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SUBMISSION TO THE AUSTRALIAN GOVERNMENT, DEPARTMENT OF HEALTH CONSULTATION ON SPECIALIST DEMENTIA CARE UNITS

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Executive Summary

Painaustralia welcomes the opportunity to provide input to the Australian Government on the implementation of planned new Specialist Dementia Care Units (SDCUs) for people with severe behavioural and psychological symptoms of dementia (BPSD).

Poorly or unmanaged pain can lead to poorer quality of life for people living with dementia. As far as is known, dementia itself does not cause pain, however people living with dementia are at greater risk of other things that can cause pain such as falls, accidents and injuries, as well as a range of other medical conditions that can cause pain.[1] They may be less able to express emotion or communicate to their carers that they are in pain, which can also cause severe behaviours.

To address BPSD, effective pain management must be a core responsibility across aged care settings, but pain remains unrecognised or undiagnosed because of cognitive or other communicative impairments and inadequate training of aged care staff with day-to-day responsibilities for residents. [2]

The establishment of SDCUs offers an opportunity to provide person-centred, mutlidisciplinary care for people living with BPSD, but must be considered as part of a broader strategy to improve care and pain management across aged care settings.

We note the role of Severe Behaviour Response Teams (SBRT) in existing aged care settings in resolving some levels of unmet need for people with BPSD,[3] particularly undiagnosed pain, but agree a range of additional measures are necessary to ensure providers and carers can best respond to severe BPSD.

This includes the urgent need to improve the prevention, treatment and management of pain across aged-care settings in general, particularly to support aged care practitioners to make accurate referrals to more specialist services as well as potentially preventing the escalation of pain conditions and BPSD.

About Painaustralia

Painaustralia is the leading national peak body to develop and inform national pain strategies and policies and was formed in 2011 to work with government, health professional and consumer stakeholders to facilitate implementation of the National Pain Strategy.

Painaustralia's primary mission is to improve the quality of life for people with pain and their families and minimise the burden of pain on individuals and the community. Effectively tackling pain – as a complex physical, psychological and environmental condition – is in the interest of every Australian.

With over 150 members and partners across a diverse range of stakeholders including consumers, medical specialists, pharmacists, academics, carers, pharmaceutical companies, allied health professionals and others with an interest in pain, Painaustralia consults our network widely to inform practical and strategic solutions to address this complex and widespread issue.

Painaustralia also provides essential sources of information for consumers, medical practitioners and researchers.

Summary of Recommendations

1. To better support and care for people living with BPSD, pain management must be an urgent priority for reform across Australian Government aged care policy reform agendas.

This will recognise the specific and substantial relationship between pain, dementia and severe BPSD and enable service-wide improvements to improve quality of life for people with BPSD. It will also alleviate the risk that best-practice pain management is not limited to specialist services, like SDCUs.

Painaustralia recommends the following actions:

- Develop a national pain management training program for all aged care practitioners to improve care, assessment and referral pathways to specialist services, including SDCUs.
- Develop national standards to improve the reporting of pain in aged care facilities.
- Develop a national pain management program for all people living in residential aged care to prevent the escalation of pain conditions that could lead to BPSD and increase understanding and awareness of chronic pain for aged care practitioners and residents.
- Ensure greater access to pain management services through the Aged Care Funding Instrument.
- Implement the recommendations of the National Pain Strategy to ensure best-practice pain management in all residential aged care services.

2. That as aged care sector-wide reforms are implemented, they are evaluated for their impact on the incidence of BPSDs and people living with chronic pain in residential aged care facilities.

3. That effective partnerships are developed between SDCUs and pain clinics and specialist to ensure best-practice pain management is applied in those settings.

4. That the SDCU program is evaluated for its impact on improving outcomes for people living with pain and BPSD.

Response to Submission Questions

Q1 *Are there are other system reforms that would impact on, or be impacted by, the establishment of Australian Government-funded SDCUs?*

- To better support and care for people living with severe BPSD, it is recommended that **pain management be made an urgent priority for reform across Australian Government aged care policy reform agendas,** including the Aged Care Roadmap, the Review of National Aged Care Quality Regulatory Processes, the Aged Care Workforce Strategy and the National Framework for Action on Dementia 2015-19. This would include the following considerations:

    - **Chronic and acute pain is common amongst residents of aged care facilities.** While more than half of residents of aged care facilities have a diagnosis of dementia, two in three require a high level care to manage behaviour.[4] This indicates there are a high number of people with chronic pain who have cognitive or communicative impairment and inability to report pain.

    - **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).** As noted in the consultation paper, BPSD may be caused by the expression of emotion or unmet need that the person with dementia cannot otherwise express, e.g. pain, frustration, fear.[5]

    - **Poorly or unmanaged pain can lead to poorer quality of life for people living with dementia.** As far as is known, dementia itself does not cause pain, however people living with dementia are at greater risk of other things that can cause pain such as falls, accidents and injuries, as well as a range of other medical conditions that can cause pain.[6]

    - **Evidence suggests that pain is poorly or undertreated in residential aged care** including suboptimal use of analgesics.[7] Cognitive or other communicative impairments of residents, inadequate training of aged care staff with day-to-day responsibilities for residents and workload that prevents adequate pain assessment are also barriers to effective treatment.[8]

    - **Untreated or poorly managed pain can perpetuate the pain condition and reduce quality of life and has significant impacts on mental health,** with 30-40% of people with chronic pain also living with depression.[9] It can also lead to inappropriate use of physical or chemical restraints[10] or reliance on antidepressants.[11]

    - **Evidence also shows people with dementia are being under-treated for pain** compared with cognitively-intact people, despite similar levels of potentially painful conditions. In one study, pain was detected in just 31.5% of cognitively impaired residents compared to 61% of cognitively intact residents, despite both having similar incidence of potentially painful conditions.[12]

    - To address BSPD, the issue of **pain management across the sector deserves greater attention** in policy and practice, while noting efforts are being made to foster greater awareness and education of pain management.

- It is recommended that a **national pain management training program for aged care practitioners is developed and implemented.**
    - There is currently no identified, national or uniform pain management training program for aged care practitioners in Australia.
    - 41% of age care practitioners reported having received no training on assessment of pain in people with dementia while 98% indicated additional training in dementia would be beneficial.[13]
    - Ongoing education for residential aged care staff should be tied to accreditation to address a lack of knowledge of pain and its treatment.
    - It may also include the appointment of a nominated pain champion within each facility to oversee pain education and training.
    - The education and training should include:
        - ◊ best-practice management of chronic pain in older people;
        - ◊ recognition of non-verbal Behavioural and Psychological Symptoms of Distress which are often signs of pain in residents with dementia;
        - ◊ assessment of pain in residential aged care facilities, including self-report, observational and sensory testing,[14] including the increasing role of technology in assessment;[15]
        - ◊ clear referral pathways for the treatment of chronic pain, which can be escalated depending on the situation. This would include understanding of 'step up' pathways to refer to SDCUs as proposed in the consultation paper.
    - A range of existing education and programs could be used such as the industry-led Pain Advocacy Nurse in Aged Care (PANACEA) Learning module[16] which fits within the Australian Pain Society Residential Aged Care Facilities Management Guidelines.[17]
- It is recommended **national standards are developed to improve reporting of pain.** This will improve practice to prevent and intervene in BPSD and improve referral pathways to SDCUs or other specialist services.
    - Improved and standardised reporting will ensure:
        - ◊ residents are 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);
        - ◊ residents unable to report pain must be observed through carefully structured procedures;
        - ◊ 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;
        - ◊ 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
        - ◊ 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.

- It is recommended a **national pain management program for people living in residential aged care is developed and implemented.**
    - There is no specific national pain management program for residents of aged care facilities, yet the provision of an 'off the shelf' program would greatly assist aged care providers to run programs in their facilities for those experiencing chronic pain.
    - The provision of a national program that supports self-management of ongoing pain could prevent the escalation of pain conditions that could lead to severe behaviours, as well as enhance understanding of chronic pain among residents and aged care practitioners.
    - Pain management programs do not need to be delivered by health professionals, but they do need to be delivered by someone with appropriate training.
    - There are a range of existing programs that could be drawn on to develop a national model including the Seniors ADAPT pain management program, which is a group-based, outpatient treatment program for people aged over 65. In a study involving 140 patients, Seniors ADAPT was found to be more effective than exercises and usual care in helping improve participants' levels of distressing pain, pain interference in activities, mood and unhelpful attitudes to pain. The principles and approaches of the program could be adapted for a national scheme. The Institute also offer a pain management education program for culturally and linguistically diverse (CALD) communities.[18]
    - The industry-sponsored Pain Advocacy Nurse in Aged Care (PANACEA) program has been developed to assist nursing staff to identify and optimally manage pain in residents of aged care facilities, and has recently been incorporated into Catholic Healthcare facilities.
    - Initiatives supporting pain management for residents in aged care facilities would be informed by the Australian Pain Society's Pain in Residential Aged Care Facilities (RACF) Management Guidelines (2nd edition, 2018), which should be distributed across providers.
- It is recommended that **greater access to pain management services are made available to residents of aged care facilities, including SDCUs, through the Aged Care Funding Instrument.**
    - This includes ensuring there is adequate funding for allied health care, including pain assessments and support of appropriate person-centred care plans.
    - It should also include ensuring there is adequate funding for complex chronic pain cases that require referral to tertiary care.
- To improve pain management across residential aged care facilities, and to ensure best-practice and quality pain management within the SDCUs once established, it is **strongly recommended the Australian Government implements the recommendations of the National Pain Strategy (2010).**[19]
    - The National Pain Strategy, launched seven years ago, provides a blueprint for the treatment and management of acute, chronic and cancer pain and is an important resource for specialists, health care administrators and state departments of health, who have made some investments in response to the Strategy.
    - The Strategy's objectives, developed by a broad coalition of stakeholders, remain relevant today, as well as the key priorities for reform and investment.

Response to Submission Questions

Q2 *What other risks and issues need to be considered in introducing SDCUs into the existing service systems for people with very severe (tier 6) BPSD?*

- It is recommended that capacity to provide more **effective and enhanced pain management services across the aged care sector is prioritised to alleviate the risk that mainstream residential aged care services reduce focus and investment of resources and effort in developing skills and capacity to identify and address causes of BPSD,** including pain management.
    - Pain management programs should also not be limited to specialist services, like SDCUs, but be made available across the residential aged care sector.

Q3 *Are there alternatives to the establishment of SDCUs that would better address the current system issues, which should be considered by Government?*

- It is recommended that the **system-wide options outlined in Q1 are implemented and evaluated for overall impact on the incidence of BPSD and outcomes for people living in residential aged care.**

Q16 *Are there alternatives to the establishment of SDCUs that would better address the current system issues, which should be considered by Government?*

- It is recommended that **effective partnerships are developed between SDCUs and pain clinics to ensure best practice pain management.**
    - A multidisciplinary approach is often more effective than overreliance on analgesic medications. Access to physical and psychological modalities of pain management, pain specialists and multidisciplinary pain clinics should be considered for residents of SDCUs.
    - For SDCUs located in rural or remote areas, the use of telehealth should be explored to link to pain specialists and clinics based in metropolitan areas. This could include both ongoing professional development of SDCU practitioners and specific pain specialist services and consultations for residents of SDCUs.

Q30 *What factors should be considered in evaluating the SDCU program?*

- Given the specific and significant relationship between pain and BPSD, it is recommended the SDCU program is the subject of ongoing evaluation of outcomes which may include:
    - referral pathways to SCDUs that are related to pain;
    - pain management and treatment within the SDCU setting and its impact on patient outcomes;
    - use of pharmalogical and non-pharmalogical pain management strategies in SDCUs; and
    - availability of continual professional development for SDCU practitioners.

Reference

1 https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf
2 https://www.racgp.org.au/afp/2015/april/pain-management-in-residential-aged-care-facilities/
3 https://consultations.health.gov.au/ageing-and-aged-care/specialist-dementia-care-units/
4 https://www.gen-agedcaredata.gov.au/Resources/Access-data/2014/December/Residential-aged-care-and-Home-Care-2013%E2%80%9314-suppo
5 https://consultations.health.gov.au/ageing-and-aged-care/specialist-dementia-care-units/
6 https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf
7 https://www.racgp.org.au/download/Documents/AFP/2015/April/April_Focus_Gibson.pdf
8 https://www.apsoc.org.au/PDF/Publications/Pain_in_Residential_Aged_Care_Facilities_Management_Strategies.pdf
9 https://www.ncbi.nlm.nih.gov/pubmed/17350169
10 https://www.dementia.org.au/sites/default/files/20120410_ConsumerEngagementAgedCareReformProcess.REPORT.pdf
11 https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf
12 https://www.ncbi.nlm.nih.gov/pubmed/11854774
13 https://www.dementia.org.au/files/EOI_ExecSummary_Web_Version.pdf
14 https://www.racgp.org.au/download/Documents/AFP/2015/April/April_Focus_Gibson.pdf
15 https://tenplay.com.au/news/national/october-2017/new-app-aims-to-help-dementia-sufferers-express-their-pain
16 https://www.mundipharma.com.au/education/panacea/
17 https://www.apsoc.org.au/PDF/Publications/Pain_in_Residential_Aged_Care_Facilities_Management_Strategies.pdf
18 http://sydney.edu.au/medicine/pmri/
19 http://www.painaustralia.org.au/improving-policy/national-pain-strategy

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