

## **Input into National Consensus Statement - essential elements for safe and high-quality end-of-life care**

Submission by the

Australian Physiotherapy Association

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## Australian Physiotherapy Association (APA)

The APA's vision is that all Australians will have access to quality physiotherapy, when and where required, to optimise health and wellbeing, and that the community recognises the benefit of choosing physiotherapy. The APA is the peak body representing the interests of Australian physiotherapists and their patients. It is a national organisation with state and territory branches and specialty subgroups.

The APA represents more than 31,000 members. The APA corporate structure is one of a company limited by guarantee. The APA is governed by a Board of Directors elected by representatives of all stakeholder groups within the Association.

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## Executive Summary

The Australian Physiotherapy Association (APA) is pleased to provide feedback to the Australian Commission on Safety and Quality in Health Care (ACSQHC) survey on the updated *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (the Statement).

We welcome the clarity of the Consensus Statement and its comprehensive elements and the opportunity to input into further inclusions.

The complexity of end-of-life care delivery – in that it spans across a number of settings and funding streams including residential aged care, hospital care and home care – presents challenges in ensuring consistent provision of high quality care.

Knowledge of and access to services is often lacking among those with end-of-life needs and their general practitioners, who are hindered in their ability to refer to specialist health care practitioners such as physiotherapists due to a lack of funding options.

Coordination of the care through a formal structured funding mechanism with a pathway for people to access these services and knowledge of where these services exist is required and would be very beneficial in supporting those with life-limited illnesses and their families. Knowledge of physiotherapy services must be improved among healthcare professionals. Patient-centred among specialist palliative care teams can also be prioritised via referral to physiotherapists. There is evidence of inadequate referring at present to meet patient need. There is a lack of awareness or misconceived perception of the inappropriateness of terminally ill patients to rehabilitation, often resulting delayed access to physiotherapy for end of life care.

Physiotherapists play an important role in end-of-life care. They are experts in maintaining physical function and independence, which is critical to maximising quality of life and dignity for those with life-limiting illnesses. Physiotherapists are essential in the communication of a person's care needs to other members of healthcare team.

Developing the physiotherapist workforce to attract and retain them in this important field of care is much needed.

Recognising emotional and physical burn-out and the need to support care and support workers in this sector must also be prioritised. Acknowledging and treating the trauma of the work environment is essential to ensure a sustainable and high quality workforce.

The APA is available to provide ACSQHC further information to expand on our submission.

## Physiotherapy and end of life care

Physiotherapists have an important role of physiotherapists in palliative care. Physiotherapists' role in palliative care is diverse and patient specific, including:

- delivering pain and symptom management
- delivering lymphoedema management
- managing breathlessness
- • educating carers about safe transfer and handling techniques and/or mobility and exercise programs
- • assisting with early discharge enabling patients to die in their homes
- • assisting with improvements in fatigue and appetite, and
- • facilitating maintenance or improvement of functional aspects of quality of life.

Working as part of multidisciplinary health teams, physiotherapists can help patients and their families achieve these goals in the face of declining health by balancing multiple comorbidities and side effects of treatment. Exercise plans and pain relieving treatments are adapted for patients' changing needs as their illness progresses, effectively supporting them through their journey.

A person feeling more comfortable or stronger may be able to maintain or regain independence in even simple daily activities restoring dignity and quality of life.

Each person with life-limiting illness or approaching the end of their lives presents with their own unique health complexities, functional and social goals.

Physiotherapists help patients and their families set achievable goals, mostly based on maintaining independence with everyday personal care tasks and mobility, and enable many to receive care in their homes.

Physiotherapists specialising in palliative care work across several clinical areas including cancer, neurology, cardiorespiratory, rehabilitation, renal and aged care.

The Clinical Oncology Society of Australia (COSA) position statement on exercise and cancer supports exercise throughout all stages of a patient's treatment and noted that physiotherapy-led exercise prescription is an established safe and effective intervention to counteract many of the adverse physical and psychological effects of cancer and its treatment.

## Survey responses

<p>1. Feedback on elements - is the content of each element relevant and applicable?</p>	<p>The elements cover the multiple aspects of care of those who are dying. The content is comprehensive and speak to an ideal of how palliative care services can be managed and monitored, however there could be an additional element specifically about access to specialised services. Across states and territories palliative care is provided in many settings and the adequate access is limited by the dying person and their support people having knowledge of and access to these services. Nominating a person to manage and coordinate care is not always feasible as there is no one system to facilitate this and also to formalise and fund the planning of multidisciplinary care across various settings. A dying person often accesses many services and healthcare teams across organisations through the palliative care and end of life continuum. This statement can speak more to handing over, documentation or communication of any prior supportive care, end-of-life discussions completed by services and a person between organisations, with the aim of ensuring ongoing, consistent care coordination between services. There needs to be an ongoing, active end-of-life management plan that all services can access (through my health record or an alternative) and obtain input from various healthcare professionals, nominated decision maker or dying person.</p> <p>Examples of this are in cases where care may be managed by a general practitioner in the community. They may have limited ability to refer to other providers and the access is limited by funding for these services. There needs to be support for the provision of the coordination of the care through a formal structured funding mechanism with a pathway for people to access these services and knowledge of where these services exist.</p> <p>This statement could also highlight the need for documentation to be concise, not exhaustive but effective in communicating the dying person's needs to both health professionals and consumer/family/carers. Health professionals are time poor and documentation needs to be kept to a standard where it is not time-consuming but still addresses all key areas of end-of-life care management of the person.</p>
<p>2. Can the revised version be applied to all</p>	<p>No.</p>

settings where end-of-life care is delivered?	<p>These elements are idealised – this type of care is difficult to provide outside of the formal palliative care services.</p> <p>Palliation in residential care settings has many complexities relating to existing structural and funding issues. How are these standards able to be followed when there are limitations on access to multidisciplinary care, specialists and GPs in these settings? Communication difficulties for people with complex issues such as hearing, speech, cognitive, language, and with no advocate or support decision maker, make planning comprehensive care difficult. Access to care plans is limited by the way information is collected stored and accessed in both home and residential settings, with limitations on how these records can be kept up to date without significant IT infrastructure.</p>
3. Is the language and structure of this revised version clear and relevant?	<p>Yes. Language is clear and relevant.</p> <p>We welcome the inclusion of the section on LGBTQI+ re trauma informed care however believe other people in the community also must be supported and emphasised – e.g. People living with mental health conditions, people living with dementia, people who have lived with disability, chronic disease or have reduced literacy/communication difficulties or economically disadvantaged and children. The extensive population of our Australian migrant and refugee communities must also be a focus, many of whom have specific cultural and religious needs around end-of-life care prior and beyond death and may have experienced trauma in health settings.</p>
4. Will the revised National Consensus Statement be useful for improving end-of-life care?	<p>Yes.</p> <p>These guidelines are useful as a way for services to be planned and monitored as well as setting out pathways for them to apply best practice care.</p> <p>The “consensus” requires the service providers to be aligned to the statements – how will these services be guided and supported to implement the recommendations?</p>
5. Please provide any other feedback	<p>Issues for palliative care-</p> <p>Many people living in the community may not be referred for palliative care services until the condition has progressed to the short term end of life phase, thus the ability for implementation of multidisciplinary care is limited and ad-hoc. Better access to care planning tools and information for health workers,</p>

specifically primary care general practitioner, nurse and allied health would enable these standards to be applied.

Many settings such as residential care have limited access to specialised care including allied health and psychological services. The document does not address access issues and the funding of these, including the funding of coordination of services. To address the lack and delay of comprehensive care, improving awareness of the roles of the multidisciplinary team and importance of early referrals to allied health such as physiotherapists across all settings needs to be highlighted in this document.

Documentation of palliative care plans must be made more timely and accessible. The implementation of my health record systems needs to be strongly linked to these standards.

Training for workers involved in palliative care is important however this may not be provided without support from services. Emotional and physical burnout for workers impacts their ability to provide adequate empathic care – how can these elements be realistically applied in a setting that is constantly under pressure, under staffed and underfunded.

A focus on empowering and educating the dying persona and their support people could be an element that helps the person take more control in the process to support decision making.

4.10 – pain relief, symptom control and manage physical symptoms – there is many ways this can be interpreted. Physiotherapists work in palliative care settings to assist with maintaining physical ability and pain management in that there can still be an active approach to dying. People need to be assisted to communicate their needs and access appropriate health professionals.

## Conclusion

The physiotherapy profession is committed to delivering safe, evidence-based and high quality of care to Australians nearing their end of life. We look forward to working with the Commission on future reform to optimise the comfort, dignity and support available to all Australians with life-limiting illnesses.