

Essential Component 1: Informing community expectations and perceptions on death and dying – standards comparison

National Palliative Care Standards, 5th Edition

Relevant standard	Relevant action (where available) against Essential Component 1
<p>2. Developing the care plan The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan</p>	<p>2.1 Care planning is informed by the assessment process and reflects a person-centred, holistic approach that incorporates cultural, spiritual, physical, psychological and social needs.</p>
<p>3. Caring for carers The needs and preferences of the person's family and carers are assessed, and directly inform provision of appropriate support and guidance about their role</p>	<p>3.3 There are systems in place to ensure that the person's nominated family and carers are supported to participate in the provision of health care in accordance with the preferences of the person, their family and carers.</p>
<p>4. Providing care The provision of care is based on the assessed needs of the person, informed by evidence, and is consistent with the values, goals and preferences of the person as documented in their care plan</p>	<p>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.</p>
<p>5. Transitions within and between services Care is integrated across the person's experience to ensure seamless transitions within and between services</p>	<p>5.7 Services assist local community-based service providers in building their capability to assist people to be cared for in their home, where this aligns with the person's preferences.</p>
<p>7. Service culture The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care</p>	<p>7.1 The values and culture of the service explicitly support the provision of person-centred palliative care.</p> <p>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.</p>

Relevant standard	Relevant action (where available) against Essential Component 1
<p>8. Quality improvement Services are engaged in quality improvement and research to improve service provision and development</p>	<p>8.1 An ongoing quality improvement process is implemented to review clinical performance and outcomes, and to identify, implement and evaluate improvement activities.</p> <p>8.2 Data about the effectiveness of palliative care delivery is collected, reviewed and reported locally.</p> <p>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.</p>

National Safety and Quality Health Service Standards, 2nd Edition

Relevant standard	Relevant action (where available) against Essential Component 1
<p>1. Clinical governance</p> <ul style="list-style-type: none"> • Governance, leadership and culture • Patient safety and quality systems 	<p>1.2 The governing body ensures that the organisation’s safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people.</p> <p>1.4 The health service organisation implements and monitors strategies to meet the organisation’s safety and quality priorities for Aboriginal and Torres Strait Islander people.</p> <p>1.8 The health service organisation uses organisation-wide quality improvement systems that:</p> <ol style="list-style-type: none"> a. identify safety and quality measures, monitor and report performance and outcomes b. identify areas for improvement in safety and quality c. implement and monitor safety and quality improvement strategies d. involve consumers and the workforce in the review of safety and quality performance and systems. <p>1.9 The health service organisation ensures that timely reports on safety and quality systems and performance are provided to:</p> <ol style="list-style-type: none"> a. the governing body b. the workforce c. consumers and the local community d. other relevant health service organisations. <p>1.13 The health service organisation:</p> <ol style="list-style-type: none"> 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 c. uses this information to improve safety and quality systems.

Relevant standard	Relevant action (where available) against Essential Component 1
<ul style="list-style-type: none"> • Clinical performance and effectiveness 	<p>1.14 The health service organisation has an organisation-wide complaints management system, and:</p> <ol style="list-style-type: none"> a. encourages and supports patients, carers and families, and the workforce to report complaints b. involves the workforce and consumers in the review of complaints c. resolves complaints in a timely way d. provides timely feedback to the governing body, the workforce and consumers on the analysis of complaints and actions taken e. uses information from the analysis of complaints to inform improvements in safety and quality systems f. records the risks identified from the analysis of complaints in the risk management system g. regularly reviews and acts to improve the effectiveness of the complaints management system. <p>1.15 The health service organisation:</p> <ol style="list-style-type: none"> 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 c. incorporates information on the diversity of its consumers and higher risk groups into the planning and delivery of care. <p>1.27 The health service organisation has processes that:</p> <ol style="list-style-type: none"> 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. <p>1.28 The health service organisation has systems to:</p> <ol style="list-style-type: none"> a. monitor variation in practice against expected health outcomes b. provide feedback to clinicians on variation in practice and health outcomes c. review performance against external measures d. support clinicians to take part in clinical review of their practice e. use information on unwarranted clinical variation to inform improvements in safety and quality systems f. record the risks identified from unwarranted clinical variation in the risk management system.

Relevant standard	Relevant action (where available) against Essential Component 1
<p>2. Partnering with consumers</p> <ul style="list-style-type: none"> • Partnering with patients in their own care • Health literacy • Partnering with consumers in organisational design governance 	<p>2.6 The health service organisation has processes for clinicians to partner with patients or their substitute decision-maker to plan, communicate, set goals, and make decisions about their current and future care.</p> <p>2.7 The health service organisation supports the workforce to form partnerships with patients and carers so that patients can be actively involved in their own care.</p> <p>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.</p> <p>2.10 The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that:</p> <ul style="list-style-type: none"> 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 d. information needs for ongoing care are provided on discharge. <p>2.11 The health service organisation:</p> <ul style="list-style-type: none"> 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. <p>2.12 The health service organisation provides orientation, support and education to consumers who are partnering in the governance, design, measurement and evaluation of the organisation.</p> <p>2.13 The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs.</p>

<p>5. Comprehensive care standards</p> <ul style="list-style-type: none"> • Clinical governance and quality improvement to support comprehensive care • Developing the comprehensive care plan • Delivering comprehensive care 	<p>5.4 The health service organisation has systems for comprehensive care that:</p> <ol style="list-style-type: none"> 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. always identifies the clinician with overall accountability for a patient’s care. <p>5.13 Clinicians use processes for shared decision making to develop and document a comprehensive and individualised plan that:</p> <ol style="list-style-type: none"> a. addresses the significance and complexity of the patient’s health issues and risks of harm b. identifies agreed goals and actions for the patient’s treatment and care c. identifies the support people a patient wants involved in communications and decision-making about their care d. commences discharge planning at the beginning of the episode of care e. includes a plan for referral to follow-up services, if appropriate and available f. is consistent with best practice and evidence. <p>5.14 The workforce, patients, carers and families work in partnership to:</p> <ol style="list-style-type: none"> a. use the comprehensive care plan to deliver care b. monitor the effectiveness of the comprehensive care plan in meeting the goals of care c. review and update the comprehensive care plan if it is not effective d. reassess the patient’s needs if changes in diagnosis, behaviour, cognition, or mental or physical condition occur. <p>5.15 The health service organisation has processes to identify patients who are at the end-of-life that are consistent with the <i>National Consensus Statement: Essential elements for safe and high-quality end-of-life care</i>.</p> <p>5.19 The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.</p> <p>5.20 Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the <i>National Consensus Statement: Essential elements for safe and high-quality end-of-life care</i>.</p>
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Relevant standard	Relevant action (where available) against Essential Component 1
<p>6. Communicating for safety</p> <ul style="list-style-type: none"> • Communication at clinical handover • Communication of critical information 	<p>6.8 Clinicians use structured clinical handover processes that include:</p> <ol style="list-style-type: none"> 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 f. ensuring that clinical handover results in the transfer of responsibility and accountability for care. <p>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:</p> <ol style="list-style-type: none"> a. clinicians who can make decisions about care b. patients, carers and families, in accordance with the wishes of the patient. <p>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.</p>
<p>8. Recognising and responding to acute deterioration</p> <ul style="list-style-type: none"> • Detecting and recognising acute deterioration and escalating care 	<p>8.6 The health service organisation has protocols that specify criteria for escalating care, including:</p> <ol style="list-style-type: none"> a. agreed vital sign parameters and other indicators of physiological deterioration b. agreed indicators of deterioration in mental state c. agreed parameters and other indicators for calling emergency assistance d. patient pain or distress that is not able to be managed using available treatment e. worry or concern in members of the workforce, patients, carers and families about acute deterioration. <p>8.7 The health service organisation has processes for patients, carers or families to directly escalate care.</p>

National Consensus Statement (Adult and Paediatric)

Relevant standard	Relevant action (where available) against Essential Component 1
<p>6. Leadership and governance Policies and systems for end-of-life care</p>	<p>Adult</p> <p>6.1 Patients, and their families and carers should be partners in the development and governance of organisational systems for delivering end-of-life care.</p> <p>6.2 The health service executive should consider how best to allocate resources within the context of the organisation’s strategic plan to support the delivery and effective functioning of systems for providing end-of-life care.</p> <p>6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include:</p> <ul style="list-style-type: none"> • governance arrangements • roles and responsibilities • communication and documentation processes • processes for advance care planning and limiting medical treatment • alignment with systems for recognising and responding to clinical deterioration • access to specialist palliative care advice and services • an interface with external services, such as community and social care providers, residential aged care facilities and external hospice providers <p>6.5 Policies and processes should be in place regarding advance care directives, organ and tissue donation, limitations of medical treatment and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with appropriate clinical practice and the patient’s expressed wishes.</p> <p>6.6 A formal governance process should be in place to oversee the development, implementation and ongoing review of systems for end-of-life care. If a committee has this role, it should:</p> <ul style="list-style-type: none"> • have appropriate responsibilities delegated to it and be accountable for its decisions and actions to the executive • monitor the effectiveness of interventions and education • have a role in reviewing performance data • provide advice about the allocation of resources • include consumers, interdisciplinary team members, managers and executives. <p>6.9 Organisations should work with local community-based service providers to build capacity for people to be cared for in their preferred place of death (for example, at home).</p>

Relevant standard	Relevant action (where available) against Essential Component 1
	<p>Paediatric</p> <p>6.1 The health service organisation should partner with families to develop and govern systems for delivering paediatric end-of-life care.</p> <p>6.2 The health service executive should consider how best to allocate resources within the context of the organisation’s strategic plan to support the delivery and effective functioning of systems for providing paediatric end-of-life care.</p> <p>6.3 The health service organisation should create a formal organisational policy framework for paediatric end-of-life care which applies across the acute health service, including:</p> <ul style="list-style-type: none"> ● governance arrangements ● roles and responsibilities ● communication and documentation processes ● processes for advance care planning and limiting medical treatment ● alignment with systems for recognising and responding to acute deterioration ● criteria and processes for accessing help for end-of-life issues that are causing concern (for example, ethical or legal advice) ● access to specialist paediatric palliative care advice and services ● the interface with external services, such as community and social care providers, and external hospice providers ● clear dispute resolution processes, including access to mediation, bioethics and legal support in situations of complex end-of-life decision-making or conflict. <p>6.5 The health service organisation should establish policies and processes for advance care planning, organ and tissue donation, limitations of medical treatment, symptom management and end-of-life decision-making to ensure that the care delivered in response to deterioration is consistent with appropriate clinical practice, the child and their parents’ expressed wishes, and the best interests of the child.</p> <p>6.6 The health service organisation should establish a formal governance process to oversee the development, implementation and ongoing review of systems for end-of-life care. If a committee has this role, it should:</p> <ul style="list-style-type: none"> ● have appropriate responsibilities delegated to it and be accountable for its decisions and actions to the executive ● monitor the effectiveness of interventions and education ● have a role in reviewing performance data ● provide advice about the allocation of resources ● include consumers, interdisciplinary team members, managers and executives.

Relevant standard	Relevant action (where available) against Essential Component 1
	<p>6.7 The health service organisation should develop systems to ensure that essential resources required for the provision of safe and high-quality paediatric end-of-life care (for example, private space for family meetings, equipment and medications, memory making materials, access to toys and education resources) are always operational and available.</p> <p>6.8 The health service organisation should work with local community-based service providers and families to build capacity for children to be cared for in the preferred place of care (for example, at home).</p>
<p>7. Education and training Clinicians have the skills and knowledge to provide end-of-life care</p>	<p>Adult 7.3 Patients, families and carers should be invited to participate in providing education about end-of-life care, since patient stories can be powerful tools for teaching. It is important that patients, families and carers are adequately supported to share their experiences.</p> <p>Paediatric 7.3 The health service organisation should invite children and families to participate in providing education about paediatric end-of-life care, since patient stories can be powerful tools for teaching. It is important that children and families are adequately supported to share their experiences.</p>
<p>9. Evaluation and feedback The quality of end-of-life care is measured and improved</p>	<p>Adult 9.1 Data about the effectiveness of processes and systems for delivering end-of-life care should be collected, reviewed and reported locally (including over time).</p> <p>Paediatric 9.1 The health service organisation should collect, review and report locally (including over time) data about the effectiveness of processes and systems for delivering paediatric end-of-life care.</p>
<p>10. Supporting systems Systems align with NSQHS Standards to improve outcomes</p>	<p>Adult 10.5 Health services should work with community care providers to ensure that systems are in place for communicating and accessing advance care directives or plans developed in community care settings.</p> <p>Paediatric 10.5 The health service organisation should work with community care providers to ensure that systems are in place for communicating and accessing advance care plans developed in community care settings.</p>

Standards for General Practice (RACGP), 5th Edition

Relevant standard	Relevant action (where available) against Essential Component 1
Core Standard 1: Communication and patient participation	C1.3 Informed patient decisions
Core Standard 2: Rights and needs of patients	C2.1 Respectful and culturally appropriate care
Core Standard 4: Health promotion and preventive activities	C4.1 Health promotion and preventive care
GP Standard 2.1: Continuous and comprehensive care	GP2.1 b. Our practice provides continuity of care and comprehensive care

Aged Care Quality Standards (Australia)

Relevant Standard	Relevant action (where available) against Essential Component 1
1. Consumer dignity and choice	
2. Ongoing assessment and planning with consumers	
6. Feedback and complaints	

End-of-life and Palliative Care Framework (NSW Health)

Relevant standard	Relevant action (where available) against Essential Component 1
1. Care is person centred	<p>Care should be based on the unique, holistic needs and preferences of the person receiving care. It should respect their preferences and their dignity. The individual, their families and carers are equal partners in the decisions relating to their care and treatment. Provision of care should be based on assessed need and be flexible in response to the person's changing needs and preferences so that:</p> <ul style="list-style-type: none"> • there are options for care that empower people to make their own choices in relation to the care they receive, including where they receive care • processes are in place to fully inform individuals and their families of the service options. <p>There is support to enable individuals and their families to make choices and care decisions. This helps people to receive holistic care, with social, cultural, emotional, physical, medical and spiritual factors all considered and supported.</p>

Relevant standard	Relevant action (where available) against Essential Component 1
2. There is recognition and support for families and carers	<p>Families and carers play a pivotal role in the end-of-life and palliative care service system. It is essential their role is recognised, valued, and supported. Health services should support for families and carers to be involved in planning and providing care, and to access the services they need to carry out this role.</p> <p>Families and carers should have access to targeted resources, information, and advice to help navigate the system – particularly in regard to accessing services, as well as encouraging access to local support networks.</p> <p>Access to good quality information is central to coping and is essential for families and carers as it helps them better manage their role in caring for their loved one</p>
4. Care is well-coordinated and integrated	<p>People needing end-of-life and palliative care may receive care from multiple services across several settings. Care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings.</p>
5. Access to quality care is equitable	<p>There can be significant variation in access to end-of-life and palliative care services across NSW. There are groups across NSW who need greater support to access end-of-life and palliative care services.</p>

Clinical Principles for End-of-life and Palliative Care (NSW Health)

Relevant standard	Relevant action (where available) against Essential Component 1
Key action 5: Open and respectful communication	<p>Communication that is open, respectful, culturally safe and agreeable enables effective conversations regarding expectations with the person, their family and carers. This ensures coordination of care is maintained with both internal and external care providers who commonly collaborate on end-of-life and palliative care. This type of communication centres around empowering the patient, their family and carers.</p> <p>Action: Processes are in place to provide the person, their family and carers with clear, health literate and appropriate information regarding available care, and how it may be provided. This includes setting expectations of the roles of care providers, the individual, families and carers. Considerations of cultural and linguistic needs is also recommended.</p>
Key action 8: Place of death	<p>Supporting people to receive care and die in their preferred place requires consistent open communication, health literate information and access to relevant services and equipment. Consideration of the care setting and whether the clinical needs of the person can be met should interface with systems to prevent or minimise unnecessary hospital admissions. If home is the preferred care setting, consideration of availability of community health and support services to meet the person and their family or carer's needs is important.</p>

Relevant standard	Relevant action (where available) against Essential Component 1
	<p>Action: Processes are in place for identified and embedded local pathways which support people to:</p> <ul style="list-style-type: none"> • identify their preferred place of death • be cared for in the place of their choosing (where it is safe and feasible to do so) • die as close to home as possible, if this is the preference. <p>Regular assessment of the appropriateness of the preferred setting is also encouraged.</p>