

**pain**australia

AGED CARE AMENDMENT  
(STAFFING RATIO DISCLOSURE)  
BILL 2018

October 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 Standing Committee on Health, Aged Care and Sport Inquiry into the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018 (the Bill).

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 adequate aged care staffing to ensure safety and quality of 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. The aged care sector workforce is a critical element in the provision of quality services, and this workforce must be available in sufficient numbers, and be of a high quality to minimise the impact of pain on consumers.

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 respectively—the issue of effective pain management in aged care provided by a skilled workforce 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 is strongly supportive of its intent to legislate the quarterly publication of ratios of aged care recipients to staff members for each residential care service operated by approved providers. We applaud and endorse the Bill's aim of creating greater public transparency in the provision of residential care services and informing members of the public in any choice they may make regarding residential aged care services.

In addition, our submission raises other key issues for the Senate's consideration:

- The need to protect the human rights of aged care recipients
- The need to focus on quality of aged care service provision, in particular an emphasis on adequate training and education of aged care staff as well as access to best practice pain management strategies in residential aged care.

## The Prevalence Of Untreated Pain In Aged Care

It is estimated up to 80% of aged care residents have chronic pain,<sup>2,3</sup> 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.<sup>4</sup> 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.<sup>5</sup>

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.<sup>6</sup>

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.<sup>7</sup>

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.<sup>8</sup>

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.<sup>9</sup>

## Key Issues To Committee To Consider In Relation To Bill

### Protecting Human Rights of aged care recipients

The provision of quality aged care and support in a suitable environment is a central human right. The United Nations Principles of Older Persons states that:

*“Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care, or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”<sup>10</sup>*

These principles are applicable to all older people accessing residential and home-based aged care in Australia, including people older living with chronic pain.

Over the course of the last 12 months however, 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 (both of which PainAustralia has provided submissions to). 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.<sup>11</sup>

In light of recent revelations, it is essential to have legislation that protects the human rights of aged care recipients. Preventing 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,<sup>12</sup> 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.”*<sup>13</sup>

The Bill will create greater public transparency in the provision of residential care services and enable members of the public to have access to crucial information that supports their decision making, and thus will be a step in the right direction for aged care in Australia.

## Quality of care

While ensuring access to appropriate staff levels is crucial to improve the quality of Australian aged care, the number of older Australians with chronic pain is significant, and the core business of both residential and home-based aged care services increasingly includes providing care to people living with chronic pain. It is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people living with chronic pain, as part of their core business.

The aged care sector workforce is a critical element in the provision of quality services, and to ensure quality, the workforce must have the appropriate education and training, skills, and attributes to provide the care that is needed. This includes the capacity to provide quality care to people living with chronic pain, who are often frail and vulnerable, may have cognitive impairment and often have complex care needs.

- **Inadequate education and training of residential aged care staff leading to under-reporting of pain**

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.<sup>16</sup>

In its report *Encouraging Best Practice in Residential Aged Care Program*, the University of Wollongong states (p38):

*“One of the issues in residential aged care is that clinicians with the most knowledge and expertise (registered nurses and general practitioners) have the least involvement in the day-to-day care of residents.”*<sup>15</sup>

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.

Education and training of staff is vital 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.

It has been shown that Behavioural and Psychological Symptoms of Dementia (BPSD) are often an expression of emotion or unmet need (for example, pain)<sup>16</sup> and appropriate training 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.

This would be consistent with the Australian Government's *National Safety and Quality Health Service Standards* (Standard 1 Governance and quality improvement systems), which highlight the need for governance systems that set out clear policies, procedures and protocols for "implementing training in the assigned safety and quality roles and responsibilities."<sup>17</sup>

- **Insufficient education about best-practice pain management for aged care residents**

Many older people believe that pain is a normal part of ageing and there is little potential for improvement. They also fear addiction to pain medications; they are concerned that pain may suggest worsening of disease; they are worried they will be seen as people who complain too much; and are also reluctant to seek help for fear of further functional dependence due to disease progression.<sup>18</sup>

Programs such as Seniors ADAPT have shown that age is not a factor in being able to improve function and quality of life, given education in best-practice pain management and the right support.

Managing pain at end-of-life is also an important consideration. It requires much more than analgesic and other medication to manage pain. It needs to prevent suffering but should also consider physical and psychological factors as well as spiritual and cultural beliefs and attitudes towards dying. For example, some people may not wish to receive a strong painkiller because of side-effects.

Residents who have sufficient physical and cognitive ability should have the opportunity to be actively involved in their own pain management. They should also be encouraged to develop a plan detailing their pain management wishes at end-of-life.

## 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 to legislate adequate access to a skilled workforce.

Leadership at a national level that prioritises safety and quality for consumers is an urgent need for aged care. We look forward to the opportunity to provide input to the Senate's inquiry.

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