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Parliament House
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Re: *Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*

The Health Care Consumers' Association (HCCA) was incorporated in 1978 and is both a health promotion charity and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a member based organisation and for this submission we consulted with our members through the HCCA Health Policy Advisory Committee and the Health of Older Persons Consumer Reference Group.

Thank you for the opportunity to put forward consumer views on the quality of care in Residential Aged Care Facilities in Australia.

Yours sincerely

Darlene Cox
Executive Director

HCCA Submission to the Australian Government House of Representatives Standing Committee on Health, Aged Care and Sport

Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia

Submitted 23 February 2018

Executive Summary

As the peak member-based consumer advocacy organisation in the ACT, the Health Care Consumers Association (HCCA) has a longstanding interest in the quality of care in Residential Aged Care Facilities (RACFs) in the ACT. HCCA has long been aware that the quality of care offered by RACFs in our jurisdiction is both highly variable, and too often inadequate. Unfortunately, despite our persistent advocacy in this area HCCA has yet to observe sustained improvement in the quality of care offered across the residential aged care sector in the ACT. In general, consumers' rights and interests are insufficiently protected, and mistreatment of RACFs residents continues to occur with disturbing regularity.

Recommendations

To protect consumer rights and interests in residential aged care, HCCA recommends that:

- The Australian Government require all RACFs to participate in a comprehensive quality monitoring system with easy-to-understand and timely public reporting on quality of life as well as quality of care measures;
- Clinical and administrative managers in all RACFs set and model the expectation that (i) consumer and staff feedback and (ii) complaints about mistreatment and poor quality care are welcomed as opportunities for quality improvement and followed through for positive impact;
- Accreditation of RACFs continue to be undertaken by an Commonwealth Government agency, as a primary responsibility of government;
- In recognition that many people do not have ready access to the My Aged Care website, the Australian Government explore additional ways of sharing information about the quality of care provided in RACFs prospective RACF residents, including by supporting not-for-profit advocacy services to advise individuals about issues to consider when choosing an RACF;
- The practice of unannounced audits of RACF accreditation compliance be continued and expanded;

- The National Aged Care Quality Indicator Program be made compulsory rather than voluntary, and expanded to take in additional measures of aged care quality that matter to consumers (e.g. general health, functional status, mental health, comfort, nutrition, emotional wellbeing, opportunities for recreation, privacy, choice, and autonomy);
- The Australian Government implement a compulsory star rating scheme for RACFs, in order to present comprehensive quality information in a format that is easy for the public and aged care consumers to understand; and share this information publicly, in a system similar that implemented by the United Kingdom's Care Quality Commission;
- Ratios of nursing staff to RACF residents be increased, including outside of 9am to 5pm weekday working hours;
- Independent advocacy services – such as those offered nationally by the members of the Older Persons Advocacy Service – be expanded to ensure all RACF residents, including those who do not have friends, family or other representatives, have the assistance they require to address unsatisfactory aspects of their care; and
- An Official Visitors scheme be introduced across the RACF sector, to provide additional transparency around the operations of RACFs and an additional avenue for residents to raise concerns related to their care.

Defining residential aged care

RACFs are places where older people who can no longer reside at home both live and receive the care they require. The care provided in RACFs ranges from "personal care to assist with activities of daily living through to nursing care on a 24-hour basis".[1] RACFs offer short-term as well as permanent care, are subsidised by the Commonwealth Government's allocation of public funds, and are currently accredited by the Australian Aged Care Quality Agency,[2] although HCCA understands that the functions of the Australian Aged Care Quality Agency will soon be transferred to a new Australian Government agency. RACFs are sometimes referred to as aged care homes, nursing homes, hostels or aged care hostels.

RACFs are distinct from retirement communities or retirement villages. Though the latter sometimes provide health care services, retirement village residents live independently and do not require assistance with daily activities.[3] Retirement villages are regulated by State and Territory governments rather than the Commonwealth, and in contrast to RACFs they undergo voluntary accreditation under an industry-managed scheme rather than compulsory accreditation by a government agency.[4] Some RACFs are co-located with retirement villages and are managed by the same provider, but these two components of a single facility fall under quite different regulatory and legislative frameworks. This is not always made clear to residents and potential residents of these facilities, and this complex regulatory situation can cause understandable confusion for consumers of these services.

Specific Issues

1. The incidence of all mistreatment of residents in residential aged care facilities and associated reporting and response mechanisms, including the treatment of whistle blowers.

1.1. Incidence of mistreatment of residents in aged care facilities

Health care consumers in the ACT experience variable quality care in RACFs. As is the case nationally, many people continue to experience poor quality care despite the Australian Government's efforts to lift the quality of RACF care including through the initiatives outlined in the 2016 *Aged Care Roadmap*.[5] HCCA hears regularly from health care consumers who have recent first-hand experience of poor quality care and/ or mistreatment in RACFs. In the ACT, local media report regularly on cases of poor care and mistreatment. Recent cases include:

- Staff at The Canberra Hospital made a complaint to the Aged Care Complaints Commission after a resident of an aged care facility managed by Southern Cross Care was admitted to hospital with a maggot infested head wound in December 2016;[6]
- Three RACFs in the ACT were found to have unreasonably limited residents' access to independent advocacy services;[7] and

- The ACT Human Rights Commission found that St Andrews Village's nursing staff were inexperienced, and that staff lacked the skills to administer residents' medication appropriately.[8]

Although complaints-handling bodies in each of these cases found these providers ultimately adequately improved the care they offered, these recent cases highlight quality of care issues that affect residents across the RACF sector. As is the case across the health care system, it is likely that many instances of poor quality care and mistreatment never result in a formal complaint, nor achieve transparent public view.

Mistreatment of RACF residents includes abuse, neglect, poor quality medical care, inadequate personal care and undignified treatment. HCCA members have recent first-hand experiences of mistreatment that include:

- People with limited mobility being left alone or unattended for long periods of time, denying them sufficient opportunity for social interaction or enjoyable recreational activities;
- Being asked to spend an unreasonable amount of time in bed (for example, being put to bed at three o'clock in the afternoon) – possibly occurring as under-staffed RACFs seek to manage low staff numbers and/ or shift hand-over;
- Being given food that is medically inappropriate, for example not being provided with a low sodium meal or a diabetic meal when this is medically indicated;
- Having no choice about what to eat, which is distressing for people who cannot eat certain foods for cultural or religious reasons and for people used to eating food they find palatable;
- Poor management of pressure injuries and inadequate prevention of pressure injuries - compounded in many instances by being left sitting or lying for long periods of time;
- Being over-medicated with sedatives – likely in an inadequate and inappropriate attempt to manage the difficult behaviours of some residents; and

- Not receiving necessary clinical care overnight, often because fewer clinical staff are employed outside of day-time and weekday working hours.

HCCA's members have also made the organisation aware of cases in which residents of aged care facilities have been roughly handled by RACF staff, in which residents have acquired bruises that were never explained, and in which family members have strongly suspected but were unable to prove that their family member was being physically abused by a staff member.

Mistreatment of RACF residents occurs in the context of a residential aged care system that struggles to provide consistently high quality care. One person who contributed to this submission recently spent several weeks in an RACF receiving respite care. She described a facility with comfortable individual rooms for residents, and many staff who worked hard to make the facility a pleasant place to be. However, she felt the staff were so busy they never had time to talk with residents, and both staff and residents told her they saw little point suggesting improvements in care at their regular staff or residents' meetings because they felt these were unlikely to be followed up by management. One evening the facility under-catered and did not have enough food to prepare dinner for all residents, so some went without a meal. This experience paints a picture of a facility struggling with common challenges for the quality of RACF care, among them low numbers of nursing and care staff, variable capacity to provide basic services to residents (such as appropriate meals at appropriate times), and variable quality staff and resident consultation processes.

In many of the instances of poor quality care described above, an inadequate ratio of clinical staff and suitably skilled personal care staff to residents contributes to a systemic environment conducive to mistreatment of residents. An increased ratio of nursing staff and appropriately skilled care staff to residents across the RACF sector would improve the quality of care these facilities are able to deliver and reduce the likelihood of mistreatment.

1.2. Reporting and response mechanisms

Unfortunately in our jurisdiction the present complaints system has been ineffective in identifying the majority of quality of care issues, let alone resolving them. It is

often very difficult for consumers to make a complaint. As an organisation that advocates for consumer rights in accessing health care we are familiar with the barriers people experience in making complaints. Making a complaint takes time and energy. There is an emotional cost too. As consumers of aged care services, we are often unwell or struggling with our health and capacity. Many people are too busy dealing with what life presents – such as caring responsibilities, or recovering from illness – to make a complaint they recognise as appropriate to make.

Moreover, many people who experience or suspect mistreatment have a real, and not unreasonable, fear that if they complain they will acquire a reputation among staff as "troublemakers" and expose themselves (or their aged family member or friend) to further mistreatment. As is the case across the health system, consumers often fear that if they complain about their care-givers they will jeopardise the quality of care they receive. It is fair to say that some aged care facilities suffer from a workplace culture in which feedback, complaints and advocacy are not welcomed nor viewed as opportunities for improvement. Shifting this culture requires leadership and commitment from service managers (clinical and administrative), as well as practical processes to invite and welcome both formal and informal feedback from residents and their visitors. Staff of RACFs do not always feel encouraged to bring inappropriate behaviour by their colleagues to the attention of their managers. Change in this area must be led by senior managers who have the power to set expectations in this regard.

2. The effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the *Charter of Care Recipients' Rights and Responsibilities* in ensuring adequate consumer protection in residential aged care.

The *Aged Care Roadmap*[9] envisaged that:

> *"Government will establish and maintain consumer protections (including accreditation against core standards, compliance and complaints mechanisms) and encourage quality improvement by registration category. This includes mandating consumer involvement in the quality*

assurance process across end-to-end aged care; and ensuring reporting against standards is transparent and publicly available.'

The Roadmap also committed to "differentiated performance information on a single set of core standards and quality indicators will be published on the service finder in My Aged Care". While these are appropriate aims and HCCA welcomes the progress in these areas to date, our members remain concerned that the existing aged care standards remain insufficient and too easy to pass. This needs to be changed and HCCA sees this as a priority. In the words of one of our members: ***"We need a system with teeth that will protect people from poor care and mismanagement".*** The Australian Government's recent announcement that the Australian Aged Care Quality Agency will be disbanded and its functions transferred to a new Australian Government agency provides an opportunity to strengthen RACF quality assurance, public reporting on performance, and accreditation processes as well as compliance and complaints mechanisms.

2.1. Accreditation services

In most instances, RACFs receive significant advance notice of the date of accreditation audits. Unfortunately this means that RACF operators can alter their day-to-day operations in order to present a misleading picture of their usual quality of care. HCCA is therefore supportive of the practice of unannounced audits of RACFs, and would like to see this practice continued and expanded.

HCCA is concerned that the private sourcing of accreditation services - which we understand remains an area of interest for the Australian Government[10] - would denude consumer protections in residential aged care. While HCCA recognises the imperative on Governments to expend finite healthcare budgets judiciously, the private provision of accreditation services seems to us to open the door to a form of industry self-regulation that would be to the detriment of consumers and the quality of aged care we receive. While industry 'in-house' accreditation bodies have a part to play in lifting standards of service, their assessment processes tend to focus on praising and publicising selected positive aspects of a service rather than being comprehensive and exacting. If entrusted with the function of assuring that care

providers satisfy minimum standards of safety and quality, we believe they would tend to find excuses for service providers who fell short of meeting the standards, rather than render them liable to compliance action by Government. HCCA believes the accreditation function should remain the principal responsibility of Government.

2.2. Complaints handling processes

Despite the many barriers to making a complaint (See Section 1.2. above), many people do complain about the quality of care they received in residential aged care. Nationally, the majority of aged care complaints relate to residential aged care: the Aged Care Complaints Commissioner reported that 79 per cent of all complaints received in the 2016-17 financial year were about residential aged care. Most issues related to medication administration and management, falls prevention and post-fall management, and personal and oral hygiene. In the ACT a clear majority of aged care complaints relate to residential aged care: of the 71 complaints made to the Aged Care Complaints Commissioner about aged care in the ACT last year, 51 were about issues in residential facilities.[11]

Given this trend, HCCA believes that there needs to be more focus on reporting on the quality of care in RACFs, and making this information publicly available in ways that are easily understood by aged care consumers and the public. This would increase the accountability of providers and help consumers and families make informed decisions about care.

2.3. Consumer information about quality of care

Concerns about quality within RACFs are regularly raised in the media when questionable care practices or carer behaviour are exposed, but it remains very difficult for consumers to assess the quality of care offered by different facilities.

Consumer protection in residential aged care would be significantly improved if consumers had access to better information on which to confidently assess quality of care. At present, only limited performance information is published. While useful information is provided in the Audit Reports for individual RACFs that are available on the My Aged Care and Australian Aged Care Quality Agency websites, not all

older people nor their family members can readily access this information: around 15 per cent of Australian households do not have an internet connection, and in rural and remote Australia that percentage rises to over 20 per cent.[12] HCCA recommends that the Australian Government invest in additional ways of sharing information about RACF quality with prospective RACF residents, including resourcing appropriately skilled and knowledgeable not-for-profit aged care advocacy services to advise individuals about issues to consider when choosing an RACF, including sharing available information about quality of care.

While the Audit Reports are helpful, they are framed in a language of compliance that is appropriate for the purpose of accreditation, but not readily understood by aged care consumers. Nor do the Audit Reports provide all the information we require to make informed judgements. For example, a HCCA member recounted the following story of finding a place in a residential aged care facility for her mother. Her mother had fallen and broken her hip and needed nursing home care as she could not return home. The family was under significant pressure from hospital nursing staff to find a place and accept an offer. But the family were reluctant to take the first offer as they wanted to know things like: What is the general health of other residents? How long do people generally live at each facility? Is the quality of life good? Do they have access to health care? Does the facility have arrangements for general practitioners or nurse practitioners to visit? And what about dental care? How many complaints has the facility received and what were the issues of concern? How active is the resident and family advisory group? The Audit Reports provide some but far from all of this information.

The information on My Aged Care and the Australian Aged Care Quality Agency websites also do not provide the option for people to readily compare the quality of care provided at different facilities. By contrast, the UK Care Quality Commission administers a star rating system, in which aged care homes are assessed at providing care that is “outstanding”, “good”, “requires improvement” or “inadequate”. RACFs are required to display this information in a readily visible location on site, and on their websites (if they have them). The Commission also publishes an online interactive map that allows people to directly compare the quality of care provided by residential aged care facilities in their area.[13] This approach allows people to compare the quality of care offered at different facilities, and allows those facilities

that provide excellent care (as distinct from simply meeting minimum standards) to demonstrate this. HCCA recommends that the Australian Government implement and oversee a similar star rating system in Australia, that would allow people to readily compare the quality of care provided by different RACFs.

In the absence of meaningful data about these aspects of quality of care, consumers are too often left to judge quality on superficial measures. Many new aged care facilities shine with their stylish architecture and décor, and carefully stage managed tours to prospective residents. What really matters is reporting on quality of care. Health care consumers need to know about the mix and skills of staff, the nutritional quality of meals, the activity schedule, and access to primary care and rehabilitation services. We also need to know about extra services fees or additional expenses. This is an essential component of the information required to enable consumers to give fully informed financial consent.

Consumers simply cannot make informed choices about residential aged care without access to the right information. A consumer who participated in a previous HCCA consultation on residential aged care commented that:

> *"The capacity to make informed choices depends on consumers being able to readily access all the relevant information and to be resourced and supported in the decision making process. This cannot be just words. If we are to facilitate informed user choice there will need to be a strong and ongoing commitment to supporting consumers in their role".*

The provision of useful and appropriate information for consumers is important, both about the services available in RACFs and the likely outcomes of these services. In residential aged care as in many areas of health care, the information available on health outcomes is often of poor quality and low reliability. Unfortunately, service providers can often skew this information to their benefit, without improving the outcomes for service users. Across health and human services, data reporting remains generally process oriented and business focussed, rather than looking at the needs of service users to ensure high quality health, social and personal care to meet the needs of our ageing community, as well as the quality and respectfulness of the services provided.

RACFs are places for people to live, as well as to rehabilitate and receive the clinical services they need, such as wound dressing and medication. As a consequence, consumer perceptions of what constitutes quality of care encompasses broader issues than in mainstream health services such as hospitals and rehabilitation centres. Indicators for quality of life in residential care could include general health, functional status, mental health, comfort, emotional wellbeing, opportunities for recreation and diversion, privacy, choice, and autonomy. Health care consumers need a structured and comprehensive quality monitoring system with public reporting that takes the multifaceted experience of RACF care into full account.

HCCA is hopeful that future iterations of the National Aged Care Quality Indicator Program will move beyond the current appropriate but limited measures of aged care quality (pressure injuries, use of restraint and unplanned weight loss[14]), to take in additional measures of quality of care that matter to consumers. The addition of consumer experience data based on a survey of a sample of residents in each facility to supplement annual Audit Reports is also a move in the right direction,[15] however it remains the case that this data will not provide all the information consumers need to make fully informed judgements about quality of care. By contrast, The United States has introduced, and continues to refine, a compulsory system of assessment within its nursing homes, aimed at monitoring quality of care and clinical outcomes. HCCA's position is that there is an urgent need for mandated quality indicators that are publicly reported.

HCCA notes also that the Aged Care Roadmap assumes that competition on quality will ensure that better services flourish and poor quality ones don't. While this might be a theoretical expectation, this relies not only on the availability of much more relevant information to consumers and families, but also a market where demand is equal to or less than supply. In a providers market, where demand exceeds supply as appears often to be the case, the incentive for consumers and carers is to get into any place at all. Market mechanisms cannot be relied upon as a major driver of quality in these circumstances.

2.4. Monitoring quality of care

Monitoring of quality of care can be improved. HCCA is pleased to see that recently the My Aged Care website was upgraded to provide historical as well as recent Audit Reports for each facility, including when facilities have changed names and/or operators. This is important as it allows consumers to have a clearer sense of what has happened at a facility over time, particularly given that change in ownership and name is not an uncommon occurrence.

Audit Reports should also be released in a timely manner. Significant time can elapse between re-accreditation processes, meaning it is very difficult for consumers to have up-to-date information about quality of care on which to draw in their decision-making. There can also be a lag time of weeks to months between an audit visit and the release of an Audit Report. This means that if a consumer or carer were making a decision about whether or not to accept an offer at a particular RACF they would have no up-to-date information on which to draw. Consumers need up-to-date information if we are to make informed choices.

The content of the audit reports also needs to be improved. For example, the profile on staffing in these audit reports has raw numbers. If a service lists a dietician it would be useful to know if this person is full time or part time.

3. The adequacy of consumer protection arrangements for aged care residents who do not have family, friends or other representatives to help them exercise choice and their rights in care.

Friends or family can recognise when a person's care is appropriate or inappropriate, and can advocate for their needs and help staff to anticipate or to resolve issues. Family and friends also often take on a role in escalating issues to RACF management, providing feedback and when necessary instigating a complaints process. People who do not have involved friends or family do not have this support, and are therefore at enhanced risk of poor quality care and mistreatment.

Access to independent advocacy services is important for all RACF residents, but is essential to ensure the consumer protection of aged care residents who do not have family or friends to help them exercise their rights and choices in care. HCCA suggests that need and demand for independent advocacy services – such as those

offered nationally through the Older Persons Advocacy Network - will continue to grow as the aged care population increases. Services of this kind will require appropriate resourcing in order to meet current and future demand.

HCCA also recommends that a national Official Visitors Scheme be established across the RACF sector. We regard the ACT Official Visitors Scheme, which includes Official Visitors for Children and Young People, Mental Health, Corrections, Disability and Housing (Homelessness), as a good model for work of this kind in our jurisdiction. In the ACT, Disability Official Visitors do visit residential aged care facilities where younger people with disabilities live.[16] HCCA suggests that a national Official Visitors Scheme for all RACF residents be implemented in partnership and close collaboration with existing Official Visitors schemes operating in several states and territories. An Official Visitors scheme for RACFs would provide an additional avenue for residents to raise concerns related to their care, and increase the transparency of the operations of RACFs. In contrast to advocacy services, Official Visitors need not wait for a resident to make a complaint about their care, and as a result have the opportunity to identify systemic problems in care when residents or staff are reluctant or afraid to complain.

4. Concluding remarks

HCCA looks forward to seeing how our feedback and comments shape improvements in the quality of care offered by RACFs. Please do not hesitate to contact us if you wish to discuss our submission further. HCCA would be happy to clarify any aspect of our response.

5. References

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