
painaustralia

MEDICAL RESEARCH FUTURE FUND DEMENTIA, AGING AND AGED CARE MISSION ROADMAP

FEBRUARY 2020

INTRODUCTION

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.

Painaustralia welcomes the opportunity to provide input into how the Dementia, Ageing and Aged Care Mission should best invest their research funds into enabling Australians to improve the quality of life for people as they age. The impact of dementia, ageing and aged care in Australia is considerable and continues to grow as the older population of Australia grows. In 2017, 15% of Australia's total population (approximately 3.8 million people) were aged 65 and over. By 2057, this figure is projected to grow to over 8.8 million, 22% of the population.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.

As noted under Priority Area 4.4 of the National Framework for Action on Dementia 2015 – 2019, 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.²

In particular, 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.

Our submission makes the following recommendations for the Dementia, Ageing and Aged Care Mission Roadmap:

- **Recognition of the prevalence of pain among the aged care population and across aged care settings as well as the relationship of untreated pain to incidents of severe behaviours.**
- **Raise awareness and education about best practice pain management and the adoption of a multidisciplinary approach into aged care. APS Pain in Residential Aged Care Facilities Guidelines should be adopted and implemented across aged care settings.**
- **The adoption of a multidisciplinary best practice pain management approach in aged care.**
- **Implementation of 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.**
- **Bridge the health gap across our rural and remote communities including the cultural needs of Aboriginal and Torres Strait Islander people.**
- **Strengthen consumer protections for residents to help them exercise their choice and rights in care.**

PREVALENCE OF CHRONIC PAIN

Chronic pain is a prevalent condition among our older generations 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.

It is estimated up to 80% of aged care residents have chronic pain,^{3,4} 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.⁵ This suggests a high proportion of people with chronic pain also have cognitive or communicative impairment and inability to report pain.

This suggests a high proportion of people with chronic pain also have cognitive or communication impairment and 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 or undertreated, including the suboptimal use of analgesics.⁶

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.⁷

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 expression of emotion or unmet need that the person with dementia cannot otherwise express, e.g. pain, frustration, fear.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 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.⁹

Recommendation:

Recognition of the prevalence of pain among the aged care population and across aged care settings as well as the relationship of untreated pain to incidents of severe behaviours.

INSUFFICIENT EDUCATION ABOUT BEST-PRACTICE PAIN MANAGEMENT.

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.¹⁰

Programs such as Seniors ADAPT by the University of Sydney and Pain Management Research Institute¹¹ 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.

The Australian Pain Society (APS) has developed an evidence-based document specifically aimed at helping aged care facilities to meet best-practice pain management outcomes, Pain in Residential Aged Care Facilities- Management Strategies, 2nd Edition, which should be promoted across aged care as a useful resource that aids best practice pain management.

Aged Care recipients 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.

Taking a multidisciplinary approach to embedding areas like nutrition across aged care are crucial in improving health outcomes. Nutrition, Good sleep and exercise are foundational tools in enhancing one's health and preventing the future onset of disease and deteriorating health.

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.¹²

Recommendation:

Raise awareness and education about best practice pain management and the adoption of a multidisciplinary approach into aged care. APS Pain in Residential Aged Care Facilities Guidelines should be adopted and implemented across aged care settings.

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 have 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 and community aged care staff leads to underreporting of pain

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 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.¹³

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.”¹⁴

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 also 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)¹⁵ 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 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."¹⁶

Recommendation:

The adoption of a multidisciplinary best practice pain management approach in aged care.

BEST PRACTICE PAIN MANAGEMENT IN THE COMMUNITY.

The traditional image of aged care is often associated with residential care. While it is true that most of the expenditure is in the residential care sector, in fact most people stay independent and remain in their home, connected to family and community for the duration of their lives.

For some, home support and home care packages provide the level of support they need to maintain their independent living, with about two thirds of aged care consumers accessing basic support at home. Only a small proportion of senior Australians are accessing residential care at any point in time, yet nearly 70 per cent of aged care expenditure is on residential aged care.¹⁷

We need to pay more attention to changing consumer need and do more to support consumers in their preferred setting. One way to ensure that older Australians can be supported to live in their communities is to enable access to best practice pain management in the community.

Sadly, right now older people with chronic pain are left with two main options to get the best-practice treatment they should have. They are either forced to wait over a year to access multidisciplinary pain services and allied health through public hospitals or 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 chronic pain's individual effects, 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,¹⁸ and a critical component of the National Strategic Action Plan on Pain Management. If implemented, the Plan will be the world's first fully funded government response to comprehensively addressing the burden of pain, most urgently needed across aged care.

Recommendation:

Implementation of 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.

HEALTH AND WELFARE IN REGIONAL AUSTRALIA

Across the spectrum of health and welfare people in rural, regional and remote Australia experience worse health outcomes. They have less access to services and are exposed to increased health risks. Service access data reveals¹⁹ that people in remote areas access MBS services at up to half the rate as people in metropolitan areas and the health workforce is under-represented.

The lack of places in rural and remote communities' results in more and more Australians with increasing community aged care needs accepting packages that do not cater for those needs on the basis that something is better than nothing.

Some health professional disciplines don't exist in many remote areas. In others, professions like optometrists, occupational therapists, dietitians and podiatrists are represented at between one fifth and one third the rate of metropolitan areas.²⁰ This is a vital gap that needs to be bridged, especially if we want older Australians to remain in their homes and communities.

For rural and remote aged care services to be delivered through a consumer demand driven model will require a significant change in emphasis in the current system of allocation of aged care places outside the major cities. Service models for remote and very remote communities must be flexible, small and integrated—for example as part of a Multi-Purpose Service combining hospital and aged care places funded jointly by Commonwealth and state/territory governments or as part of a community delivered service incorporating residential and community outreach aged care services.

Aboriginal and Torres Strait Islander people comprise 45% of the population in very remote communities. It is vital that the delivery of aged care services in remote and very remote Australia meets cultural needs and allows Aboriginal people to maintain their links to country and family. This also means a very different, flexible and responsive approach is necessary. This is a requirement to deliver both home based and residential aged care employing and supporting a culturally appropriate and culturally safe workforce.²¹

Recommendation:

Bridge the health gap amongst our rural and remote communities including the cultural needs of Aboriginal and Torres Strait Islander people.

EMPOWERED CONSUMERS AND CARERS AT THE CENTRE OF AGED CARE

Aged care in Australia remains one of the few services where consumers are not routinely engaged as part of the quality assessment process. On the contrary, current safety and quality systems have created outcomes where we see multiple reports of consumers indicating they are fearful of complaining or making negative comments about service quality because they fear retribution on their loved ones and have limited options to access alternative care.

Aged care in Australia needs to put consumers at the front and centre of service delivery, to match consumer expectations across nearly every other service sector in the country. We also need to empower consumers to have choice over the setting of their aged care services.

More and more consumers are now looking to age in place, with demand for home care packages and community based aged care far exceeding current supply. Building awareness of pain and its management is central to ensuring that consumers can be supported to self-manage their pain.

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then it is also important to recognise that carers are an essential part of the equation. Thirty six percent of all carers are over the age of 65 and most are caring for a partner,²² however right now there is no emphasis on education and training programs that enable carers and informal support to provide essential community-based care such as holistic pain management.

Recommendation:

Strengthen consumer protections for residents to help them exercise their choice and rights in care.

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. 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 support quality of life for people living with dementia and chronic pain conditions

We hope our submission provides the MRFF with the impetus to prioritise pain management as an important element in research that can provide 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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