National Consensus Statement: Essential elements for safe and high-quality end-of-life care

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Lived Experience Australia Ltd
Contact: Sharon Lawn
Chair & Executive Director
slawn@livedexperienceaustralia.com.au
PO Box 12, Oaklands Park SA 5046
Phone 1300 620 042
ABN: 44 613 210 889

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Our core business is to advocate for systemic change to improve mental health care across the whole Australian health system. This includes advocating for empowerment of consumers in the broad range of issues that impact their mental and physical health, empowering consumers in their own care and contact with health and social services, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion and wellbeing. Our submission comes from the perspectives and experiences of people with lived experience of mental health challenges, their families, and carers.

We welcome the opportunity to provide our submission to the ACSQHC Partnering with Consumers program as part of its work on revising the National Consensus Statement: Essential elements for safe and high-quality end-of-life care. We understand that this work will determine the essential elements required in health care systems to ensure safe and high-quality care for patients who are approaching the end of life. As stated, the changes to the National Consensus Statement reflect the following:

- Guidance for specific patient groups where care may differ from usual end-of-life care including paediatrics which has been a separate document until now
- Adapting language and terminology so it applies in all end-of-life care settings and increasing the information around the role of family
- Changing the essential element Components of Care to Comprehensive Care, in alignment with language used in the National Safety and Quality Health Service (NSQHS) and Primary and Community Healthcare Standards
- Combining Education and Training, and Supervision and Support, into one element
- Physical space to meet the individual needs of the patient and the family, including spaces where families can gather has been added as an organisational requirement
- Inclusion of bereavement processes
- Strengthening a number of elements including Person-Centred Communication and Shared Decision Making, Systems to Support High-quality Care and Leadership and Governance
- Consideration of pandemics on care provision.

Feedback on the Consensus Statement

NB. We note the request to answer 'yes' or 'no'. It would have been useful to have a third option 'partially', given we confirm many aspects of the document, but make suggested revisions and additions in some sections.

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

○ Yes

◉ No - Please explain

Essential element 2: Person-centred communication and shared decision making

Supported decision-making may be necessary for such patients. Supported decision-making means that clinicians assess the patient's decision-making capacity and maximise opportunities for participation by patients with impaired capacity. This might mean deferring decisions until the patient is more able to participate – for example, until treatable causes of impaired decision-making, such as depression or

delirium, are ameliorated. Where this is not possible, clinicians should work with carers and families to support patients to be as involved in decision-making as their capacity at the time will allow.

We suggest, for example, that workers could ask family members to provide suggestions for strategies to support care and communication with the person. Document TOP 5 strategies – and place on bedside chart. Present one question, instruction, or statement at a time. Confirm the person's answer by reflecting to them as a statement. E.g.," you would like your shower now" and monitor their response either verbal or non-verbal.

We also recognise that end-of-life care can reflect a return essentially to institutional care for people who may have experienced institutional care at other stages of their life, especially where the person is placed in aged care, hospice care, hospital, and so forth. We are particularly concerned for the person-centred needs of care leavers (individuals who spent time in orphanages, experienced guardianship) or experienced the trauma within other institutions such as mental health settings. 'Returning' to some settings for end-of-life care may well come with many fears and triggers to trauma that may not be realised by the staff in those settings. We know that this is particularly apparent in aged care settings where quite 'ordinary' requests or processes may lead to the person having flashbacks to earlier trauma. The intersection between mental health, past trauma, Dementia and end-of-life care is particularly complex. We strongly recommend that this consensus statement has some focus on this intersection and that the need for training in trauma-informed care for all staff and volunteers in all settings is clearly stated.

Essential element 3: Multidisciplinary collaboration and coordination of care

People often receive care from a range of organisations with different systems, roles, and approaches to managing end-of-life care. Healthcare workers involved in a dying person's care have varied experience, values and perspectives on planning and providing end-of-life care. Multidisciplinary collaboration is a process where healthcare workers from different disciplines and/or health services share clinical information to optimise the delivery of comprehensive care for a patient.

LEA would support establishing a key liaison person and having a two-way relationship between hospital palliative care service and community palliative care service.

Patients often receive care from a range of organisations with different systems, roles and approaches to managing end-of-life care. Interdisciplinary teams include individuals with varied experience, values and perspectives on planning and providing end-of-life care. Unless an identified person takes overall responsibility for coordinating a patient's care, and ensuring effective communication and collaboration, patients can receive discordant information and poorly coordinated care.

Please see further comments in our responses to question 6.

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?

○ No

◉ Yes - please explain

We are concerned that the needs of people with severe mental illness may not be met by the requirements. We have made a number of comments about this in response to question 6 below.

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

○ Yes

◉ No - please explain

We are concerned that there are many people with severe mental illness who reside in settings where their end-of-life care needs are not recognised as such by staff in those settings. For example, we are aware of a

person who resided in a women's shelter where she was left to self-manage much of her day-to-day care, even though she became increasingly unable to get out of bed. Pain management was not assessed and, because she felt she was lucky to have any roof over her head (because she had spent many years either homeless and experiencing family violence, and was a 'care leaver'), she didn't think she could ask for basic needs like a pillow to elevate in bed so she could spend her last weeks in more comfort. When the staff felt she was more burden to their routine than they could manage (e.g., when she could no longer shower herself and they perceived her as 'smelly'), they moved her to a nursing home setting where she died alone not long after.

There are likely a number of 'institutional' settings where the revised version of the consensus statement might not be applied because the staff in those settings simply wouldn't see it as their business, wouldn't upskill themselves in line with the requirements, and so forth.

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

⊙ Yes

⦿ No - please explain

We generally agree; please see responses to Question 6 below for some specific concerns.

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

⦿ Yes

⊙ No - please explain

6. Please provide any other feedback
Introduction
p.5 It is unclear why the statement in the first box here is needed re substitute decision-makers, family, carers, etc. Given substitute decision-makers are those with legal authority (as per the Glossary), the purpose of the statement is unclear, particularly in the context of the end of this sentence - 'if this is what the person at end-of-life prefers'. What if the person is unable to inform this preference? (Hence, the need for substitute decision-maker?)

p.6 Would it be useful and timely to include NDIS providers as an example of the collaborative partners? There is so much focus currently on access and entry to NDIS, which services a significant population of people with disability. However, that sector has, to date, engaged in virtually no dialogue about palliative care / end-of-life care. Many people who receive NDIS belong to priority populations known to have multiple complex care needs that also mean that they are at increased risk of dying earlier than the general population without disability. For example, we know that people with severe mental illness/psychosocial disability die approximately 20 years earlier. We know that, for many, their NDIS support workers may be the main or only people to see them in their home. As the NDIS matures, the role of such providers in the long-term will be increasingly recognised by systems such as those providing end-of-life care. Therefore, they are likely to become an important addition to the care coordination / multi-disciplinary eco-system of supports around the person, particularly where family and carers may or may not be present in the person's life.

Currently, the palliative care and NDIS systems are quite siloed and there is little awareness of each other across these systems and how they might work collaboratively for this priority population. Professor Lawn is currently supervising a PhD Candidate (Kathy Boschen) on this topic. Kathy has undertaken and published a scoping review of available policy documents, academic, and grey literature to map evidence about

system supports and gaps for Australians with psychosocial disabilities and life-limiting diagnoses.[1] Kathy and co-authors found no peer-reviewed or grey literature on the phenomena. Therefore, they undertook three further investigations of the existing evidence: experiences of NDIS participants living with psychosocial disabilities; the death, dying, and palliative care supports and experiences of NDIS participants of any disability type; and the experiences for people living with severe mental illness and life-limiting diagnoses. They concluded that NDIS participants living with severe and persistent mental illness often experience poor end-of-life outcomes. Kathy is currently completing further research activities for her PhD on the death, dying, and palliative care experiences of this population. This includes interviews with consumers, family/carers, and stakeholders involved in the delivery of mental health, palliative care and NDIS.

Section A: Care Processes

p.9 Line 5 – For consistence and accuracy, we think this statement should be revised '…to provide comprehensive care and achieve a person's goals.' Elsewhere in the document, you refer to wishes, preferences and goals. We are also cognisant that not all of these can be realistically 'achieved', depending on the circumstances involved; so this word may need to be reconsidered too.

In addition to shared decision-making being critical to ensuring people are partners in their own care, we believe that supported decision-making is also important to state here, to be more inclusive of all individuals and groups, particularly those who are often deemed to lack capacity and may have experienced stigma and discrimination as a consequence of their disability status and conditions. We know, for example, that people and people with severe mental health conditions may come to palliative care services following significant and lengthy lived experience of receiving adverse experiences of disempowering and/or coercive care within mental health services. We also know that people with complex communication needs (e.g., cerebral palsy, deaf, intellectual disability) who also have mental health conditions may be poorly served in these systems. That is, capacity of the person is not the issue; rather, capacity of the system to ensure practices to ensure that they can communicate effectively with the person and seek the person's input (on the person's terms) is more often or not the issue.[2]

The statement that 'Healthcare workers should be aware of the referral criteria, processes and timelines for accessing specialist palliative care service' seems somewhat overlooked amongst the other detail here. It is such a crucial process to ensure effective communication across the various systems. Often, it has been our experience that this is exactly where and how some people fall through the gaps in systems. The statement in its current form and positioning has no impact and context in which to recognise its importance to care processes.

p.10 1.2 This statement about various people who can request palliative care relies on the person being aware that they can do so, workers being sufficiently aware of end-of-life care needs, and the person having family members or carers in their life (which they may not have). We are particularly concerned for people with mental health challenges who reside in settings that may or may not cater to these needs or have awareness. This includes shelters, institutional settings large and small, and other settings that are really on the periphery where the person may or may not have any active and formal services involved routinely in supporting and advocating for them within systems.

Essential element 2: Person-centred communication and shared decision-making

p.11 line 3 – There seems to be a grammatical issue here? ('are listed 1.3'). Should this be 'as listed in 1.3'?

Also, the statement re 'to actively engage with families through out the dying process' may be quite problematic for some individuals who have no family, or no contact with family, especially where they have experienced trauma and abuse within their family history.

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[1] Boschen, K.; Phelan, C.; Lawn, S. NDIS Participants with Psychosocial Disabilities and Life-Limiting Diagnoses: A Scoping Review. Int. J. Environ. Res. Public Health **2022**, 19, 10144. https://doi.org/10.3390/ijerph191610144

[2] Please contact for further information about PhD research in progress on the topic of complex communication needs.

Our experience is that some people have no-one who they can name and have act as substitute decision-makers, families and carers; some people have a neighbour or other person in the community who may be one of the few people who they see and who knows them. We believe that 'friends' should also be named somewhere in the statement. There is some mention of them later in the document only. This is particularly important given the person may in-fact be the intimate partner of the person, but this is not formally recognised.

RE the statement about capacity and supported decision-making, only providing the example of deferring decisions is not really helpful and it doesn't emphasise the set of skills and values to really and truly provide supported decision-making as part of everyday practice from a person-centred perspective. Fundamental to supported decision making must be the believe that, unless the person is not awake, they must always be assumed to have an opinion about what they want or need in that moment, big or small, and they must be asked in a way that brings their views into focus. In mental health contexts, where peoples' human rights can sometimes be threatened in the context of beliefs about their 'capacity', it is too easy to apply this assumption as a blanket. 'I may be detained, but I still know I like chocolate not vanilla ice-cream'. Capacity to make decisions, even small ones, must be respected.

p.12 'check that the person understands' doesn't seem to make sense as a statement, given the earlier part of this statement! Which person is being referred to here?

The Box with information about 'Children' could also use the word 'developmental' because, in this field, age is recognised as inadequate as a marker of other aspects of assessment such as capacity. We also wonder if there are any specific legal or other considerations for older adolescents that should be mentioned here.

p.13 2.12 – 'decision-making needs' sounds too generic and unclear, which then makes it open for misuse or ambiguity and confusion for staff when they need to apply these statements to practice.

Essential element 3: Multidisciplinary collaboration and coordination of care

p.14 – 'improves personal satisfaction' should probably indicate who is meant here?

Also, it would be good to indicate that the person and their family receive a copy of 'the plan' in some form that they understand. Family and carers, in our experiences, are often the holders of significant valuable information and they also provide significant communication support across systems, filling gaps, correcting misinformation and errors, and so forth.

Essential element 4: Comprehensive care

p.16 Who assesses quality of life and how is it determined? We would hope that it is not predominantly focused on clinical and physical criteria, and that the person leads this process, if able, or the people in their informal network who know them best, and what is important to the person at end-of-life.

Likely, how is 'uncomfortable and burdensome' assessed; given many treatments are uncomfortable and burdensome and various stages of treatment.

In the Box about 'Children', we believe that referral pathway to relevant adult health services MUST be available or at least offered.

The information in the Box about Dementia is vague and needs more context? There could also be mention of mental health and trauma intersections for some individuals.

p.17 4.5 We think that the second sentence here deserves its own dot point.

Essential element 5: Responding to concerns

p.18 What happens if the concerns are about the health professionals providing care. Much of the content of this element if focused on the person at end-of-life being cast negatively. More could be said about legal issues and reporting, where there may be misconduct by people around the person.

Section B: Organisational prerequisites

p.19 line 5 – families' should be families.

The term 'cultural' is somewhat conflated on this page, with switching between its meaning within systems (organisational culture) and in the sense of cultural groups based on language, ethnicity, etc. We suggest revision to make it clearer.

Essential element 7: Support, education and training

p.21 We think volunteers should also be included in the list of those who can be affected in workplaces when dealing with death and dying.

A dedicated Box about mental health and the issue of trauma and training would be a good addition here.

Essential element 8: Care setting and bereavement support

p.23 8.5 Is it worthwhile to mention the needs of bereaved children specifically here, rather than them being capture within the term 'family'? Also, what if the person who died is the carer?!

Essential element 9: Evaluation, audit and feedback

p.24 9.5 – Re last dot point, we wonder if there is value in striving to collect data on time lapse between recognition and referral regarding people within mental health service systems and NDIS (especially given our comments and concerns in this submission).

Essential Element 10: Systems to support high-quality care

p.25 9.6 We wonder if complaints reports should also be added here as a method for collecting data?

p.26 Given our comments about NDIS, as an example of the various types of services that may involve people at end-of-life, we believe that the statement 'Implement processes to improve communication between health services at transitions in care' should not only be 'health services'.

Finally, we are conscious that there are so many Standards documents across the various sectors (Aged Care, Mental Health, NDIS, etc) and are concerned that the issue of trauma and the potential for care processes and end-of-life to retrigger past trauma for some individuals, will be lost within services trying to meet the various standards.

Contact

We thank the Australian Commission on Safety and Quality in Healthcare for the work it is doing on this important national issue. We wish you every success with the next steps. We would be keen to discuss further, any clarification or issues raised here with you.

Your sincerely

Professor Sharon Lawn
Lived Experience Australia Ltd
Board Chair and Executive Director
Email: slawn@livedexperienceaustralia.com.au
Mobile: 0459 098 772

Helene Langley
Lived Experience Australia Ltd
Board Director & VIC Advisory Forum Coordinator
Email: hlangley@livedexperienceaustralia.com.au