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# SUBMISSION TO EVALUATION OF NATIONAL FRAMEWORK FOR ACTION ON DEMENTIA

**JANUARY 2020**

# INTRODUCTION

Painaustralia is pleased to provide input to the Evaluation of the National Framework for Action on Dementia 2015 – 2019 (the Evaluation).

Our submission makes the following recommendations for the Evaluation of the National Framework for Action on Dementia:

- The Evaluation recognises the prevalence of pain among residents of aged care and its relationship to incidents of mistreatment and severe behaviours.
- The Framework ensures that all staff in residential aged care facilities receive mandatory, high quality training in pain management and dementia care, including a biopsychosocial model of care and alternatives to physical and chemical restraint.
- The Framework builds on the commitments to the National Strategic Action Plan on Pain Management to enhance access to best practice, community-based pain management services for older people living with chronic pain.
- A focus on embedding pain management across the aged care Safety and Quality framework to ensure providers are responsive to chronic pain across aged care.
- The Framework considers targeted national pain programs that can be developed and implemented in residential and community aged care for staff, consumers, family and friends or representatives.

# BACKGROUND

## Dementia and Chronic Pain

Notwithstanding acute pain from recent injury or surgery, the vast majority of cases of pain experienced by aged care residents are chronic pain. Chronic pain is usually considered as pain that has lasted beyond the time expected for healing following surgery, trauma or other condition—usually three months.[1]

The prevalence of acute and chronic pain among those with dementia should be recognised as a significant factor in severe behavioural and psychological symptoms of dementia (BPSD), which may be caused by the unmet needs that the person with dementia cannot otherwise express, e.g. pain, frustration, fear.[2]

As noted under Priority Area 4.4 of the Framework, BPSD can be distressing and have a severe impact on the person with dementia, their carers and families, care workers, and the broader health system.

People living with dementia have shared stories of an aged care system that is 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.[3]

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.

It is estimated up to 80% of aged care residents have chronic pain,[4,5] however more than half of the residents (52%) in aged care facilities in Australia have a diagnosis of dementia while two in three (67%) in these facilities require high-level care to manage behaviour.[6] This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and an inability to report pain.

While chronic and acute pain is common among residents of aged care facilities, the evidence suggests that pain is misunderstood, poorly managed and undertreated, including the suboptimal use of analgesics.[7]

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.[8]

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.[9]

**Recommendation**
The Evaluation recognises the prevalence of pain among residents of aged care and its relationship to incidents of mistreatment and severe behaviours.

# KEY ISSUES

## 1. Pain Management and Quality use of Medications in Residential Aged Care

The Aged Care Royal Commission has confirmed that there is primarily a pharmacological approach to pain management in Residential Aged Care. Studies indicate that up to 91% of aged residents can be prescribed analgesics, with nearly 30% taking regular opioids. The concurrent use of sedatives is also high, with 48.4% of those taking regular opioids also taking an anxiolytic/hypnotic[10].

*We were told there was a one-hour window around the designated time for any medication and that included pain meds. This was difficult for my dad as his pain increased very quickly when it was time for a new pain med. So after half an hour he was in heaps of pain. Towards end of life it became increasingly difficult as we would have to press the buzzer. It could take twenty minutes for someone to come then they would have to get a nurse which could take another half an hour. He was calling out 'please help me' 'make it stop' and it was so hard to help him. I had to continually ask for there to be a better pain management routine for him and it took days of asking before something happened.*

***Carer of person in residential aged care***

Another complication when treating pain in older people is the prevalence of comorbidities and high rates of polypharmacy, increasing the risk of adverse drug events. Research indicates that rates of polypharmacy were highest among those aged 80–84 years (43.9%) or 85–89 years (46.0%). The prevalence of polypharmacy among PBS concessional beneficiaries aged 70 or more increased by 9% during 2006–2017 (from 33.2% to 36.2%), but the number of people affected increased by 52%.[11]

Even though polypharmacy can be appropriate in residential aged care population groups, there is substantial evidence for its potential harm and the importance of rationalising unnecessary medicines such as opioids or antipsychotics, particularly in older people.

Research also indicates inappropriate initiation of opioid patches in Australian residential aged care facilities. Contrary to best practice, a third of residents initiated on fentanyl patches were opioid-naive in the 4 weeks before initiation.[12] This creates a dangerous situation and exposes residents to potentially fatal opioid related harm.

Opioid use is also associated with an increased risk of fall and an increased likelihood of death in older adults.[13] The risk presented by using a primarily pharmacological approach is a strong reason to embed best practice pain management as a central measure of medication management to ensure better outcomes for people living with dementia.

*Our mother had delirium due to pain issues and staff (including GP) instead believed it was BPSD and overdosed her on antipsychotics instead of treating causes of pain*

***Carer of person in residential aged care***

It is estimated that about half of the people in aged care and about 80% of those with dementia are receiving psychotropic medications, often for management of BPSD. There is sound evidence to suggest that in some cases these medications have been prescribed inappropriately[14]

Professor Brian Draper, Conjoint Professor, School of Psychiatry UNSW, in a submission to the Senate Inquiry into the Care and Support of People with BPSD said:

*"I am firmly of the view that this long term overuse of psychotropic drugs in residential care is largely indicative of a combination of a number of factors – poor facility design, poorly trained staff, inadequate numbers of staff and lack of suitable activity programs for residents. The behaviours being treated by drugs are exacerbated or indeed at times caused by these issues. Psychotropic drugs are used because GPs and residential care staff can see no other solution.*

## 2. The importance of Multidisciplinary care

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 functioning and wellbeing. This is a key recommendation of the National Pain Strategy and its implementation blueprint, the National Strategic Action Plan for Pain Management.[15]

As the Royal Commission has been informed, 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.

The current standards 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 may not be identified.

**Recommendation**
The Framework ensures that all staff in residential aged care facilities receive mandatory, high quality training in pain management and dementia care, including a biopsychosocial model of care and alternatives to physical and chemical restraint.

Older people with chronic pain and comorbidities like dementia are often left with two main options to get the best-practice treatment they need. They are either forced to wait over a year to access multidisciplinary pain services and allied health through public hospitals or they pay a premium for poor insurance coverage that largely neglects the needs of chronic pain patients. The result is that older people are often inappropriately pushed into seeking acute or residential aged care, a situation which often does not provide adequate pain management.

The evidence now shows that given the individual effects of chronic pain, interdisciplinary assessment and treatment may produce the best results for people with the most severe and persistent pain problems. This can include non-opioid medications, special physical exercises, psychological approaches such as Cognitive Behaviour Therapy and techniques for how to self-manage and mitigate pain.

This holistic, patient-centred, multi modal approach to treatment is also a key recommendation of Painaustralia's National Pain Strategy, and a critical component of the National Strategic Action Plan on Pain Management.[16] Once implemented, the Plan will be the world's first fully funded government response to comprehensively address the burden of pain, which is most urgently needed across the aged care sector.

**Recommendation**
The Framework build on the commitments to the National Strategic Action Plan on Pain Management to enhance access to best practice, community-based pain management services for older people living with chronic pain.

# 3. Quality of Care and Education and Training of Staff

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 for people living with dementia have the capacity to provide quality care for chronic pain management, especially as the comorbidity of dementia and chronic pain results in older people who are often frail and vulnerable, have cognitive impairment and often have other complex care needs.

Inadequate education and training of residential and community 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 in assessment of pain in people with dementia, while 90% of care professionals indicated that additional training in dementia would be beneficial.[17]

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."*[18]

The Australian Pain Society (APS) in its guidelines Pain in Residential Aged Care Facilities- Management Strategies, 2nd Edition, indicates that staff workloads may also be to blame, with a lack of time for adequate pain assessment on a regular basis. These Guidelines should be promoted across aged care as a useful resource that aids best practice pain management.

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, and maybe unable to communicate verbally, pain may trigger behavioural changes and any such changes should be investigated. These changes may also be observed by carers or family members.

*As mum deteriorated her pain increased. She had multiple falls requiring hospital admission. There was inadequate supervision to prevent falls. She was only safe when she was unable to get up herself.*

***Carer of person in residential aged care***

It has been shown that BPSD and pain[19] can be addressed by appropriate staff training. Aged care staff with day-to-day responsibilities for residents should have adequate knowledge and skills in pain assessment and management, this includes people with dementia or other cognitive impairment.

*Tried to implement allied health services to aid in treatment plan which wasn't received well. Some days was almost constantly reporting pain however current treatment routine wasn't adjusted*

***Carer of person in residential aged care***

This would be consistent with the Australian Government's *National Safety and Quality Health Service Standards* (Standard 1 Governance and quality improvement systems), which highlights 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."[20]

The roll out of a single set of quality indicators may assist in the comparison across residential aged care facilities resulting in greater transparency in relation to quality for consumers. There may also be a need to develop a more nuanced approach to Accreditation which would include whether a facility has met or exceeded the expected outcomes.

Painaustralia is also concerned that pain management is not being adequately addressed through the new standards. For instance, we are concerned to note that the new aged care quality standards do not acknowledge or consider the high risk and prevalence of chronic pain. This is despite nearly 80% of residents in residential aged care reporting chronic pain. It is clear that there is a need for providers to have a specialist capacity to manage pain appropriately.

*Pain not assessed well, not assessed after an intervention, simply asking the person doesn't help, they know the staff are busy and don't want to bother them. Stronger drugs are always the option and an option that leaves them as zombies too.*

***Carer of person in residential aged care***

In our submission to the Aged Care Royal Commission, Painaustralia has recommended embedding pain management across the new single quality standards as well as the quality indicators to ensure providers are responsive to chronic pain across aged care.

**Recommendation**
A focus on embedding pain management across the aged care Safety and Quality framework to ensure providers are responsive to chronic pain across aged care.

## 4. Insufficient education about best-practice pain management for aged care residents and carers

Many older people believe that pain is a normal part of ageing and there is little potential for improvement. They often:

- fear addiction to pain medications;
- are concerned that pain may suggest worsening of disease;
- are worried they will be seen as people who complain too much; and
- are reluctant to seek help for fear of further functional dependence due to disease progression.[21]

Programs such as Seniors ADAPT by the University of Sydney and Pain Management Research Institute[22] have shown that age is not a factor in being able to improve function and quality of life, given the right education in best-practice pain management and the right support.

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.

Another important aspect that has a major impact on resident health and quality of care is nutrition. As identified in the Nutrition Chapter (2) in the APS Guidelines, malnutrition and dehydration can directly affect pain experiences. Media reports and anecdotal consumer evidence suggests that there is insufficient attention paid to nutrition across aged care currently.

Training for food service staff needs to be implemented and monitored, as often those putting together the menu are not qualified to ensure that the menu meets the nutritional needs of the residents. Allowances for better quality food and having more staff to assist with mealtimes could reduce malnutrition and improve the pain experiences and quality of life of residents in aged care facilities. This can be cost effective considering the current cost of malnutrition. Taking a multidisciplinary approach to embedding areas like nutrition across aged care are crucial to improving health outcomes.

**Recommendation**
The Framework consider targeted national pain programs that can be developed and implemented in residential and community aged care for staff, consumers and family, friends or representatives.

# 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. This particularly impacts the significant number of residents with dementia or other cognitive impairment, who have pain that is under-treated and are suffering unnecessarily.

This is an issue that can be prevented through appropriate workforce education, training and adequate regulatory reform of the quality system.

A multidisciplinary, industry-wide approach will be essential to address these issues. Crucial to achieving this best-practice pain management, will be appropriate education and training of staff (particularly in the identification of non-verbal signs of pain).

An emphasis also needs to be on education for aged and community care residents, their families and carers with enough capacity to self-manage their pain where appropriate. Importantly, focus should also be given to Safety and Quality frameworks that supports quality of life for people living with dementia and chronic pain conditions.

We hope our submission provides the Evaluation with the impetus to prioritise pain management as an important element in providing better care for people living with dementia. As Commissioner Richard Tracey noted in his opening remarks, we have 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. Appropriate pain management in aged care will go a long way in providing the much-needed dignity for people living with dementia.

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