Australian Nursing and Midwifery Federation submission

National Consensus Statement

Essential elements for safe and high-quality end-of-life care

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INTRODUCTION

The Australian Nursing and Midwifery Federation (ANMF) is Australia's largest national union and professional nursing and midwifery organisation. In collaboration with the ANMF's eight state and territory branches, we represent the professional, industrial, and political interests of more than 320,000 nurses, midwives, and carers across the country.

Our members work in the public and private health, aged care, and disability sectors across a wide variety of urban, rural and remote locations. We work with them to improve their ability to deliver safe and best practice care in each and every one of these settings, fulfil their professional goals and achieve a healthy work/life balance.

Our strong and growing membership and integrated role as both a professional and industrial organisation provide us with a complete understanding of all aspects of the nursing and midwifery professions and see us uniquely placed to defend and advance our professions.

Through our work with members, we aim to strengthen the contribution of nursing and midwifery to improving Australia's health and aged care systems, and the health of our national and global communities.

Our members are involved in the delivery of nursing care, including end-of-life care in all sectors of the health and aged care systems. Member representation, feedback, collective knowledge and experience, places the ANMF in a prime position to make clear recommendations to improving end-of-life care across settings.

The broadening of contexts to which the draft National Consensus Statement applies is admirable, but to this extended scope come added responsibilities and requirements. One of these is to address the needs of nurses, midwives and other health practitioners working in non-specialist palliative care contexts, including nursing homes[1] and acute[2] sectors. The ANMF supports the push for providing education and support to ensure optimal care and reduce unnecessary pain and suffering and transfers to acute facilities from community and nursing home settings. Educated health practitioners along with adequate and safe staffing including access to palliative care advanced practice nurses and nurse practitioners are the keys to supporting and improving care for people with life limiting illnesses through to the end-of-life.

The National Consensus Statement will raise the awareness of employers and organisations of the need for health practitioners who have access to fundamental and ongoing professional development and education regarding end-of-life care. One example, results from the recent legislation requiring registered nurses to be onsite 24 hours per day in nursing homes, acknowledging the importance of this group of health practitioners and their role in end-of-life care. End-of-life care in nursing homes can be substandard reportedly due to inadequate staffing or lack of staff experienced in assessing and providing appropriate and effective end-of-life care [3] [4] suggesting the need for increased numbers of registered and enrolled nurses and care workers and education for those delivering care to people at the end-of-life. Guidance on appropriate skill mix must also be available for those organising staffing and services. Ensuring all nurses are well equipped to provide end-of-life care is essential to this change. The National Consensus Statement offers the opportunity to make this clear to employers and organisations.

The ANMF welcomes the opportunity to provide feedback on the draft National Consensus Statement, offering the following feedback to strengthen the document for use by those providing end-of-life care. This response addresses the survey questions. In addition, an annotated copy of the draft National Consensus Statement is attached and provides comments and suggestions regarding the text.

1. Feedback on elements - is the content of each element relevant and applicable?

Each essential element is relevant, applicable, and supported by the ANMF. However, the breadth of the audience sometimes results in statements that may read as ambiguous, and make it difficult to determine how each essential element will be applied and by whom (individual workers, employing health services and/or aged care providers). This ambiguity may result in disregard for the National Consensus Statement or a situation where the responsibility for implementing the essential elements falls to the nurses and in some cases midwives providing end-of-life care, despite less than adequate staffing, support, funding, or resources from the health service or aged care provider.

Including definitions of workers employed in end-of-life care and applying them appropriately throughout the consensus statement would help to clarify for workers, employers and service providers where responsibilities lie. Definitions should include,

- Health practitioners who are regulated under the National Law with a scope of practice (for example registered nurses, nurse practitioners, medical practitioners, pharmacists),
- Health professionals who are not regulated under the national law but hold recognised tertiary qualifications (for example social workers and speech pathologists) and
- Care workers, (however titled) who are unregulated and have a role but do not have a scope of practice.

Clarity about the roles and responsibilities of each member of the nursing, midwifery and broader multidisciplinary team, ensures the person appropriately qualified or trained delivers the particular element of end-of-life care. For example, only an authorised health practitioner should carry out medication administration and care workers should not be expected or directed to administer medicines.

The addition of essential element 1: Recognising end-of-life is welcomed. Recognising dying is important for management and planning. It must also be remembered that any person may experience acute, reversible conditions in the presence of a life-limiting illness, and the ability to assess for and determine reversibility is essential. The broadening of contexts means that there will be a group of nurses and other health practitioners who lack experience in providing end-of-life care and recognising dying. The ANMF suggests that the provision of education is important in ensuring nurses and other health practitioners know that comprehensive assessments remain elementary to care, including the identification of reversible illnesses even in the presence of a life-limiting condition, triggering further discussions relating to goals of care. This information should be included in the National Consensus Statement.

Advance care planning is an important part of palliative and end-of-life care to enable a person's wishes to be followed and care driven by the person's values. The document must stress that advance care planning involves ongoing discussions that should be revisited regularly and acknowledge that directions may change with the goals of care. Adequate resourcing of aged care, especially in nursing homes, is required to guarantee access to palliative care advanced practice nurses and palliative care nurse practitioners to support people, families and carers to make informed end-of-life decisions and to allow them, where possible, to die in their place of choice.

Overall, the essential elements in Part A are well constructed and applicable across contexts. The elements in Part B are appropriate in most cases, but the ANMF suggest some rewording or less specificity to ensure a conceptual approach.

The level of detail in some essential elements may affect the ability of the health practitioner or organisation to apply them across contexts, especially where it is unclear who holds responsibility for the action. For example, the detail included in 9.2 suggests the health practitioner is solely responsible for organising, conducting and evaluating audits; however, it must be clear that the health service or aged care provider has a responsibility to set up processes and provide resources that allow such work.

2. Are there any patient populations where end-of-life care needs will not be met by the requirements set out in this revised version?

Essential element 2 addresses person-centred care but the ANMF suggests there are a few populations worthy of further mention and direction, namely Aboriginal and Torres Strait Islander populations, culturally and linguistically diverse populations, people with disabilities and people who are socially disconnected/isolated or experiencing homelessness.

Access to and engagement with health information is essential in providing person-centred care. To this end, people must be able to access information and engage in conversations using their language of choice to ensure decision-making is shared and understood and consent informed. This access is especially important for end-of-life conversations and advance care planning and guaranteeing health practitioners establish clear communication channels to plan goals of care. The ANMF suggests that the National Consensus Statement includes recognition of the need for systems that enable access to appropriate interpreter and culture advisor services by people receiving end-of-life care, their families, and health practitioners, as well as the provision of language and culturally appropriate literature and resources.

There is little mention within the National Consensus Statement about people living with disabilities, including those with an intellectual disability. The ANMF suggests more reference to these groups with advice and direction for finding this information and appropriate and accessible resources that consider the person's disability and cognitive and sensory limitations.

3. Can the revised version be applied to all settings where end-of-life care is delivered?

The effectiveness of the National Consensus Statement will depend on the availability of an appropriately educated workforce that is supported by the health service or aged care provider in the ways outlined in the statement.

4. Is the language and structure of this revised version clear and relevant

The structure of the document seems logical. Along with those issues mentioned previously, the ANMF has identified some concerns with language and/or terminology:

- Essential element 4 (p. 16) states that Doctors *are under no obligation*… (p. 16). The ANMF suggests the term Medical Practitioner be used throughout the document, and the statement be extended to include Nurse Practitioners who use advanced, comprehensive assessment techniques in screening, diagnosis, prescribing and treatment, with many working in palliative care settings.[5] The use of the term *practitioner* is in line with National Law.

- While the ANMF acknowledges the importance of including information about people with dementia, we question the reference to Namaste Care. Is this to provide an example of an evidence-based care model? To avoid confusion, the ANMF suggests the document states the reason for the inclusion of Namaste Care, with a recognition that other models of care already exist or may be developed in the future.
- Essential element 4.9 states the need to *reassure the person at the end-of-life that, although care priorities may change, comprehensive, compassionate care will continue.* This statement is very specific and difficult to demonstrate. It might be better to say that *there will be continuity of care through to the end of their life even when/if the person's goals of care change.*
- Essential element 6.3 suggests organisations develop an End-of-Life policy. The ANMF supports the inclusions listed and suggests the following additions:
    - Processes that ensure access to specialist services by non-specialist areas. This inclusion is especially important in areas that do not have specialist palliative care inpatient services, such as some rural and remote settings;
    - Processes to ensure people receiving end-of-life care have access to services outside of normal business hours;
    - Provision of care for the person's support network, including after the person's death;
    - Access to emotional and professional support for all working with people at the end-of-life; and,
    - Processes to ensure the regular review of advance care plans by appropriate health practitioners.
- To communicate the essential elements effectively, it must be clear to whom statements refer so users understand who is responsible for implementation and application. For example, the second paragraph of the initial description of essential element 7 states, *it is important that systems are in place to facilitate access to peer support, mentoring, and appropriate clinical supervision.* The ANMF suggests this also includes mention of *health practitioners,* and, *that access is supported by the organisation and management.*
- Data collection is an important and prominent aspect of end-of-life care to ensure access to funding and planning for quality improvement. Data must be collected and stored safely and ethically with processes that ensure personal information is respected and remains confidential. People receiving end-of-life care, their families, and carers must understand what data is collected, how it is stored, and how it is used. In an age of digital health records and electronic information transfer, processes that ensure a person's information is safe and ethically gathered are essential and must be included in a national consensus document.

Additional ANMF comments are in the accompanying annotated draft of the National Consensus Statement.

5. Will the revised National Consensus Statement be useful for improving end-of-life care?

Any methods put forward to help ensure high quality, evidence-based person-centred care for those at the end-of-life are welcome. Comments in this submission and an annotated draft National Consensus Statement provide suggestions to ensure the Consensus statement is clear, lacks ambiguity, and provides guidance that is useful and translatable into practice across a broad variety of contexts.

6. Please provide any other feedback

Essential element 2 suggests that health services should consider the dignity of risk when developing end-of-life processes. While people at the end-of-life have the right to exercise dignity of risk, including where they die, it must be clear that this cannot be at the expense of the practitioner's safety. Exercising dignity of risk may mean reduced access to services. It is important the person understands their choices and resulting consequences and that their expectations are well managed. As such, managing expectations to ensure informed decision-making is essential for end-of-life care and should be included in the Consensus Statement.

CONCLUSION

Thank you for this opportunity to provide feedback on the draft *National Consensus Statement Essential elements for safe and high-quality end-of-life care.* The ANMF supports provision of high quality, person-centred, evidence-based, end-of-life care, recognising the need for educated and skilled nurses who collaborate with other health practitioners and healthcare workers in the delivery of care. This submission has identified some issues that, if addressed, could strengthen the draft National Consensus Statement and support those receiving and delivering care.

REFERENCES

[1] Mitchell, Geoffrey, Megdelawit Melaku, Allison Moss, Glenda Chaille, Blessing Makoni, Lannette Lewis, and Allyson Mutch. "Evaluation of a Commissioned End-of-Life Care Service in Australian Aged Care Facilities." *Progress in Palliative Care* 30, no. 4 (2022): 229-37.

[2] Virdun, Claudia, Tim Luckett, Karl Lorenz, Patricia M Davidson, and Jane Phillips. "Dying in the Hospital Setting: A Meta-Synthesis Identifying the Elements of End-of-Life Care That Patients and Their Families Describe as Being Important." *Palliative medicine* 31, no. 7 (2017): 587-601.

[3] Spilsbury, Karen, Barbara Hanratty, and Dorothy McCaughan. "Supporting Nursing in Care Homes." *The RCN Foundation Patient Care and Professional Development for Nursing Staff in Care and Nursing Homes: A Research and Consultation Project* (2015).

[4] Mitchell, Geoffrey, Megdelawit Melaku, Allison Moss, Glenda Chaille, Blessing Makoni, Lannette Lewis, and Allyson Mutch. "Evaluation of a Commissioned End-of-Life Care Service in Australian Aged Care Facilities." *Progress in Palliative Care* 30, no. 4 (2022): 229-37.

[5] Australian Nursing and Midwifery Federation. "Nurse Practitioners. ANMF Policy". Melbourne: ANMF, 2020. https://www.anmf.org.au/media/odomf2xq/p_nurse_practitioners.pdf