

31 January 2023

National Dementia Action Plan Public Consultation
By email: dementioplan@health.gov.au

Re. ANZSPM Response to the draft National Dementia Action Plan

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) welcomes this opportunity to provide our thoughts on the draft National Dementia Action Plan.

ANZSPM is a specialty medical society that supports the professional needs of medical practitioners as they work to improve the health outcomes of every person with a life-limiting illness, and their family/whānau, in Australia and Aotearoa. Our focus is on palliative and end-of-life care (PEOLC), but our influence also affects the healthcare system via our advocacy for holistic care, improved communication skills, and education and resources to support professionals in shared decision making with patients. ANZSPM members are medical practitioners. Our members include Palliative Medicine specialists as well as general practitioners and other medical practitioners who either practice or have an interest in Palliative Medicine. Our Strategic Plan can be found [here](#).

We provide our comments on specific aspects of the Action Plan below.

Commendations

ANZSPM commends the multi-jurisdictional and long term, 10-year approach taken to planning and implementation as a joint initiative between the Australian government and State and Territory governments. ANZSPM is concerned to take a person-centred approach to its own priority setting and its members are deeply committed to ensuring the best possible healthcare outcomes for people living with life-limiting illnesses. ANZSPM is particularly pleased to see the attention paid in the Action Plan to cultural safety as a basic principle in delivering healthcare, and to the specific needs of Aboriginal and Torres Strait Islander Australians who are living with dementia, their families and carers. We see the commitment to actioning the Plan, and measuring and reporting on outcomes from dementia care investments and services, as particularly important.

Comments

Palliative care can be defined as: “an approach to care that improves the quality-of-life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO definition of palliative care). As such, palliative physicians bring a depth of understanding of the patient



journey as one that involves family and close carers and all aspects of the journey and this understanding is of great assistance to the care team. The extent to which this expertise forms part of current service environments, management and care for people with dementia, their families and carers is unknown and anecdotally poor. While the Australian Clinical Practice Guidelines and Principles of Care for People With Dementiaⁱ emphasise the importance of the palliative approach for people with advanced dementia, we propose that the National Dementia Action Plan will be strengthened if it pays more attention to ensuring that palliative medicine knowledge and skills are brought to bear across the dementia care journeyⁱⁱ. Adoption of palliative approaches to improve the dementia care journey will involve a multidisciplinary approach, health services planning that takes account of the unpredictable nature of decline, and a focus on both physical and psychological symptomsⁱⁱⁱ. Further, research has shown that as end of life approaches for dementia patients, there is an increase in distressing symptoms^{iv}, the frequency and pattern of which are similar to, or more pronounced than, those in patients with terminal cancer^{vvi}, demonstrating the need for increased investment in palliative care for dementia patients.

- There is a strong emphasis in the Plan on survivorship and living well with dementia. However with no current cure, all will reach a stage in their journey where they have advanced dementia and in need of a palliative plan and care.
- Palliative care planning following diagnosis and before the EOL stage is therefore of paramount importance, particularly to anticipate loss of function at end stage and also to provide ways forward for people living with dementia, their families and carers.
- An integrated and multi-disciplinary approach to care, which includes palliative approaches and takes account of the key transitions in care for people with dementia, is vital and will deliver important improvements in people's understanding of and attitudes to dementia.
- Expert knowledge of palliative approaches to loss of function, breathlessness, severe pain can ensure the EOL stage is one of quality care for both patients and their carers and extended families.
- While palliative care is relevant to all aspects of the draft Plan, it can make its most important contributions to improving post-diagnostic care and support and improving treatment (Objective 3), coordination and support along the dementia journey (Objective 4), and supporting people caring for those living with dementia (Objective 5).
- To make these important contributions, workforce capacity and capability constraints will need to be addressed (Objective 6) and identified research gaps will need to be filled (Objective 7).
- There is a lack of evidence as to the value of palliative approaches to dementia care as a result of the length of time the dementia care journey can take and the difficulties of involving people in research at end stage. Addressing this lack of evidence should be a priority for Objective 7.
- The lack of dementia-informed palliative care services represents a significant training and workforce gap that needs to be addressed. Filling this gap will require attention to building the evidence base around what constitutes quality palliative approaches for people living with dementia (Ref: Fox, Timmons et al:2022).
- Discussion of pain, or reduced mobility, or other symptoms that manifest for people with dementia may provide a positive way forward for people who are uncomfortable with or wish to reject their dementia diagnosis. Discussion of symptom management can empower the person in this instance and help to normalise the dementia journey as one where there are management options.

- The proposal to audit dementia skills across the healthcare workforce should also identify those with palliative care knowledge and skills within the dementia healthcare workforce. This will pave the way for a strengthening of the connections between the two practitioner communities in a context where they both have a great deal to offer each other towards quality dementia care outcomes.
- The lack of definition and workforce coverage of the palliative journey will need to be addressed across a wide range of care contexts (rural, regional, remote, particular vulnerable communities, peri-urban populations).
- Filling skills gaps will require not only continued support for existing dementia training programs but also a strengthening of GP and specialist training programs for palliative and dementia care and so will necessarily involve formal education, RACGP and RACP training pathways.
- There is an urgent need to improve transitions in care, and to ensure providers at each level of care have both a clear role to play and the training, advisory support and resources to deliver that service. The extent to which this work can be nurse-led will need careful consideration.

This advice has been prepared with input from our Palliative Care for Older Persons Special Interest Group, chaired by Dr Elissa Campbell. We trust our comments are of assistance as you finalise the National Dementia Action Plan and we would welcome the opportunity to contribute further, as needed. Please reach out to our Chief Executive Officer, Janice Besch (ceo@anzspm.org.au), if you have any questions or would like further information on any of the points we have raised.

Yours sincerely,



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President ANZSPM

ⁱ Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016.

ⁱⁱ Dementia Australia; Palliative Care Australia. Policy Statement: Palliative Care and Dementia. May 2018.

ⁱⁱⁱ Sampson EL et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. Palliative Medicine – Sage Journals. Volume 32, Issue 3, March 2018, Pages 668-681.

^{iv} Mitchell SL et al. The Clinical Course of Advanced Dementia. The New England Journal of Medicine. Vol 361, No 16, October 2019.

^v McCarthy EP, Phillips RS, Zhong Z, Drews RE, Lynn J. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. J Am Geriatr Soc 2000; 48:Suppl, S110-S121.

^{vi} Boyd M, Frey R, Balmer D, Robinson J, McLeod H, Foster S, Slark J, Gott M. End of live care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. BMC, May 2019.