

25 September 2018

Dear Dr McCarthy

CONSULTATION TO DEVELOP THE DETAILED TERMS OF REFERENCE FOR THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

Painaustralia welcomes the opportunity to provide input to the Department of Health's consultation to develop the detailed terms of reference for the Royal Commission into Aged Care Quality and Safety.

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain. Members include pain and other specialists, health practitioners, health groups, consumers and researchers. Painaustralia works with our network to inform practical and strategic solutions to address this complex and widespread issue. The issue of safety and quality of care across aged care is an important one for us and our members.

The consequences of untreated pain not only impact the individual resident, there is greater distress to their families and a greater burden of care for staff.

With an ageing population—the Australian Bureau of Statistics projects that by 2064 there will be 9.6 million people aged 65 and over, and 1.9 million aged 85 and over, constituting 23% and 5% of Australia's projected population respectivelyⁱ—the issue of effective pain management in aged care is an issue that is in the interest of every Australian.

Chronic pain is a common condition among residents of aged care facilities and effective pain management should be a core responsibility of all providers. Unfortunately, evidence suggests many residents with pain are poorly treated or under-treated.

Painaustralia recommends that the Terms of Reference include:

- a specific reference to pain management across aged care, especially among people with cognitive and neurological conditions with reference to a Human Rights focus on understanding the needs of aged care recipients;
- the need to empower consumers and carers to be at the front and centre of aged care;
- appropriate education and training of the aged care workforce;
- implications of the regulatory framework for safety and quality of care including the lack of consistent quality measures and the lack of publicly available information about providers and quality;
- barriers to accessing palliative care; and
- impact of the aged care funding instrument.

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THE PREVALENCE OF UNTREATED PAIN IN AGED CARE

It is estimated up to 80% of aged care residents have chronic pain,^{ii,iii} however more than half of residents (52%) in aged care facilities in Australia have a diagnosis of dementia while two in three (67%) require high-level care to manage behaviour.^{iv} This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and inability to report pain.

Evidence also shows that people with dementia in particular are living with pain and are being under-treated compared with cognitively intact persons, despite having similar levels of potentially painful disease.^v

In one study, pain was detected in just 31.5% of cognitively impaired residents compared to 61% of cognitively intact residents, despite both groups being equally afflicted with potentially painful disease.^{vi}

People living with dementia have shared stories of an aged care system unable to meet their needs with reports of incidences that span physical, psychological and sexual abuse; inappropriate use of restraints; unreported assaults; and people in extreme pain at end-of-life not having access to palliative care.^{vii}

Untreated or poorly treated chronic pain can perpetuate the pain condition and severely reduce function and quality of life. It impacts personal relationships and can have profound emotional and psychological ramifications.

For many people, feelings of anxiety, sadness, grief and anger related to the pain can create a burden that is difficult to manage and may lead to the emergence of mental health problems. Major depression is the most common mental health condition associated with chronic pain, with rates of 30% to 40%, and there are also high rates of generalised anxiety disorder and post-traumatic stress disorder.^{viii}

These statistics are especially concerning in light of research by the National Ageing Research Institute that more than 50 percent of those living in aged care facilities have either anxiety or depression or both disorders, and just under 50 percent enter residential care with a pre-existing depressive condition.^{ix}

KEY ISSUES TO CONSIDER IN DRAFTING TERMS OF REFERENCE

Human Rights focus to aged care

Over the course of the last 12 months, there have been a number of examples in the media of providers in the aged care sector providing poor care and failing to respond to the needs of consumers, resulting in a series of inquiries into the quality of care provided in residential aged care facilities, including the Senate Standing Committee on Community Affairs Inquiry into the effectiveness of the Aged Care Quality Assessment and Accreditation Framework and the Ministerial Review of National Aged Care Quality and Regulatory Processes. These inquiries have resulted in large scale evidence gathering exercises, which have clearly highlighted that the human rights of aged care recipients in Australia have been routinely violated.

This includes many barriers in access to timely and appropriate pain management. While access to pain management is acknowledged globally as a fundamental human right in the Declaration of Montreal,^x which has been endorsed by the World Medical Association, Australia's aged care facilities are clearly falling short of effective pain care and the intent of this Declaration.

Empowered consumers and carers at the centre of aged care

Aged care in Australia remains one of the few services where consumers are not routinely engaged as part of the quality assessment process. On the contrary, current safety and quality systems have created outcomes where we see multiple reports of consumers indicating they are fearful of complaining or making negative comments about service quality because they fear retribution on their loved ones and have limited options to access alternative care.

Aged care in Australia needs to put consumers at the front and centre of service delivery, to match consumer expectations across nearly every other service sector in the country. We also need to empower consumers to have choice over the setting of their aged care services.

More and more consumers are now looking to age in place, with demand for home care packages and community based aged care far exceeding current supply. Building awareness of pain and its management is central to ensuring that consumers can be supported to self-manage their pain.

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then it is also important to recognise that carers are an essential part of the equation. Thirty six percent of all carers are over the age of 65 and most are caring for a partner,^{xi} however right now there is no emphasis on education and training programs that enable carers and informal support to provide essential community-based care such as holistic pain management.

Workforce education and training

In 2016-17 the most common complaints provided to the Aged-Care Complaints Commissioner related to medication administration and management, falls prevention and post-fall management. If pain is better assessed and managed in the first place, quality of life and quality of care would be improved significantly.

Inadequate education and training of residential aged care staff is largely responsible for the under-reporting of pain in cognitively impaired residents—impacting some of the most vulnerable people in our society.

A recent survey found that 41% of care professionals reported having received no training on assessment of pain in people with dementia, while 90% of care professionals indicated that additional training in dementia would be beneficial.^{xii}

The Australian Pain Society (APS) in its guidelines *Pain in Residential Facilities – Management Strategies*, indicates that staff workloads may also be to blame, with a lack of time for adequate pain assessment on a regular basis.^{xiii}

Education and training of staff is a vital component for the provision of high quality residential aged care, because when people with dementia or other cognitive impairment are in pain, although they are unable to tell anyone verbally, pain may trigger behavioural changes and any such changes should be investigated. These changes may be observed by carers or family members.

Behavioural and psychological symptoms of dementia (BPSD) are also often an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain)^{xiv}. In the absence of effective pain management strategies, BPSD is often addressed through inappropriate use of chemical and physical restraints that can lead to much worse outcomes and harm for consumers.^{xv}

Appropriate training for aged care staff would help to identify this. Aged care staff with day-to-day responsibilities for residents should have adequate knowledge and skills in pain assessment and management, including for people with dementia or other cognitive impairment.

The Royal Commission should have a particular focus in understanding the role poor education and training have had to play on the quality and safety of aged care.

Regulatory frameworks and implications for safety and quality of aged care

Critical to providing high quality residential aged care is developing industry standards and protocols to ensure providers establish systems for aged care staff to conduct regular pain assessments for individual residents.

Currently no such standards and protocols are in place, and without them, there is no requirement for providers to implement this essential level of care for individuals. Notwithstanding acute pain from recent injury or surgery, the vast majority of cases of pain experienced by aged care residents are chronic pain. This is described as ongoing pain, either recurrent or daily.

Despite the high prevalence of pain in our aged care facilities and the high rate of unmanaged pain, the Australian Aged Care Quality Agency's Accreditation Standards mention pain only in brief:

Standard 8.2 Pain management: All care recipients are as free as possible from pain.^{xvi}

There is no requirement for a best-practice approach to care and no requirement to help the resident achieve better quality of life. The standard also fails to acknowledge the need for ongoing pain assessments or the need to identify pain in non-verbal patients.

A significant body of research has shown that medication alone is not an effective solution and that a holistic approach to pain management, known as multidisciplinary pain management, is the best way to minimise the impact of pain, reduce disability and improve function and wellbeing. This is a key recommendation of the National Pain Strategy.^{xvii}

The standard also fails to acknowledge the need for ongoing pain assessments for non-verbal residents. Cognitively intact residents may also face challenges in communicating pain, which could lead to under-reporting and under-treatment. If residents cannot express their pain and the workforce is not trained to manage BPSD then pain is not identified, and facilities have been repeatedly accredited despite having a significant proportion of residents living in pain and with other standards failures.

The current accreditation process for aged care facilities relies on self-assessment, with facilities inspected by the Australian Aged Care Quality Agency just once a year and assessors speaking to only a minimum of 10% of residents during inspections. Over 95% of facilities pass accreditation which seems extraordinary in light of genuine quality of care issues such as poor pain management.

The risk of overlooking serious failures is therefore high, especially in the case of people with dementia or other cognitive impairment. In people with cognitive impairment who are non-verbal, untreated chronic pain can result in BPSD and lead to inappropriate use of chemical and physical restraints.^{xviii}

It is estimated that about half of people in aged care and about 80% of those with dementia are receiving psychotropic medications. There is sound evidence to suggest that in some cases these medications have been prescribed inappropriately.^{xix}

Lack of consistent quality indicators

Aged care in Australia is unique in that there is no nationally consistent and measured quality indicators. For a person or their carer considering placement in a residential aged care facility, or considering a new home care package provider, there is no consistent information that can aid in this decision-making process, for instance whether a facility or provider has met or exceeded the expected outcomes. There is much to be learned in this regard from the public health system. Another example of how this might work is provided in the health care sector by the Australian Commission of Safety and Quality in Healthcare (ACSQHC), through the development and implementation of the National Safety and Quality Health Service (NSQHS) Standards.

Lack of publicly reportable information

As highlighted in the many instances of consumer stories that have surfaced over the course of the past year, people often make the decision to move a loved one into a residential care facility purely on the basis of marketing and promotional information, predominantly provided by service providers.

Although the accreditation status of a residential aged care facility is publicly available, these documents are often difficult to interpret and that there is a lack of transparency as to how that relates to quality of care. Ultimately, it is vital that safety and quality mechanisms span consumer experience and quality of life within aged care services and that they are reported in a way that is both accessible and meaningful to consumers.

Barriers to accessing Palliative Care

In 2010–11, 75% of the 116,481 people aged at least 65 years who died in Australia had used aged care services in 12 months before their death^{xx}. The older a person was when they died, the more likely they were to have been accessing a service at the time of death.

There is evidence to suggest that many people, especially those with cognitive impairment, may experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation over their choices regarding end of life care.^{xxi}

Nationally there were 231,500 permanent residents in Australia in 2014–15 with completed ACFI appraisals, yet only 1 in 25 of these indicated the need for palliative care.^{xxii}

Clearly, right now our aged care services are not doing enough to provide recipients with access to appropriate and timely aged care. Ensuring the availability of high-quality palliative and end-of-life care services in aged care facilities and people's own homes, will enable more

older Australians to have a good death, better support their families and carers during the dying and bereavement processes and facilitate the better allocation of scarce health resources, and this should be a pivotal consideration for the Royal Commission's inquiry.

Impact of the Aged Care Funding Instrument (ACFI)

Residential aged care in Australia is predominantly funded by the Commonwealth Government through tax revenue with some finance coming from other levels of government and user co-contributions. Funding for each individual resident's care needs is determined by the Aged Care Funding Instrument (ACFI) with residents receiving a subsidy paid directly to the residential aged care provider.

The sum paid to the residential aged care provider is dependent upon the extent of the resident's care needs with the ACFI used to determine the total amount of the subsidy in three areas: Activities of Daily Living (ADL), Behavioural Supplements, and Complex Health Care supplements.

However, a recent evaluation of the tool notes that it is 'no longer fit for purpose'. Firstly, the ACFI subsidy level is not related to the factors that determine the need for care. This is a fundamental flaw in the ACFI as it inevitably leads to negative consequences where providers are rewarded for admitting higher subsidy residents who will be relatively less expensive to care for.

Professor Kathy Eagar, who led the research team, from the Australian Health Services Research Institute based at the University of Wollongong notes that the ACFI in fact provides 'perverse incentives' to providers^{xxiii}, in effect rewarding them to keep elderly residents more dependent on care.

"A person who can't walk, is completely bedbound and who has a wound ulcer is very different to look after than a person who's mobile with a wound ulcer. And yet the ACFI treats those two items as though they're independent of each other." ^{xxiv}

Most significantly, funding freezes to the ACFI in 2016, have resulted in the reduction of subsidy for the complex health care supplement which particularly impacts high-needs residents with complicated pain-management regimes. This has led to the removal of essential pain management services such as necessary physiotherapy and palliative care and diminished the capacity of the sector to provide appropriate levels of pain management in aged care.

Despite the recommendations of the University of Wollongong report, ^{xxv}the ACFI remains unchanged, compounding the issues faced by residents of aged care every day. It is vital that the Royal Commission consider the impact of the current aged care funding mechanisms on the safety and quality outcomes of care.



CONCLUSION

While access to pain management is acknowledged globally as a fundamental human right and the Australian Government recommends best-practice care for aged care residents, Australia's aged care facilities are falling woefully short of effective pain care.

A significant number of residents have pain that is under-treated and are suffering unnecessarily (particularly those with dementia or other cognitive impairment), something that could be avoided through appropriate workforce education and training and adequate regulatory reform of the accreditation and funding system.

Leadership at a national level that prioritises a multidisciplinary, industry-wide approach will be essential to address these issues. It should include an Aged Care Quality Assessment and Accreditation Framework that supports quality of life. This will be achieved with best-practice pain management, along with appropriate education and training of staff (particularly in the identification of non-verbal signs of pain); appropriate funding that meets the needs of each aged care recipient, appropriate reporting policies and protocols; and education for aged care residents with sufficient capacity to self-manage their pain where appropriate.

We look forward to the opportunity to provide input to the Royal Commission into Aged Care Quality and Safety as it provides us with a generational opportunity to create an aged care environment that affords dignity to the older and frail- some of the most vulnerable people in our society. With an ageing population, effective pain management is an issue that is in the interests of every Australian.

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