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Australian Commission on Safety and Quality in Health Care
Level 5, 255 Elizabeth Street
Sydney, NSW, 2000

Submitted via online form: https://www.surveymonkey.com/r/PZWFB29

Response to the consultation on the updated Australian Commission on Safety and Quality in Health Care (ACSQHC) *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*

The Australian Psychological Society (APS) welcomes the ACSQHC revision of the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (the Statement), which aims to incorporate contemporary evidence and practices that support safe and high-quality end-of-life care across institutional, hospice and home settings where end-of-life healthcare is provided.

The APS appreciates the opportunity to provide a response to this consultation draft of the Statement. Working to improve the lives of all Australians is our core business. This includes advocating on behalf of our members and the community for the reform of Australian health and social support systems to improve wellbeing using evidence-based and practice-based evidence approaches to health promotion, prevention, early intervention and treatment.

As with all our work at the APS, we consider issues in light of the global Sustainable Development Goals (SDGs) and the broader social determinants of health[1]. Our response to this consultation is informed by the aim of *SDG 3 Good Health and Wellbeing* to "ensure healthy lives and promote well-being for all at all ages".

If any further information is required from the APS, I would be happy to be contacted through the national office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Yours sincerely,

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Chief Executive Officer

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and evidence-based research to this submission.

Survey Question Responses

Consultation about the updated Australian Commission on Safety and Quality in Health Care (ACSQHC) *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (the Statement)

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

Introduction

- Regarding the statement, "The health care that people receive in the last years, months and weeks of their lives can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers." – this seems to focus only on pre-death grief and distress. This does not align with the stated aims and principles of this Statement to incorporate contemporary evidence and practices that support safe and high-quality end-of-life care.

Recommendation 1: Add a sentence immediately after the above statement to say something like: "Additionally, family, friends and carers benefit from psychosocial support both before a death and after to promote their general health, wellbeing and quality of life."

- The APS commends the clear statement within the Scope section of the Statement, that end-of-life care is person-centred care, and note that health consumers and carers were consulted in the design of the Statement, along with institutional health care settings, professionals, experts and government stakeholders. In the Purpose section of the document, however, consumers and carers are omitted as an audience for the Statement, directly or indirectly.

Recommendation 2: Include consumers and carers as a Statement audience.

- The APS commends the clear assertion within the Scope section that the Statement applies to all people who would benefit from receiving safe and high-quality end-of-life care in all services where healthcare is provided to people approaching the end of life, including in hospitals, hospices, residential aged care facilities and home settings.

    While we agree with the statement In the Scope section that: "When death occurs quickly as a result of sudden and unexpected events, such as acute illness or trauma, care can and should be aligned with the Consensus Statement. However, some actions in the Consensus Statement may not be appropriate or possible in these circumstances.", we are concerned about the way this has been approached in the document which could lead to misinterpretations that safe and high-quality end-of-life care in situations of acute illness or trauma, such as might occur in hospital emergency departments (noting more than half of deaths in hospital are emergency admissions[2]) is less relevant than in situations where people are likely to die in the short to medium term.

Recommendation 3: Revise the approach/language to reduce the potential for misinterpretation that the Statement is less applicable in situations where sudden death occurs or in certain settings such as emergency departments (e.g., clearly state the importance of grief and bereavement support for family and carers in these situations,

use a boxed feature to highlight when and how the application in these settings may vary).

Guiding Principles

- The APS commends the content of the Guiding Principles within the Statement. These mostly reflect the current evidence for safe and quality end-of-life care and align with the following key themes identified by the ACSQHC-commissioned 2022 literature review of end-of-life care that informed the Statement revision[3]:
    - Person-centred care
    - Caring for family and carers pre and post death
    - Environment of care
    - Clinician capacity and delivery of care

    [N.B. At the time of responding to this submission, we were advised that the ACSQHC-commissioned 2022 literature review specific to aged-care was not publicly unavailable.]

    We note, however, that a Guiding Principle about grief is absent and is an important inclusion in relation to psychosocial support.

    Recommendation 4: *Incorporate a principle such as, "Grief is a normal response to loss, both before and after death, and should be supported appropriately based on evidence."*

Essential Elements

- There is an opportunity to better align all the Essential Elements sections with the Guiding Principles and stated Scope of the Statement. For example, the content or language/approach/tone in the various elements give the following (unintended) impression at times:
    - health worker/clinician considerations take precedence over person-centred care and partnering with consumers in healthcare
    - there is no or a limited role for allied health professionals and others with expertise in providing psychosocial support
    - considerations in institutional settings as an end-of-life care environment are the same as those for the home environment as a healthcare setting for end-of-life care
    - there is less importance/urgency to address safe and high-quality end-of-life care in situations of sudden and traumatic deaths versus the situation where people will die in the short to medium term
    - grief and bereavement support for carers, families and staff can be discrete and siloed rather than an integral part of contemporary delivery of safe and high-quality end-of-life care.

    Recommendation 5: *Adapt the approach/language/tone throughout the Statement elements to present an approach that is less siloed and more person- and family-centred as well as offering a stronger sense of patient, family and professional partnership and being more inclusive of the home environment as a place of end-of-life health care.*

    Recommendation 6: *Incorporate more explicitly the expert role of allied health workers such as psychologists, counsellors and social workers, and death and dying professionals such as death doulas.*

    Recommendation 7: *Aboriginal liaison officers and the role of psychosocial support workers for other diverse groups (e.g. people with disability, dementia, LDBTQI+) should also be more present throughout all the elements. This should also include the support they may require given they are potentially more prone to burnout because*

they do not have the same access to debriefing and clinical supervision that other professions (e.g., counselling, psychology) have, yet may be more at-risk because they are embedded in the communities they serve.

Recommendation 8: Integrate the importance of grief and bereavement care throughout the Statement sections – there are opportunities to do this in many of the Essential Elements, not only as part of Essential Element 8: Care setting and bereavement support. Some examples are provided below:

- **Essential Element 2**
  Refer to having conversations about preparing for caring, and preparing for death and grief[4]
- **Essential Element 4**
  Include recognition of the multiple losses and potential for grief experienced during dying for both the person/patient and their family and friends. In fact, pre-death grief and distress is often high, and higher than after death.[5]
- **Essential Element 7**
  "All healthcare workers should have a shared understanding of the local terminology, policies, processes, and practices associated with end-of-life care." could be changed to something like: "All healthcare workers should have a shared understanding of the local terminology, policies, processes, and practices associated with end-of-life care and bereavement care."

  "Dealing with death and dying can be challenging for healthcare workers, and can also affect other staff members such as administrative staff, food servers and cleaners." could be changed to something like: "Dealing with dying, death and grief can be challenging for healthcare workers, and can also affect other staff members such as administrative staff, food servers and cleaners."

  "Ensure a policy exists outlining supervision and support to healthcare workers who care for people who are dying." could be changed to something like: "Ensure a policy exists outlining supervision and support to healthcare workers who care for people who are dying or have died, and their family and friends."

  "Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care." could be changed to something like: "Offer ongoing formal training in communication skills to healthcare workers at all levels, as these skills are critical to the delivery of end-of-life care and bereavement care."

- The boxed content highlights important considerations for safe and high-quality care for diverse groups. There are some edits and omissions that could be addressed.

Recommendation 6: The boxes titled as considerations for "Children" to be updated to "Children and Young People" to accurately reflect the age ranges/stages that the boxed content refers to.

Recommendation 7: Include more boxes to highlight unique considerations for other diverse groups in the Australian community, including Aboriginal and Torres Strait Islander people and people with disabilities (e.g., supported decision-making considerations for people with intellectual, communication or psychosocial disabilities).

Essential element 8: *Care setting and bereavement support*

- The APS commends the inclusion of an Essential Element dedicated to the care setting and bereavement support, and as noted in feedback above, we have identified opportunities to ingrate this essential aspect of safe and high-quality end-of-life care more throughout the Statement. The recommendations below apply to

Essential Element 8 but can also be considered with regard to content and language/approach/tone throughout the other Statement sections.

Recommendation 8: Ensure the correct use of the term bereavement. For example, the following statement appears to be based on an incorrect view/internet reference that claims bereavement is a process – rather, bereavement is the event of a person's death: "Bereavement support includes the emotional, psychosocial and spiritual support provided to family and loved ones before and after the death of a person to assist them with coping with issues related to grief, loss and adjustment.[23] See the submission reference list for examples of other appropriate literature that could be helpful.

- The APS agrees that "Early assessment and supportive measures to address bereavement needs of families should be taken to minimise adverse physical and emotional responses."

  However, there is currently no consensus regarding which assessments should be used, and many existing assessment tools are not fit for purpose in busy clinical settings. Information that may be helpful is provided in literature cited in the submission reference list - see [6–8].

<u>Glossary</u>

Recommendation 9: Key terms like grief and bereavement should be defined here. These are important oversights given the number of actions related to these issues.

- Bereavement – the experience of having lost a significant person through death

- Grief – the response to loss, both death and non-death losses, and affects all aspects of life including emotions, thoughts, behaviours, finances, and relationships.

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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?

- Aboriginal and Torres Strait Islander people, people with disability, especially for those with intellectual, psychosocial or communication disabilities who require supported decision- making processes for end-of-life care.

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

- As noted above, more consideration about content and language and approach is required to make this Statement more applicable to the home setting.
- Also as noted above, more consideration is also required for the application of this Statement to emergency care settings. We are especially concerned about institutional and organisational readiness for matters associated with safe and high-quality bereavement support and care in emergency department settings – such as providing appropriate and safe physical and emotional spaces for families and carers to spend time with and care for the body of their loved one after death due to factors including: bed management pressures in emergency departments/hospitals and limited onsite mortuary or viewing services in hospitals during the critical period after death and before the body is collected by a funeral service[9,10].

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

- Language/approach considerations have been flagged in other feedback throughout this submission.

• There are some grammatical issues e.g. "The LGBTIQ+ community have…" should be "The LGBTIQ+ community has…"

5. Will the revised National Consensus Statement be useful for improving end-of-life care?
• Members shared with us their professional, and sometimes also their lived experience of end-of-life care for loved ones. Common themes emerged around poorly integrated care and limited or no psychosocial services for the dying person or grief and bereavement care being provided pre- and post-death for family and loved ones, in both public and private institutional settings. • Feedback from our members generally commended the Statement Principles and intent of the revised Statement as urgently needed to address these issues. In addition to the feedback that we have already incorporated above about grief and bereavement care and related issues, we note that our members also expressed concerns about the pace of the system change and staff capacity building required to achieve the vision of contemporary safe and high-quality end-of-life care. They also raised questions and concerns about how healthcare systems and healthcare workers will be supported around new voluntary assisted dying (VAD) legislation. • Members also referred to the role of improving "death literacy"[11], which they currently identified as lacking in our society and as a specific safety gap in our health systems.   The APS, therefore, agrees with the key points of conclusion identified in the ACSQHC-commissioned 2022 literature review that has informed the development of this revised Statement. The authors of that review concluded that organisational readiness, in the context of increasing pressures on care delivery, will be critical to achieving contemporary safe and high-quality end-of-life care as envisioned in the Statement. In particular, we also agree that, "the spotlight (is) on health service organisations to ensure that teams and individuals are supported and enabled to provide (safe and high-quality end-of-life) care" (p. 2)[3].   *Recommendation 10:* Implement urgently the points of recommendation in the ACSQHC-commissioned 2022 literature review (additional to Recommendation 1 to revise the Statement which is currently the subject of this consultation) to the work of building organisation readiness and capacity of workers in end-of-life settings. These Recommendations are: *Recommendation 11*: That the Commission consider a new strategy to support health service organisations to understand the importance of, and implement, the National Consensus Statement, including the development of resources to support health service organisations[3 (p. 2)].   *Recommendation 12:* That the Commission consider development of a clinical care standard for bereavement care[3 (p. 2)].   *Recommendation 13:* That the Commission consider assessing the contribution of innovative digital technology and equipment in end-of life care processes, and provide the sector information to support best practice for the utilisation of technology in the delivery of end-of-life care[3 (p. 2)].   *Recommendation 14:* That the Commission examine the review findings for implications for the audit toolkit and consider liaising with stakeholders to identify gaps in the End-of-Life Care Audit Toolkit and possible opportunities for new components[3 (p. 2)].

6. Please provide any other feedback.

- **Recommendation 16:** *Include additional references that reflect contemporary evidence around grief, bereavement and psychosocial support – see examples in the submission reference list below.*

References

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15. Aoun, S. M., Breen, L. J., White, I., Rumbold, B., & Kellehear, A. (2018). What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliative Medicine*, *32*(8), 1378–1388. https://doi.org/10.1177/0269216318774995

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