

**SUBMISSION TO THE REVIEW OF
EFFECTIVENESS OF THE AGED
CARE QUALITY ASSESSMENT AND
ACCREDITATION FRAMEWORK
FOR PROTECTING RESIDENTS
FROM ABUSE AND POOR
PRACTICES, AND ENSURING
PROPER CLINICAL AND
MEDICAL CARE STANDARDS ARE
MAINTAINED AND PRACTISED**

AUGUST 2017

CONTENTS

1. EXECUTIVE SUMMARY	3
Painaustralia Recommendations	4
2. INTRODUCTION	6
3. BACKGROUND	7
4. KEY ISSUES	8
4.1 Inadequate education and training of residential aged care staff leading to under-reporting of pain	8
4.2 Insufficient education about best-practice pain management for aged care residents	10
4.3 Inadequate accreditation standards in relation to pain and inadequate accreditation processes	12
4.4 Lack of coordinated national approach	14
5. CONCLUSION	15
ENDNOTES	16

1. EXECUTIVE SUMMARY

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.

This is despite 95% of aged care facilities passing accreditation and highlights a serious problem: residents are being left in pain. Unrecognised or undiagnosed pain as a result of cognitive or other communicative impairments and inadequate training of aged care staff with day-to-day responsibilities for residents about pain assessment and management is common.

There are also challenges with reporting pain in cognitively intact people, and the lack of protocols for pain assessment and reporting within facilities and industry guidelines are inadequate to ensure quality care.

Where residents are assessed as having pain, the accreditation standard of ensuring residents are as “free as possible from pain” does not acknowledge best-practice multidisciplinary care or address quality of life issues, but rather encourages over-use of medication. As long as the resident is medicated for pain, then the facility is seen to be providing adequate care. This is contrary to best-practice pain management.

Poorly or unmanaged pain can lead to poorer quality of life for residents and distress for their families, inappropriate use of chemical and physical restraints, and a greater burden of care for staff.

It is critical that reforms are made to Australia’s Aged Care Quality Assessment and accreditation framework, to ensure effective best-practice evidence-based pain management is available to all residents of aged care facilities. This should be a fundamental right for all older residents in aged care.

Painaustralia Recommendations:

1. Education and training for aged care workers (including day-to-day staff) tailored to the needs of individual facilities must be tied to the Aged Care Quality Assessment and accreditation framework. This may include the appointment of a nominated pain champion (health professional) within each facility to oversee pain education and training.
2. Education and training should ensure staff understand:
 - a. Recognition of non-verbal Behavioural and Psychological Disturbances (BPSD) signs of pain in residents with dementia;
 - b. Best-practice management of chronic pain in the elderly; and
 - c. A clear referral pathway for treatment of chronic pain, which can be escalated depending on the condition, the issues in play, or communication difficulties (addressing issues with after hours support in rural and remote communities).
3. Education tied to the Aged Care Quality Assessment and accreditation framework for aged care residents with sufficient cognitive capacity, and families, carers and support people:
 - a. Residents should be provided with appropriate education in pain management and self-management;
 - b. Residents should be provided with appropriate allied health supports to achieve better quality of life despite their pain condition;
 - c. Residents should be encouraged to participate in developing their own care plan, supported by adequately trained staff and allied health professionals; and
 - d. Residents should be encouraged to develop an end-of-life plan that includes preferences for pain management.

4. Complaints processes are strengthened to ensure a clear pathway that allows residents and their families to easily identify, articulate and progress a complaint in relation to under-reporting of pain and inadequate pain management to ensure residents are able to:
 - a. Seek best-practice multidisciplinary pain management; and
 - b. Develop an end-of-life pain care plans compatible with their wishes and their spiritual and cultural beliefs.
5. Improvements in reporting policies tied to the Aged Care Quality Assessment and accreditation framework to ensure:
 - a. Residents able to report pain should be asked on a regular basis about their pain with genuine concern (any concerns patients may have about reporting pain should be dispelled);
 - b. Residents unable to report pain must be observed through carefully structured procedures;
 - c. The possibility of the onset of pain must be considered if there is a significant change in a resident's condition and, routinely, every three months;
 - d. Regular monitoring and reporting in all aged care facilities must ensure assessment of pain management practices and processes, as part of ongoing accreditation processes for facilities.
6. The Australian Aged Care Quality Agency standards must be amended to ensure:
 - a. Best-practice multidisciplinary pain management is required where pain is identified; and
 - b. Quality of life is the intended goal for every resident who lives with pain.
7. Accreditation of aged care facilities must be amended to ensure:
 - a. Compliance with pain management is a primary accreditation standard; and
 - b. Measuring consumer satisfaction at an increased rate and frequency.
8. There is an urgent need for national leadership by the Federal Government to implement the recommendations of the National Pain Strategy—Australia's blueprint for best-practice treatment and management of pain—to ensure quality aged care.

2. INTRODUCTION

Painaustralia is a national advocacy body formed in 2011 to work with government, health professional and consumer stakeholders to facilitate implementation of the National Pain Strategy.

This submission to the review of “Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised” is made with input from members, representing the wider pain community in Australia, and on behalf of the one in five Australians and 80% of aged care residents living with **chronic pain**.^{1,2}

Painaustralia believes there is a generational opportunity to recognise and adequately address the importance of effective assessment and best-practice management of chronic pain in residential aged care facilities, which will give dignity to our frail and aged, particularly those with dementia or other cognitive impairment.

Our submission relates to the following, based on the Terms of Reference:

- a. “the effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised”;
- b. “the adequacy and effectiveness of complaints handling processes at a state and federal level, including consumer awareness and appropriate use of the available complaints mechanisms”; and
- g. “any related matters”.

In making our recommendations, Painaustralia has drawn on the Australian Pain Society (APS) guidelines *Pain in Residential Aged Care Facilities – Management Strategies* (the new guidelines are currently in second draft edition). Our recommendations are also consistent with the Federal Government’s *Draft Aged Care Quality Standards Consultation Paper* (2017).

3. BACKGROUND

While access to pain management is acknowledged globally as a fundamental human right with the Declaration of Montreal³, which has been endorsed by the World Medical Association, Australia's aged care facilities are falling short of effective pain care.

Residents of aged care facilities, especially those with dementia or other cognitive impairment, are in need of greater protection of their right to pain management.

Chronic pain is a common condition among residents of aged care facilities, however evidence suggests many residents are suffering from unrecognised or undiagnosed pain and are being under-treated, due to cognitive and communicative impairments.

It is estimated up to 80% of aged care residents have chronic pain^{4,5} 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.⁶ This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and inability to report pain.

Evidence shows 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.⁷ 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.⁸

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 a mental disorder.⁹

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.¹⁰

In people with cognitive impairment who are non-verbal, untreated chronic pain can result in Behavioural and Psychological Symptoms of Dementia (BPSD) and lead to inappropriate use of chemical and physical restraints.¹¹

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.¹²

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 respectively¹³—the issue of effective pain management in residential aged care is an issue that is in the interest of every Australian.

4. KEY ISSUES

4.1 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.¹⁴

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.”¹⁵

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.¹⁶

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 BPSD are often an expression of emotion or unmet need (for example, pain)¹⁷ 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.”¹⁸

Examples of best-practice education and training programs available for general practitioners, nursing staff and allied health professionals include:

- The Pain Management Research Institute (PMRI), University of Sydney (PMRI). The PMRI is a leader in pain education and training for health professionals, offering webinars and post graduate programs. The Director of Education is Clinical Psychologist and Pain Specialist, Professor Michael Nicholas.
- The Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists. The Faculty provides accredited online education programs, see: www.fpm.anzca.edu.au/resources/better-pain-management
- Please see the Painaustralia website for more www.painaustralia.org.au/health-professionals/education-training

Painaustralia recommends:

1. Education and training for aged care workers (including day-to-day staff) tailored to the needs of individual facilities must be tied to the Aged Care Quality Assessment and accreditation framework. This may include the appointment of a nominated pain champion (health professional) within each facility to oversee pain education and training.
2. Education and training should ensure staff understand:
 - a. Recognition of non-verbal Behavioural and Psychological Disturbances (BPSD) signs of pain in residents with dementia;
 - b. Best-practice management of chronic pain in older people; and
 - c. A clear referral pathway for treatment of chronic pain, which can be escalated depending on the condition, the issues in play, or communication difficulties (addressing issues with after hours support in rural and remote communities).

4.2 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.¹⁹

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.

Effective pain management requires multidisciplinary collaboration between doctors, nurse, pharmacists, physiotherapists or other allied health professionals, as well as aged care workers.

It should not rely only on pharmacological pain management, but should include a range of other strategies. Physical rehabilitation and regular exercise, acupuncture and massage, and Cognitive Behavioural Therapy have been shown to be helpful in pain management in aged care.

Managing pain at end-of-life is also an important consideration. It requires more than analgesic and other medication to manage pain. It needs to prevent suffering, but should also take into account 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.

Residents and family members equipped with the right knowledge and aware of the level of care they could be receiving will also have an understanding of when rights and needs are being compromised. In such cases, there must be clear pathways for referral of complaints without fear of retribution.

In an approach that recognises the value and rights of the consumer, there should be provision for appropriate investigation, monitoring and review of standards and protocols, to allow residents and their families to easily identify, articulate and progress a complaint in relation to under-reporting of pain and inadequate pain management.

Painaustralia recommends:

3. Education tied to the Aged Care Quality Assessment and accreditation framework for aged care residents with sufficient cognitive capacity, and families, carers and support people:
 - a. Residents should be provided with appropriate education in pain management and self-management;
 - b. Residents should be provided with appropriate allied health supports to achieve better quality of life despite their pain condition;
 - c. Residents should be encouraged to participate in developing their own care plan, supported by adequately trained staff and allied health professionals; and
 - d. Residents should be encouraged to develop an end-of-life plan that includes preferences for pain management.
4. Complaints processes are strengthened to ensure a clear pathway that allows residents and their families to easily identify, articulate and progress a complaint in relation to under-reporting of pain and inadequate pain management to ensure residents are able to:
 - a. Seek best-practice multidisciplinary pain management; and
 - b. Develop an end-of-life pain care compatible with their wishes and their spiritual and cultural beliefs.

4.3 Inadequate accreditation standards in relation to pain and inadequate accreditation processes

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."²¹

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.²²

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 can be accredited despite having a significant proportion of residents living in pain.

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.

Addressing these issues 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 "assigning workforce roles, responsibilities and accountabilities to individuals for patient safety and quality in their delivery of health care."

Painaustralia recommends:

5. Improvements in reporting policies tied to the Aged Care Quality Assessment and accreditation framework to ensure:
 - a. Residents able to report pain should be asked on a regular basis about their pain with genuine concern (any concerns patients may have about reporting pain should be dispelled);
 - b. Residents unable to report pain must be observed through carefully structured procedures;
 - c. The possibility of the onset of pain must be considered if there is a significant change in a resident's condition and, routinely, every three months;
 - d. Regular monitoring and reporting in all aged care facilities must ensure assessment of pain management practices and processes, as part of ongoing accreditation processes for facilities.
6. The Australian Aged Care Quality Agency standards must be amended to ensure:
 - a. Best-practice multidisciplinary pain management is required where pain is identified; and
 - b. Quality of life is the intended goal for every resident who lives with pain.
7. Accreditation of aged care facilities must be amended to ensure:
 - a. Compliance with pain management is a primary accreditation standard; and
 - b. Measuring consumer satisfaction at an increased rate and frequency.

4.4 Lack of coordinated national approach

There is a lack of leadership at the national level to improve policy in relation to best-practice treatment and management of pain. The removal of pain items from the Aged Care Funding Instrument in 2016 related to necessary physiotherapy and palliative care diminished the capacity to provide appropriate levels of pain management in aged care.

Australia already has a National Pain Strategy, developed by more than 150 stakeholder organisations and agreed to by consensus at the National Pain Summit in Canberra in 2010. This strategy has informed the development of state-wide pain strategies in most jurisdictions in Australia.

However the work of policy reform has been fragmented and under-funded and there is an enormous need for a coordinated national approach to improve treatment of acute and chronic pain and provide equitable access to effective pain management services across Australia and in every health care facility.

It is critical that the Australian Government prioritise pain care and ensure best-practice treatment and management of pain features in every policy document, standard and guideline, to ensure quality aged care.

Painaustralia recommends:

8. There is an urgent need for national leadership by the Federal Government to implement the recommendations of the National Pain Strategy—Australia's blueprint for best-practice treatment and management of pain—to ensure quality aged care.

5. 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 short of effective pain care.

A significant number of residents have pain that is undertreated and are suffering unnecessarily (particularly those with dementia or other cognitive impairment), something that could be avoided through appropriate reform of the accreditation 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 reporting policies and protocols; and education for aged care residents with sufficient capacity to self-manage their pain.

We have a generational opportunity to create a residential 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 interest of every Australian.

We would welcome the opportunity to present to the committee on these issues, which are fundamentally about protecting aged care residents from abuse or poor practices and ensuring proper clinical and medical care standards are maintained and practised.

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ENDNOTES

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- 2 Department of Health and Ageing 2012
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