SUBMISSION TO THE REVIEW OF NATIONAL AGED CARE QUALITY REGULATORY PROCESSES

JULY 2017

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working to prevent and manage pain

CONTENTS

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, however, evidence suggests many residents with pain are poorly treated or under-treated.

This is largely due to 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.

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

Where pain is assessed, there is insufficient provision of allied health support through the Aged Care Funding Instrument to allow for effective multidisciplinary 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 National Aged Care Quality Regulatory Processes, to ensure effective best-practice evidence-based pain management is available to all residents of aged care facilities.

With an ageing population, the issue of quality pain management practices in residential aged care is in the interest of every Australian.

Painaustralia Recommendations:

1. Education and training for aged care workers (including day-to-day staff) tailored to the needs of individual facilities. 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. Improvements in reporting policies 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 onset of pain must be considered if there is a significant change in a resident's condition and, routinely, every three months;

    d. 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; and;

    e. 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.

4. Expansion of support through the Aged Care Funding Instrument so that:

   a. There is adequate funding for regular allied health care, including pain assessments and support of appropriate person-centred care plans; and

   b. There is adequate funding for complex chronic pain cases that require referral to tertiary care.

5. Education 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 encouraged to participate in developing their own care plan, supported by adequately trained staff and allied health professionals; and

   c. Residents should be encouraged to develop an end-of-life plan that includes preferences for pain management.

6. 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 National Aged Care Quality Regulatory Processes 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:

- Reporting requirements, whether voluntary or mandatory, for residential aged care staff and any other care professionals involved in the provision of care in a residential setting.
- Any other matter that the reviewers consider relevant to the purpose of the review, including any other measures in addition to current statutory arrangements that may strengthen the protection of residents.

In making our recommendations, Painaustralia has drawn on the *APS guidelines Pain in Residential Aged Care Facilities – Management Strategie*s (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 Montreal,[3] 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 illness 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 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 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 respectively[13]—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]

Suitable education and training programs are available for general practitioners, nursing staff and allied health professionals through:

- 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. 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).

4.2 Inadequate pain assessment reporting standards and protocols

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.

This move 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."

Aged care staff should conduct regular assessments for both cognitively impaired and cognitively intact residents. While cognitively impaired residents may have trouble communicating pain due to problems with speech, cognitively intact residents may also face challenges in communicating pain, which could lead to under-reporting and under-treatment.

In an approach that recognises the value of the consumer, there should also 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.

Measuring consumer satisfaction should be an important element of monitoring and compliance processes, and consumer involvement will be critical to maintain a high level of care.

Regular monitoring of and reporting on all aged care facilities will also be required to ensure best practice pain management practices and processes are being implemented.

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.

Painaustralia recommends:

3. Improvements in reporting policies 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. 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; and

   e. 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.

4.3 Insufficient support for allied health care and best-practice pain management

The Aged Care Funding Instrument currently supports largely passive therapies for only short times (eg therapeutic massage for 20 minutes a week). It does not provide adequate funding for regular allied health care, including pain assessments and support of appropriate person-centred care plans or evidence-based group programs that address social isolation and supports connectedness with other residents. Consequently, it does not support best-practice evidence-based pain management.

This is despite the Australian Government *Draft Aged Care Quality Standards Consultation Paper* stating "the delivery of safe, effective and quality personal and clinical care is a basic consumer and community expectation."[19]

It also states that clinical care should be best-practice to achieve the best possible outcomes for consumers and based on the best available evidence; it should be connected care with other health professionals; it should recognise the preferences of individuals for end-of-life care; and it should recognise and respond to change in function, capacity or physical condition in a timely manner.

While chronic pain is difficult to treat and may be a lifelong chronic condition, evidence shows that multidisciplinary pain management is the most effective approach for minimising the impact of pain, improving function and quality of life and enabling participation in productive activities—whether or not there is cognitive impairment. This is a key recommendation of the National Pain Strategy.[20]

The Australian Government's own report *Encouraging Best Practice in Residential Aged Care Program* states Australian studies have shown marked improvements in pain, mood disturbance and functional impact in persons with dementia when given a coordinated multimodal approach to pain management.[21]

Effective pain management requires multidisciplinary collaboration between doctors, nurses, 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.[22]

As chronic pain is very much an experience and no two conditions are experienced the same way, there must be a focus on developing person-centred invidualised care plans. There will also be variations depending on cognitive and physical ability of the resident.

In addition, evidence shows that people with chronic pain who self-manage their pain—that is, they are actively involved in managing their pain on a daily basis—have less disability than those who are engaged in passive therapies, such as taking medications or surgery, and this is unrelated to age.[23]

In a study involving 140 patients, Seniors ADAPT (a multidisciplinary pain management program for people aged over 64 run by the Pain Management Research Institute in Sydney) was found to be more effective than exercises and usual care in helping to improve participants' levels of distressing pain, pain interference in activities, mood and unhelpful attitudes to pain.[24]

In the absence of effective pain management strategies, BPSD in residents with cognitive impairment are often addressed through inappropriate use of chemical and physical restraints, which can lead to much worse outcomes and harms.[25] Good pain management reduces confusion and distress in these residents and reduces the need for psychotropic medications.

While the vast majority of people can be treated in primary care, provided there is access to appropriate team-based care, more complex cases must be referred to tertiary care. There is an urgent need for better coordination of services and support for residents with chronic pain, something that could be managed by residential aged care staff.

Painaustralia recommends:

4. Expansion of support through the Aged Care Funding Instrument so that:

   a. There is adequate funding for regular allied health care, including pain assessments and support of appropriate person-centred care plans; and

   b. There is adequate funding for complex chronic pain cases that require referral to tertiary care.

4.4 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.[26]

However, 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 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.

Painaustralia recommends:

5. Education 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 encouraged to participate in developing their own care plan, supported by adequately trained staff and allied health professionals; and

c. Residents should be encouraged to develop an end-of-life plan that includes preferences for pain management.

4.5 Lack of coordinated national approach

There is a serious lack of leadership at the national level to improve policy in relation to best-practice treatment and management of pain.

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:

6. 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.

Leadership at a national level that prioritises a multidisciplinary, industry-wide approach will be essential to address these issues. It should include 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 aged 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 be interested in working with the Department of Health to provide further information, resources and support.

Should you wish to discuss any of the matters arising from this submission, please contact Painaustralia Chief Executive Officer Carol Bennett.

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