# Clinical principles for specialist bereavement care in NSW

May 2024

End of Life and Palliative Care Network

The information in this resource should not replace a clinician's professional judgement.

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# Contents

# Introduction

The purpose of this document is to articulate practitioner-defined principles for:

- specialist bereavement services
- providers of specialist bereavement counselling and support.

Currently, there are no established national standards for specialist bereavement services or counselling in Australia. Efforts to date have concentrated on bereavement practice in the context of palliative care provision. The Bereavement Support Standards for Specialist Palliative Care Services[1] were developed in 2012 in Victoria. However, these standards do not speak to bereavement services serving populations beyond those known to palliative care services. Palliative Care Australia has flagged a future intention to develop and implement national standards for bereavement service provision in Australia, based on best practice.[2] Grief and bereavement support is also identified as a key action within the Clinical Principles for End of Life and Palliative Care[3], and integral to appropriate recognition and support for constellations of families and carers in the End of Life and Palliative Care Framework 2019-2024[4]. A national framework, in the spirit of the Bereavement Care Service Standards[5] endorsed by the National Bereavement Alliance in the UK, or the essential recommendations of the European Association for Palliative Care Bereavement Taskforce[6], may clarify criteria to guide consistent expectations of high quality bereavement services.

This resource describes the minimum principles of specialist bereavement counselling practice and services for the NSW context, underpinned by current evidence and practice. This is necessary both within and beyond palliative care.

The development of these principles was practitioner-led and informed by significant practice experience and immersion in specialist bereavement counselling provision and service coordination. The network of NSW Bereavement Coordinators' represent a range of disciplinary orientations (counselling, social work, psychology and psychotherapy). The network is self governing and includes practitioners with a combined total of over 150 years of experience in specialist bereavement counselling, from 1993 to the present day.

The development process involved the following steps:

- Review of the 2012 Bereavement Support Standards for Specialist Palliative Care Services[1] by individual members of a network of NSW Bereavement Coordinators, with the awareness of the Australian Centre for Grief and Bereavement (now Grief Australia).
- A series of discussion meetings in late 2021 and early 2022 with the network of NSW Bereavement Coordinators, to review commentary on the 2012 Standards and discuss consensus.
- Drafting of the principles by a sub-committee of the network of NSW Bereavement Coordinators; informed by the discussion meetings and using the 2012 Bereavement Support Standards for Specialist Palliative Care Services[1] as an underpinning framework.
- Circulation of the draft principles within the network of NSW Bereavement Coordinators' to confirm consensus, and further refine the statement.

- Revision by the sub-committee of the network of NSW Bereavement Coordinators’, and re-circulation of the revised principles within the Network.
- Consultation with and revision following feedback from consumers, the Ministry of Health Aboriginal Palliative Care Network and across the clinical networks of the NSW Agency for Clinical Innovation.
- Request to the Agency for Clinical Innovation from the network of NSW Bereavement Coordinators’ to publish this practitioner-developed resource.

The ten principles outline a recommended minimum level of bereavement support for bereaved people, provided by specialist bereavement services (whether based solely in supportive and palliative care settings, or whether providing bereavement services regardless of cause of death). Criteria for meeting these principles are outlined and have been mapped to national frameworks (see Appendix 1).

### Aboriginal people and Sorry Business

The network of NSW Bereavement Coordinators’ respectfully acknowledges Aboriginal people as the traditional custodians of the lands, skies and waterways on which we live and work. We recognise Aboriginal communities as the First Peoples of Australia who never ceded sovereignty of the land. We recognise that events of the colonial past continue to cause pain and suffering for Aboriginal people and communities today and shape their experience of grief and loss in particular ways.

While there may be common themes, it is important to recognise that not all Aboriginal people share the same beliefs and customs and there will be varied experiences of grief and bereavement, within a context of significant historical loss and intergenerational trauma.[7] Aboriginal families may also belong to a particular religion and may combine beliefs, protocols, customs and processes with their Aboriginal spirituality.

Sorry Business is a term that Aboriginal people refer to during cultural practices and protocols associated with death. The most common ceremonies of Sorry Business are conducted around mourning, bereavement and funerals for a deceased person.

Sorry Business in some communities may also be conducted to grieve or mourn the loss of connection to land, or possibly where an application for recognition of Native Title is lost, in some communities the grief and trauma associated with loss of cultural connection to land is experienced as painfully as the loss of a family member.

Sorry Business is important time of mourning that involves responsibilities and obligations to attend funerals and participate in other cultural events, activities or ceremonies with the community.[8] The customs, protocols and timeframes may differ between communities.

We acknowledge the strength, wisdom, compassion and care which are embedded in Aboriginal kinship ties, language, culture and spirituality. We recognise the strong spiritual connection to Country and the importance of sensitivity to and acknowledgement of the distress for family and community when a person dies away from Country.

# Clinical principles for specialist bereavement care in NSW

## Principle 1: Access

Specialist bereavement counselling and other forms of bereavement support are accessible to bereaved people according to need, regardless of age, gender, culture, sexual orientation, socioeconomic status, religious or spiritual beliefs, physical or other disability or ability to pay. Specialist bereavement counselling and support are also available regardless of whether the deceased was known to a palliative care service. Preferences for support may be influenced by culture, spirituality, past experiences and community norms and practices.[4]

### Criteria

1. Information detailing locally available bereavement services should be readily accessible (within the constraints of resourcing), to support visibility of and access to specialist bereavement counselling and support for those in need across the population and/or region of relevance to each bereavement service.
2. Bereavement counselling and support are delivered in a manner sensitive to social, cultural and spiritual beliefs, values and practices of each client.
3. Bereavement services employ staff with relevant experience to provide counselling and support to social and cultural groups in the region of relevance. If this is not possible, they can actively develop connections with other service providers or organisations with the relevant experience.
4. Bereavement services must be culturally safe for Aboriginal people, culturally and linguistically diverse populations, people identifying as LGBTIQ+, and other priority populations.[9] Culturally appropriate referrals should include liaison and collaboration with relevant staff, e.g. Aboriginal liaison workers, Aboriginal Health Workers and Practitioners, Aboriginal palliative care workers, social workers or other culturally-specific workers such as multicultural health workers. This may include handovers with the bereaved person's consent, where a service or worker involves specialist bereavement services to establish cultural safety in the receiving service.

## Principle 2: Service coordination

Bereavement counselling and support is coordinated and comprehensive.

### Criteria

1. The structure and processes of specialist bereavement services promote continuity of care.
2. Bereavement services reflect a comprehensive approach to planning, implementation and evaluation.
3. A person with demonstrated competency, experience and relevant qualifications is accountable for the coordination of bereavement counselling and support provided by bereavement services, i.e. tertiary qualifications in counselling, social work, psychology or psychotherapy, and accreditation, membership or eligibility for membership of recognised, associated professional bodies.

4. The role, responsibilities and scope of practice of staff coordinating and providing specialist bereavement counselling are clearly described and documented in position descriptions.

## Principle 3: Training and support

Staff providing specialist bereavement counselling or support within the population or region relevant to the bereavement service will require training and support. These staff include:

- bereavement counsellors
- other staff and volunteers within bereavement services and related organisations, e.g. local health districts, who may provide forms of bereavement support (see Appendix 2 for examples of training resources).

### Criteria

1. Staff providing bereavement counselling are specialist practitioners such as counsellors, social workers, psychologists or psychotherapists with postgraduate qualifications or other training and/or experience in loss and grief. Specialist bereavement counsellors should attend regular professional clinical supervision (in accordance with the requirements of their professional registration and/or disciplinary orientation) and engage in regular professional development.
2. Other staff may conduct bereavement support or assessment within the population or region relevant to the bereavement service, e.g. health professionals from varied disciplines, including Aboriginal health workers. This staff should have regular access to continuing education and professional development on grief and bereavement. Education and professional development should be tailored to their specific context of practice or setting and include considerations for culturally safe grief and bereavement support and counselling. Access to professional supervision and opportunities for consultation with specialist bereavement counsellors for skill development and support should be facilitated.
3. Administrative staff within or connected to the bereavement service (through overarching organisations or networks of service provision) should have, at minimum, training in basic principles of grief and bereavement support strategies.
4. Volunteers involved in the provision of bereavement support within the population or region relevant to the bereavement service will have undertaken training appropriate for their setting. This should be either facilitated by and/or in consultation with the specialist bereavement service, e.g. for volunteers within Supportive and Palliative Care Services, the Palliative Care Victoria Volunteer Training module[10]. Volunteers providing bereavement support should have access to supervision and opportunities for debriefing.
5. Any volunteers who provide specialist bereavement counselling must have the same qualifications and access to clinical supervision as paid staff delivering those interventions.
6. Any staff providing bereavement counselling and support must be aware of the limits of their scope of practice. They should also use internal and external referral pathways, should a bereaved person/s require interventions that are beyond their practice scope or that of the organisation.

## Principle 4: Assessment

Assessment for psychosocial and spiritual distress is an ongoing, interdisciplinary process. Where family members and carers are known to a service prior to a death, e.g. a palliative care service, assessment should take place from the time the patient, carer and family are first known to the service and be revisited through end of life, at the time of death and following the death.

Assessment should be interdisciplinary and include conversations throughout engagement with a service. This is because risk is not necessarily static – it may fluctuate throughout end of life and in bereavement – and individuals may disclose different information to different staff at different times.[11] Additional considerations should be made for priority populations. For Aboriginal families, Aboriginal health workers, where possible, should be invited to contribute their cultural and spiritual knowledge to the assessment process.

### Pre-death assessment

The National Palliative Care Standards promote “structured assessment of bereavement that addresses emotional, behavioural, social, spiritual and physical domains.”[12] However, there is insufficient empirical evidence to support the validity of one specific tool to screen for the risk of poor bereavement outcomes prior to a person’s death.[1] A death is estimated to impact approximately eight to ten family members,[13] and the person most ‘at risk’ may not be the person who was assessed. Individuals may disclose different information to different staff at different times. It is recognised that ”safe predictions”’ about the longer-term outcomes for bereaved individuals less than six months post death are difficult to make.[14]

A comprehensive, holistic assessment should be done through a conversational, ongoing exploration of risk factors as well as strengths and resilience factors.[1] This should consider cultural, social, spiritual and religious norms and expectations. Refer people to or engage with other health professionals, e.g. social worker, psychologist, psychiatrist, where indicated.

### Post-death assessment

There is limited evidence to support bereavement follow up and assessment at specific time-points, post-death.[1, 12, 14] Given the varied ways in which people respond and adapt to bereavement, it may be difficult to predict their longer-term functioning when they are within the six-month period after a death.[1, 14] The systematic, predictive screening of all recently bereaved people is not recommended.[12]

Standardised, validated tools can be used to identify prolonged grief disorder, e.g. PG-13-R, from six months onwards, after a death.[15] This may facilitate appropriate referral and intervention.[12]

Any assessment of bereavement must address both grief that is a normal reaction to a death of someone close, as well as any other frequently co-occurring conditions and their implications,[12] to promote access to specialist support, e.g. anxiety disorders, depression, post-traumatic stress disorder, and other health concerns.

## Criteria

1. Prior to a death, a comprehensive, holistic bio-psycho-social-spiritual assessment (including consideration of risk and protective factors associated with complex bereavement) should be commenced promptly following intake for a person responsible known to a service, e.g. palliative care service, with their consent. Any other person/s of concern should also be assessed via a separate assessment, with their consent (as resources allow). All ongoing assessment and review should be based on exploration of risk and protective factors. The assessment process should be documented and include input from relevant professionals, family member/s or people identified by the person as family, whether or not they are biologically related, i.e. friends, people who joined the family through other relationships such as kinship, and other chosen family. Discussion within interdisciplinary team meetings and the use of family assessment may be required. This process continues throughout the involvement of a service prior to the death.
2. A trauma-informed approach should underpin assessment and support provided pre- and post-death. This considers the potential for aspects of end of life care to be experienced as traumatic or retraumatising. As noted previously, particular attention is needed to ensure that counselling or cultural support can be offered to Aboriginal families and other priority populations in ways that are safe from both a cultural perspective, as well as a trauma-informed approach.
3. Initial post-death follow-up and early bereavement support, e.g. follow-up phone call or letter from an involved health service, should be offered within 12 weeks of a death, to the person responsible or any person of concern (as indicated by assessment of needs, and as resources allow). This should offer initial support and assess future support needs. Any direct contact, e.g. phone call, should ideally be undertaken by a staff member with an established relationship with the patient and family. It is best practice to document bereavement follow-up and support in the bereaved person's health or personal record.
4. Any risk of suicidal behaviour, self-harm or concerns about the safety of any person, should be assessed and referred to an appropriate crisis service, mental health service or public hospital emergency department, e.g. NSW Mental Health Line (24 hours), Ph 1800 011 511; Lifeline (24 hours), Ph 13 11 14, or 13YARN (24 hours), Ph 13 92 76.
5. Bereaved individuals may self-refer or be referred (with their consent) for appropriate counselling and support through the relevant bereavement service for their population or region, or through other government, non-government or community services.
6. Self-referral is promoted for bereavement counselling, given that it indicates a client's readiness to engage with the counselling process and is associated with better counselling outcomes.[16-18]
7. For clients of bereavement services, assessment of complexity in bereavement (including anxiety, depression, trauma, prolonged grief disorder) should be holistic and undertaken with the client's informed consent, in the context of the therapeutic relationship. Assessment for prolonged grief disorder may (with client consent) involve the use of recognised, validated screening measures and tools from six months after death.[15]

## Principle 5: Bereavement support and counselling strategies

This document acknowledges the importance of evidence-based grief and loss support in pre-loss settings. As this document focuses on specialist bereavement services, consider the following documents for anticipatory care and immediate post-death bereavement support:

- End of Life and Palliative Care Framework 2019-2024[4]
- Clinical Principles for End of Life and Palliative Care[3]

Care in specialist bereavement services can be conceptualised according to the following strategies:

- universal strategies that are available for all bereaved people
- specialist individual bereavement counselling strategies for clients of the counselling service.

**Universal strategies** are aimed at reaching broad groups of people. These include:

- producing and making available information in the form of psycho-educational resources, information sessions, media, community awareness initiatives
- providing opportunities for memorialisation, e.g. memorial services, the development of special ‘spaces’, etc.
- activity based programs such as walking, meditation, music and art groups
- group, volunteer and peer support models of support, e.g. Seasons for Healing, a group program developed for and with Aboriginal communities.

**Specialist bereavement counselling strategies** are delivered through direct counselling and psychotherapy using evidence informed interventions such as:

- meaning reconstruction approaches to grief therapy[19]
- acceptance and commitment therapy[20]
- complicated grief treatment[21]
- trauma focused evidence-based interventions including eye movement desensitization and reprocessing (EMDR), narrative reconstruction therapy[22]
- cognitive behavioural therapy (CBT) for complicated grief[23]
- other evidence-based focussed psychological strategies which may include interpersonal therapy, relaxation strategies (e.g. controlled breathing, progressive muscle relaxation), skills training (e.g. problem solving, communication), psychoeducation, narrative approaches, etc.

In general, the more complicated the grief process, the greater the efficacy of specialist bereavement interventions. These interventions can be supported in various settings including virtual care.

### Criteria

1. Bereavement interventions are designed to promote accessibility across the spectrum of need. The majority of bereaved people will not need or necessarily benefit from specialist interventions.
2. Bereaved people have access to bereavement services and strategies appropriate to their self-identified needs and preferences.
3. Bereaved people are informed about the services available to them. Self-referral is promoted (see Principle 4).
4. A collection of literature and resource materials on the grief process and support services is made available to bereaved people in a sensitive and appropriate manner. This should include, where possible, translated materials for culturally and linguistically diverse families and information specifically written by and for Aboriginal communities.
5. There is a confidential system for documenting and updating bereaved people's information once they consent to engage with bereavement services, whether for counselling or group support. Information includes relevant history, assessment, intervention and support services, date and type of contact, progress, other service provider involvement and outcomes.
6. Drawing upon the Dual Process Model of Coping with Bereavement, support and interventions address both the grief-related (managing the feelings related to grief) and life-focused (managing the demands of daily living) challenges of coping with loss.[24]

## Principle 6: Community education, collaboration and health promotion

High quality communication and promotion of bereavement issues is important. The availability and accessibility of specialist bereavement counselling is communicated with relevant stakeholders, including bereaved people. Collaborative working relationships with interdisciplinary colleagues, community organisations and consumers are prioritised. Information regarding grief and bereavement is available for general practitioners, employers, community members and other relevant stakeholders.

### Criteria

1. There is a clearly documented system for self-referrals and actively supporting the client in accessing the specialist bereavement service.
2. Bereaved people have ready access to information about a range of grief support and counselling options across the continuum of need; including culturally relevant and specific resources, e.g. resources that may be provided through Aboriginal palliative care workers.
3. Clinical handover is undertaken within the context of the National Safety and Quality Health Service Standards.[25]
4. Bereavement services participate in community education and health promotion activities on loss and grief. These activities may be initiated by the bereavement service or conducted in collaboration or partnership with other relevant services.
5. Information and consultation on loss and grief is provided to interdisciplinary colleagues, community members and staff from other healthcare and support services.

6. Community and consumer engagement is embedded within service development and quality improvement processes.
7. There is ongoing commitment to increasing knowledge and skill in working with Aboriginal families in culturally safe and respectful ways and, where possible, seek out training on grief and loss provided by Aboriginal staff.

## Principle 7: Privacy, confidentiality and consent

The specialist bereavement service upholds the privacy and confidentiality of its bereaved clients.

### Criteria

1. Bereavement services comply with relevant legislation, regulations and instruments in relation to the privacy and confidentiality of clients.
2. The bereaved person's verbal consent is sought prior to assessment, referral and bereavement interventions being offered. This consent is documented in the bereaved client's notes.
3. The process of obtaining consent involves providing clear and direct information about the process, communicated in a language that the bereaved person understands. Information should be provided about all steps in the process so that individuals can choose whether to opt out of some or all of the process, e.g. receiving follow-up letters and memorial service invitations.
4. Informed consent is obtained from bereaved people before information about them is collected and/or communicated to others. This includes the registration of their medical record to any bereavement services.
5. Confidential information is stored in a way that ensures the privacy of bereaved people is protected. Only authorised staff have access to the information.
6. Bereaved people are made aware of the local health district or specialty health network's specialist bereavement service policies and procedures that are available.
7. The physical environment for delivering support provides for visual and sound privacy.
8. Confidential processes exist for client feedback on the specialist bereavement service.
9. Confidentiality standards applicable to delivering all health care services apply to delivering bereavement counselling and support.

## Principle 8: Integration with health and social systems

Bereavement services are related to broader health and social networks of care, working to promote the health and wellbeing of bereaved people and the wider community.

### Criteria

1. Staff are aware of the range of other support resources available to clients and can provide information on how to access them.
2. Staff work with clients to inform and refer them to other service providers where necessary.

3. Staff within bereavement services develop and maintain effective networks to promote interagency collaboration to:
   - ensure coordinated client care and optimised service delivery
   - pursue coordinated strategies for community education health promotion
   - pursue coordinated strategies for education and support
   - advocate for bereaved persons according to their specific needs and socio-cultural-historical context.

## Principle 9: Governance and leadership

Specialist bereavement services should be supported by appropriate governance processes and mechanisms within the local health district, specialty health network or other organisational context. Leadership and accountability should be clearly defined and underpinned by appropriate policies and procedures.

### Criteria

1. A multidisciplinary group, such as an end of life committee or similar, is in place to provide leadership and accountability for specialist bereavement services.
2. Policies and procedures support the need for a bereavement response to all deaths.

## Principle 10: Program evaluation, quality improvement and research

Bereavement services are committed to improved outcomes for bereaved people through supporting and, where possible, coordinating research, program evaluation and quality improvement.

### Criteria

1. There is a clearly documented evaluation strategy that uses a combination of accepted qualitative and quantitative methods.
2. Services use existing or establish new datasets to enable information to be collected from clients, staff and other relevant services.
3. Bereavement services demonstrate a regular and active interest in research outcomes as they relate to current practice, and support rigorous, ethically approved, methodologically sound research into the field of bereavement.
4. A process of continuous quality improvement can be demonstrated.
5. Performance is monitored regarding the standards and data is used to improve performance as part of a quality improvement process.

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# Appendix 1: Mapping of clinical principles for specialist bereavement care in NSW to other recognised frameworks

## Principle 1: Access

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12*] |
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| 1.15 The health service organisation: a. Identifies the diversity of the consumers using its services, b. Identifies groups of patients using its services who are at higher risk of harm and c. Incorporates information on the diversity of its consumers and higher risk groups into the planning and delivery of care.<br>2.8 The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community.<br>2.10 The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that: a. Information is provided in a way that meets the needs of patients, carers, families and consumers, b. Information provided is easy to understand and use, c. The clinical needs of patients are addressed while they are in the health service organisation and d. Information needs for ongoing care are provided on discharge.<br>5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the National Consensus Statement: Essential elements for safe and high-quality end-of-life care.<br>5.4 The health service organisation has systems for comprehensive care that: a. | 2.4 Be respectful, sensitive and responsive to the preferences and needs of the person at the end of their life, including with regard to their identity, culture, religious beliefs, gender, orientation and loved ones (including family of choice).<br>3.3 Ensure all members of the multidisciplinary team are aware that they are responsible for: Referring people with specific needs to appropriate services.<br>4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and carers about how to access support in a format they can use.<br>7.5 Ensure healthcare workers are taught culturally safe approaches to providing end of life care to Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse groups, as well as appropriate approaches for people with disability, including dementia. | 2.6 Specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning. This includes, but is not limited to Aboriginal and Torres Strait Islanders, asylum seekers, people who have experienced torture and trauma, people who are experiencing homelessness; people living with mental illness, intellectual disabilities or dementia; paediatric populations or people from ethnically and culturally diverse backgrounds.<br>6.1 Culturally appropriate information and resources about loss and grief and bereavement support services is routinely provided to families and carers before and after the death. |

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[*] A revised version of the National Palliative Care Standards is expected to be released in 2024, however the changes are not expected to substantially alter this mapping.

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12]* |
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| Support clinicians to develop, document and communicate comprehensive plans for patients' care and treatment, b. Provide care to patients in the setting that best meets their clinical needs, c. Ensure timely referral of patients with specialist healthcare needs to relevant services and d. Identify, at all times, the clinician with overall accountability for a patient's care. | | |

## Principle 2: Service coordination

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
|---|---|---|
| 5.4 The health service organisation has systems for comprehensive care that: a. Support clinicians to develop, document and communicate comprehensive plans for patients' care and treatment, b. Provide care to patients in the setting that best meets their clinical needs, c. Ensure timely referral of patients with specialist healthcare needs to relevant services and d. Identify, at all times, the clinician with overall accountability for a patient's care.<br>5.5 The health service organisation has processes to: a. Support multidisciplinary collaboration and teamwork, b. Define the roles and responsibilities of each clinician working in a team.<br>6.4 The health service organisation has clinical communications processes to support effective communication when: a. Identification and procedure matching should occur, b. All or part of a patient's care is transferred within the organisation, between multidisciplinary teams, between clinicians or between organisations; and on discharge and c. Critical information about a patient's care, including information on risks, emerges or changes. | 4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and carers about how to access support in a format they can use.<br>4.14 Co develop bereavement models of care according to clinical settings – for example, community health or intensive care models. | 5.1 There are policies and procedures in place that support and promote continuity of care across settings and throughout the course of the person's illness.<br>5.2 The service has in place effective communication systems to support integrated care, including processes for communicating information about the care plan, goals of care, prognosis and death of the person within and between services. |

## Principle 3: Training and support

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| 1.23 The health service organisation has processes to: a. Define the scope of clinical practice for clinicians, considering the clinical service capacity of the organisation and clinical services plan, b. Monitor clinicians' practices to ensure that they are operating within their designated scope of clinical practice, c. Review the scope of clinical practice of clinicians periodically and whenever a new clinical service, procedure or technology is introduced or substantially altered.<br>1.24 The health service organisation: a. Conducts processes to ensure that clinicians are credentialed, where relevant, and b. Monitors and improves the effectiveness of the credentialing process.<br>1.25 The health service organisation: a. Conducts processes to ensure that clinicians are credentialed, where relevant, and b. Monitors and improves the effectiveness of the credentialing process.<br>1.26 The health service organisation: a. Conducts processes to ensure that clinicians are credentialed, where relevant, and b. Monitors and improves the effectiveness of the credentialing process.<br>5.18 The health service organisation provides access to supervision and support for the workforce providing end-of-life care. | 6.3 Implement a policy regarding end of life care that addresses: Training and education requirements for healthcare workers.<br>7.1 Develop and maintain a policy that describes how supervision and support will be provided to healthcare workers who care for people at the end of their life.<br>7.5 Ensure healthcare workers are taught culturally safe approaches to providing end of life care to Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse groups, as well as appropriate approaches for people with disability, including dementia.<br>7.7 Ensure healthcare workers providing end of life care are educated about how to recognise and develop strategies to cope with and resolve feelings of moral distress and burnout in themselves and their colleagues. Provide information and access to support services.<br>7.9 Ensure healthcare workers know how to access peer support, mentoring and clinical supervision. Provide this information at the commencement of employment and as part of regular professional development. This may include accessing external services for clinical supervision, counselling or debriefing. | 6.2 The service provides education about loss, grief and bereavement to staff, volunteers and other community providers.<br>6.8 The organisation has mechanisms in place for the specialist palliative care team to access education, training and supervision to meet the loss, grief and bereavement needs of the family and carers.<br>9.1 The service employs a multidisciplinary team of health professionals with recognised qualifications, credentialing and experience to meet the physical, psychological, social, cultural and spiritual needs of the person, their family and carers.<br>9.5 Staff undergo training to ensure delivery of culturally safe care.<br>9.6 Staff are trained in self-care strategies and advised on how to access personal support.<br>9.7 Volunteer programs are recognised, supported and managed in accordance with the relevant volunteer standards. |

## Principle 4: Assessment

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| 1.27 The health service organisation provides access to supervision and support for the workforce providing end-of-life care.<br>5.4. The health service organisation has systems for comprehensive care that: a. Support clinicians to develop, document and communicate comprehensive plans for patients' care and treatment, b. Provide care to patients in the setting that best meets their clinical needs, c. Ensure timely referral of patients with specialist healthcare needs to relevant services d. Identify, at all times, the clinician with overall accountability for a patient's care.<br>5.7 The health service organisation has processes relevant to the patients using the service and the services provided: a. For integrated and timely screening and assessment and b. That identify the risks of harm in the 'Minimising patient harm' criterion.<br>5.10 Clinicians use relevant screening processes: a. On presentation, during clinical examination and history taking, and when required during care, b. To identify cognitive, behavioural, mental and physical conditions, issues, and risks of harm and c. To identify social and other circumstances that may compound these risks.<br>5.11 Clinicians comprehensively assess the conditions and risks identified through the screening process.<br>5.31. The health service organisation has systems to support collaboration with patients, carers and families to: a. Identify when a patient is at risk of self-harm, b. Identify when a patient is at risk of suicide, c. Safely and effectively | 3.3 Ensure all members of the multidisciplinary team are aware that they are responsible for: Referring people with specific needs to appropriate services.<br>4.11 Develop processes to assess the risk of prolonged or complicated grief for family and other loved ones. | 1.1 Initial and ongoing assessments are carried out by qualified interdisciplinary personnel.<br>1.2 Assessment is coordinated to reduce the burden of duplication on the person, family and carers.<br>6.3 The service employs a structured assessment of bereavement that addresses emotional, behavioural, social, spiritual and physical domains.<br>6.4 The risk assessment process begins on intake to the palliative care service and continues throughout the service's involvement with the person and beyond.<br>6.5 The service uses validated tools to assess for signs and symptoms of persistent and intense distress in bereaved persons.<br>6.7 Referrals to bereavement, specialist mental health and/or counselling professionals are made when clinically indicated. |

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| respond to patients who are distressed, have thoughts of self-harm or suicide, or have self-harmed.<br>6.4 The health service organisation has clinical communications processes to support effective communication when: a. Identification and procedure matching should occur, b. All or part of a patient's care is transferred within the organisation, between multidisciplinary teams, between clinicians or between organisations; and on discharge and c. Critical information about a patient's care, including information on risks, emerges or changes.<br>6.10 The health service organisation ensures that there are communication processes for patients, carers and families to directly communicate critical information and risks about care to clinicians. | | |

## Principle 5: Bereavement support and counselling

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| 1.27 The health service organisation has processes that: a. Provide clinicians with ready access to best-practice guidelines, integrated care pathways, clinical pathways and decision support tools relevant to their clinical practice, b. Support clinicians to use the best available evidence, including relevant clinical care standards developed by the Australian Commission on Safety and Quality in Health Care. | 4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and carers about how to access support in a format they can use. | 4.2. The service takes practical steps to keep abreast with new and emerging evidence, and uses the best available evidence to inform clinical practice. |

## Principle 6: Community education, collaboration and health promotion

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
|---|---|---|
| 2.8 The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community.<br>2.10 The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that: a. Information is provided in a way that meets the needs of patients, carers, families and consumers, b. Information provided is easy to understand and use, c. The clinical needs of patients are addressed while they are in the health service organisation and d. Information needs for ongoing care are provided on discharge.<br>2.11 The health service organisation: a. Involves consumers in partnerships in the governance of, and to design, measure and evaluate, health care, b. Has processes so that the consumers involved in these partnerships reflect the diversity of consumers who use the service or, where relevant, the diversity of the local community.<br>2.13 The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs<br>6.7 The health service organisation, in collaboration with clinicians, defines the: a. Minimum information content to be communicated at clinical handover, based on best-practice guidelines, b. Risks relevant to the service context and the particular needs of patients, carers and families and c. Clinicians who are involved in the clinical handover.<br>6.8 Clinicians use structured clinical handover processes that include: a. Preparing and scheduling clinical handover, b. Having the relevant information at clinical handover, c. Organising relevant clinicians and others to participate in clinical handover, d. Being aware of the patient's goals and preferences, e. Supporting patients, carers and families to be involved in clinical handover, in accordance with the wishes of the patient and f. Ensuring that clinical handover results in the transfer of responsibility and accountability for care. | 4.13 Establish partnerships with organisations that can provide ongoing bereavement care for families and healthcare workers. | 6.2 The service provides education about loss, grief and bereavement to staff, volunteers and other community providers.<br>6.6 The service develops strategies and referral pathways, in partnerships with other providers in the community, to assist families and carers in feeling more prepared for the death and to accommodate grief into their lives after bereavement.<br>7.4 Services understand the community they serve, and use this information to both provide optimal specialist palliative care services and influence wider health, aged and social care systems that meet the needs of that community. |

## Principle 7: Privacy, confidentiality and consent

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| 1.13 The health service organisation: a. Has processes to seek regular feedback from patients, carers and families about their experiences and outcomes of care, b. Has processes to regularly seek feedback from the workforce on their understanding and use of the safety and quality systems and c. Uses this information to improve safety and quality systems<br>1.16 The health service organisation has healthcare record systems that: a. Make the healthcare record available to clinicians at the point of care, b. Support the workforce to maintain accurate and complete healthcare records, c. Comply with security and privacy regulations, d. Support systematic audit of clinical information, and e. Integrate multiple information systems, where they are used<br>1.29 The health service organisation maximises safety and quality of care: a. Through the design of the environment b. By maintaining buildings, plant, equipment, utilities, devices and other infrastructure that are fit for purpose<br>6.9 Clinicians and multidisciplinary teams use clinical communication processes to effectively communicate critical information, alerts and risks, in a timely way, when they emerge or change to: a. Clinicians who can make decisions about care, b. Patients, carers and families, in accordance with the wishes of the patient<br>6.10. The health service organisation ensures that there are communication processes for patients, carers and families to directly communicate critical information and risks about care to clinicians<br>6.11 The health service organisation has processes to contemporaneously document information in the healthcare record, including: a. Critical information, alerts and risks, b. Reassessment processes and outcomes and c. Changes to the care plan | 9.5 Ensure measures of the safety and quality of end of life care are ethically collected, accessed, used and stored with the following minimum data set: (including) Bereavement support provided | |

## Principle 8: Integration with health and social systems

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
|---|---|---|
| 5.4. The health service organisation has systems for comprehensive care that: a. Support clinicians to develop, document and communicate comprehensive plans for patients' care and treatment, b. Provide care to patients in the setting that best meets their clinical needs, c. Ensure timely referral of patients with specialist healthcare needs to relevant services and d. Identify, at all times, the clinician with overall accountability for a patient's care.<br>5.5. The health service organisation has processes to: a. Support multidisciplinary collaboration and teamwork, and b. Define the roles and responsibilities of each clinician working in a team.<br>6.4 The health service organisation has clinical communications processes to support effective communication when: a. Identification and procedure matching should occur, b. All or part of a patient's care is transferred within the organisation, between multidisciplinary teams, between clinicians or between organisations; and on discharge and c. Critical information about a patient's care, including information on risks, emerges or changes. | 4.12 Identify local support resources for bereavement referrals and provide information to bereaved family and carers about how to access support in a format they can use.<br>4.13 Establish partnerships with organisations that can provide ongoing bereavement care for families and healthcare workers. | 5.2 The service has in place effective communication systems to support integrated care.<br>6.6 The service develops strategies and referral pathways, in partnerships with other providers in the community, to assist families and carers in feeling more prepared for the death and to accommodate grief into their lives after bereavement. |

## Principle 9: Governance and leadership

| NSQHS Standards (2021)[25] | National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26] | National Palliative Care Standards (2018)[12] |
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| 1.1 The governing body: a. Provides leadership to develop a culture of safety and quality improvement, and satisfies itself that this culture exists within the organisation, b. Provides leadership to ensure partnering with patients, carers and consumers, c. Sets priorities and strategic directions for safe and high-quality clinical care, and ensures that these are communicated effectively to the workforce and the community, d. Endorses the | 6.2 Incorporate the development, implementation and ongoing review of systems for end of life care into governance frameworks and include processes for: Regular review of resource allocation, and advice on potential for improvements. | 7.1 The values and culture of the service explicitly support the provision of person-centred palliative care. |

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| organisation's clinical governance framework, e. Ensures that roles and responsibilities are clearly defined for the governing body, management, clinicians and the workforce, f. Monitors the action taken as a result of analyses of clinical incidents and g. Reviews, reports and monitors the organisation's progress on safety and quality performance.<br>1.6 Clinical leaders support clinicians to: a. Understand and perform their delegated safety and quality roles and responsibilities, and b. Operate within the clinical governance framework to improve the safety and quality of health care for patients. | | |

## Principle 10: Program evaluation, quality improvement and research

| **NSQHS Standards (2021)[25]** | **National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2023)[26]** | **National Palliative Care Standards (2018)[12]** |
|---|---|---|
| 1.8 The health service organisation uses organisation-wide quality improvement systems that: a. Identify safety and quality measures, and monitor and report performance and outcomes, b. Identify areas for improvement in safety and quality, c. Implement and monitor safety and quality improvement strategies and d. Involve consumers and the workforce in the review of safety and quality performance and systems.<br>1.13 The health service organisation: a. Has processes to seek regular feedback from patients, carers and families about their experiences and outcomes of care, b. Has processes to regularly seek feedback from the workforce on their understanding and use of the safety and quality systems and c. Uses this information to improve safety and quality systems.<br>6.2 The health service organisation applies the quality improvement system from the Clinical Governance Standard when: a. Monitoring the effectiveness of clinical communication and associated processes, b. Implementing strategies to improve clinical communication and associated processes and c. Reporting on the effectiveness and outcomes of clinical communication processes. | 9.2 Ensure processes exist for reporting data to inform governance and planning.<br>9.4 Routinely use collected data for evaluation and monitoring processes, and support data linkage where possible. Ensure systems are simple, inexpensive, feasible and fit for purpose.<br>9.5 Ensure measures of the safety and quality of end of life care are ethically collected, accessed, used and stored with the following minimum data set: (including) bereavement support provided. | 4.6 The effectiveness of care is measured according to established indicators and outcomes.<br>8.1 An ongoing quality improvement process is implemented to review clinical performance and outcomes, and to identify, implement and evaluate improvement activities.<br>8.6 The service participates in benchmarking processes to compare its service delivery over time and/or with external organisations.<br>8.7 The service supports staff to lead or participate in palliative care research wherever possible.<br>8.9 The person, their family and carers and the community are provided with opportunities to provide input into the evaluation of the service via formal and informal feedback mechanisms. |

# Appendix 2: Resources to support training and capacity building

- NSW Agency for Clinical Innovation. End of Life and Palliative Care: Additional considerations – Resources for priority populations
- Gwandalan Palliative Care. Continued Personal Development: Introduction to Aboriginal and Torres Strait Islander Palliative Care and Cultural Practice
- NSW Health Education and Training (HETI). My Health Learning Module: Enabling culturally sensitive end of life care for Aboriginal people (Course Code 395607014)

## Glossary

**Grief:** Grief is a natural response to loss, incorporating diverse emotional, psychological and physical reactions.[27] Experiences of grief are individual and unique.[1]

**Bereavement:** Bereavement is the experience of grief following the death of a significant person, and encompasses the entire experience of family members and friends in the anticipation, death and adjustment to living following the death of a loved one.**Error! Bookmark not defined.** Bereavement may impact physical, physiological, emotional, spiritual, behavioural, social, financial and vocational domains.[28] The majority of people will integrate a bereavement into their life with the support of family, friends, colleagues and others in their own community. A significant proportion will experience a moderate level of needs or complexity, and may benefit from additional support, including counselling. A smaller but significant proportion will experience adverse outcomes in bereavement, e.g. prolonged grief disorder, post-traumatic stress disorder, increased risk of self-harm, other negative psychological health outcomes, and increased risk of poor physical health outcomes including heightened cardiovascular risk).[12, 27, 29]

**Bereavement support**: Bereavement support may include helping activities such as non-judgmental listening, offering empathy and compassion. It is safe, supportive and not necessarily time-limited but based on the clinician’s assessment of need. Specialist background or professional training is not necessarily needed in order to provide bereavement support.

**Bereavement counselling**: Bereavement counselling seeks to restore functioning, facilitate well-being and reaffirm or reconstruct meaning with bereaved people.[17] Bereavement counselling necessitates client consent to engage in an agreed upon therapeutic relationship or alliance, which is reviewed over time. Key features of bereavement counselling include comprehensive, holistic assessment and the use of evidence-based interventions. A minimum level of specialist training and skills are required for the provision of bereavement counselling (for instance, tertiary qualifications in counselling, social work, psychology or psychotherapy; with postgraduate qualifications or other training and/or experience in loss and grief, and accreditation, membership or eligibility for membership of recognised, associated professional bodies – see Principle 3).

**Bereavement coordinator**: A bereavement coordinator is responsible for the management of a specialist bereavement service. A significant component of their role often includes the provision of specialist bereavement counselling (which necessitates a minimum level of training and skills, as per above definition of bereavement counselling). A bereavement coordinator’s role may also often involve coordination of bereavement support and follow-up, provision of education and consultation, provision of clinical supervision for bereavement counsellors, supervision of volunteers engaged in bereavement, and research, evaluation and service development activities. A bereavement coordinator may also undertake activities that build community capacity in bereavement care and grief literacy.

**Specialist bereavement service**: A bereavement-focused service, typically engaged in the provision of bereavement counselling by qualified bereavement counsellors, often alongside other activities (education, supervision, consultation, other forms of bereavement support).

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