

painaustralia

AGED CARE QUALITY AND SAFETY
COMMISSION BILL 2018 AND
RELATED BILL

September 2018

About Painaustralia

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.

Executive Summary

Painaustralia welcomes the opportunity to provide input to the Senate Community Affairs Legislation Committee Inquiry into the Aged Care Quality and Safety Commission Bill 2018 and the Aged Care Quality and Safety Commission (Consequential Amendments and Transitional Provisions) Bill 2018 (the Bills).

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 respectively¹—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.

In considering the Bills, Painaustralia makes the following recommendations:

- Explicit emphasis on protecting Human Rights of aged care recipients;
- Enshrining Independence of new Safety and Quality Commissioner;
- Appointment of Consumer Commissioner to support the work of the new Commission; and
- Disbanding of the existing Aged Care Quality Advisory Council and appointment of new members to the Aged Care Quality and Safety Advisory Council.

The Prevalence of Untreated Pain in Aged Care

It is estimated up to 80% of aged care residents have chronic pain,^{2,3} 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.⁴ 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.⁵

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.⁶

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.⁷

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.⁸

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.⁹

Key Issues to Committee to Consider in Relation to Bills

Explicit emphasis on protecting Human Rights of aged care recipients

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 was corroborated by the Australian Law Reform Council's report on Elder Abuse which notes that older people receiving aged care—whether in the home or in residential aged care—may experience abuse or neglect. Abuse may be committed by paid staff, other residents in residential care settings, family members or friends.¹⁰

However, as noted in the explanatory memorandum for The Aged Care Quality and Safety Commission (Consequential Amendments and Transitional Provisions) Bill 2018:

“this Bill does not explicitly engage the right of a person’s protection from exploitation, violence and abuse as contained in article 20(2) of the International Covenant on Civil and Political Rights and article 16 of the Convention of the Rights of Persons with Disabilities, this Bill provides transitional arrangements for the commencement of the Aged Care Quality and Safety Commission.”

In the light of recent revelations, it is inadequate that the Bill does not explicitly protect the human rights of aged care recipients. Protecting human rights violations is also vital for people living with chronic pain, who already face significant 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,¹¹ 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.

This was also a firm recommendation from the Review of Aged Care Regulatory Process, which notes that:

“Elderly citizens living in care facilities, many of whom suffer from disabilities and dementia associated with ageing, are especially in need of protection... Thus, we see the primary role of quality regulation as consumer protection.”¹²

In its current form, without explicitly protecting the right of a person’s protection from exploitation, violence and abuse, this bill does not go far enough.

Enshrining Independence of new Safety and Quality Commissioner

We note that the Memorandum of Explanation accompanying the Aged Care Quality and Safety Commission Bill 2018 states:

“The Commission will be led by a statutory appointed Aged Care Quality and Safety Commissioner who will be supported by an advisory body (the Aged Care Quality and Safety Advisory Council).”

Statutory office-holders and the commissions or authorities they head are primarily the creations of executive government. Executive governments initiate these bodies and appoint their leaderships, they propose their statutory powers and, importantly, fund their activities.

However as noted by Professor John Wanna, the Foundation Professor for the Sir John Bunting Chair of Public Administration, with the Australia and New Zealand School of Government (ANZSOG) based at the Australian National University, while Governments grant a certain degree of independence and latitude to these statutory office holders, this is often conventionally understood rather than specifically stipulated in statutes.¹³

Given that a Royal Commission was necessary to investigate the length and breadth of aged care safety and quality, more needs to be done to enshrine the independence of the new safety and quality commissioner in the Bill.

As highlighted by the Australian Medical Association:

*“The aged care system needs an overarching, independent, Aged Care Commissioner that provides a clear, well-communicated, governance hierarchy that brings leadership and accountability to the aged care system.”*¹⁴

Appointment of Consumer Commissioner to support the work of the new Commission

In their final report on the Review of Regulatory Process, Carnell and Patterson recommend:

“We propose establishment of an Aged Care Quality and Safety Commission. We recommend that the new Commission comprise an Aged Care Quality Commissioner, an Aged Care Complaints Commissioner and an Aged Care Consumer Commissioner. An Aged Care Commission Board would govern the Commission. Within the new Aged Care Commission, a Chief Clinical Advisor will provide clinical leadership.”

While we note that the Bill proposes the creation of the Aged Care Quality and Safety Commissioner and a Clinical Advisor, we are extremely disappointed to note that no reference is made to the Carnell Patterson recommendation of an Aged Care Consumer Commissioner.

This is a significant omission, given that the recommendations were made to ensure that greater prominence is given to the rights of consumers of aged care residential services. Leadership in education was intended to be pivotal to the new Consumer Commissioner’s role within the proposed Aged Care Commission, working alongside the Aged Care Complaints Commissioner to educate the public and providers about consumers’ rights.

In fact, as envisioned by Carnell Patterson, the Consumer Commissioner would promote and protect consumer rights. This distinctive role should therefore be highlighted and mandated especially if the Bill aims to keep consumers ‘at the heart of the reforms.’

Disbanding of the existing Aged Care Quality Advisory Council and appointment of new members to the Aged Care Quality and Safety Advisory Council.

The memorandum of explanation for Aged Care Quality and Safety (Consequential Amendments and Transitional Provisions) Bill 2018 notes that:

“this Bill provides for the continuation of the appointments of the members of the existing Aged Care Quality Advisory Council, as members of the new Aged Care Quality and Safety Advisory Council. This will enable the new Advisory Council to commence operations immediately and will provide stability and experience in the advice being provided to the Commissioner and to the Government.”

Established in 2014, the Aged Care Quality Advisory Council’s aim was to provide advice about the operations and functions of the Australian Aged Care Quality Agency including promoting continuous improvement and compliance with quality standards.

Recent catastrophic failures reported in the media highlighted that the Agency has shut down 12 homes – an average of one per month, requiring 300 residents to be rehomed in other facilities – and placed sanctions on 26 others over the course of the last year. It is clear that the Council has failed in delivering on its mandate of a period of time.

Reinstating its current members to the new Aged Care Safety and Quality Commission will only perpetuate the executive level disregard for consumer safety and quality that has led to the instigation of a Royal Commission.

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 safety and quality for consumers is an urgent priority for aged care. This should include an Independent Aged Care Safety and Quality Commission that prioritises consumers. This will be achieved by including a strong human rights focus embedded in the Bill, enshrining the independence of the aged care quality and safety commissioner, appointment of a consumer commissioner to support the work of the commission and the appointment of new and **independent** members to the Aged Care Quality and Safety Advisory Council.

We look forward to the opportunity to provide input to the Senate’s inquiry.

References

- 1 ABS, Population Projects, Australia, 2012 (based) to 2101 Cat. No. 3222.0 2013
- 2 Gibson SJ, Improvement of Pain Management in Residential Aged Care, Issues Paper
Zwakhalen S, Pain in elderly people with severe dementia: A systematic review of be-
havioural pain assessment tools, BMC Geriatrics 2006;6:3
- 3 Australian Institute of Health and Welfare, [Residential aged care and Home Care 2013-14](#)
web report 2015
- 4 Gibson SJ, The IASP Global Year Against Pain in Older Persons: Highlighting the current sta-
tus and future perspectives in geriatric pain Expert Reviews in Neurotherapeutics, 2007;7(6),
627-635
- 5 Proctor WR & Hirdes JP, Pain and cognitive status among nursing home residents in Cana-
da. Pain Research and Management 2001;6(3):119-125
- 6 Alzheimer's Australia (2013). Paper 37: Quality of residential aged care: The consumer per-
spective, p 4.
- 7 Demyttenaere K et al., Mental disorders among persons with chronic back or neck pain: re-
sults from the World Mental Health Surveys. Pain 2007;129:332-342
- 8 Aged Care Guide 2017. Aged care residents more likely to experience mental health issues.
Access online here.
- 9 Australian Law Reform Council 2017. Elder Abuse— A National Legal Response. Access
online [here](#).
- 10 International Association for the Study of Pain, [Declaration of Montreal](#) 2010
- 11 Carnell, K; Patterson, R 2017. Review of National Aged Care Quality and Regulatory Pro-
cesses. Access [online](#)
- 12 Wanna, John 2015. How independent is statutory independence? Access online [here](#).
- 13 AMA 2017. Submission to Review of Aged Care Regulatory Processes.

painaustralia

Mailing address: PO Box 9406 DEAKIN ACT 2600

Phone: 02 6232 5588

Email: admin@painaustralia.org.au

Website: www.painaustralia.org.au