by aged care homes. However, without measurable outcomes, it is not possible to *measure* the quality of care in an aged care home.

A rigorous audit of aged care homes requires the Quality Agency to abandon the Single Aged Care Quality Framework in which 44 vague standards will be replaced with 8 even vaguer standards.

Rather than tinker with the accreditation standards and outcomes, it is my view that the Quality Agency needs to go back to the drawing board and start again. It is also my view that likert-type scale and smiley faces used in the Consumer Experience Surveys are too simplistic to collect information of any genuine value.

I would welcome the opportunity to discuss my concerns with you both.

Yours sincerely



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Cc Ken Wyatt, Aged Care Minister
 Lynda Saltarelli, Aged Care Crisis
 Michael Riley, Greysafe
 Carol Williams, Elder Care Watch