Essential Component 2: Discussions about palliative and end-of-life care and planning for future goals – standards comparison

National Palliative Care Standards, 5th Edition

Relevant standard	Relevant action (where available) against Essential Component 2
1. Assessment of needs Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs	**1.1** The initial and ongoing assessments are carried out by qualified interdisciplinary personnel. **1.2** The assessment is coordinated to reduce the burden of duplication on the person, family and carers. **1.4** The person's needs are reassessed on a regular basis. **1.5** Initial and ongoing assessments are documented in the person's clinical record**.** **1.6** Ongoing assessments are used to inform the care plan and any subsequent changes to it.
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	**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. **2.2** The person, their family and carers are provided with up-to-date information appropriate to meet their needs and support informed participation in care planning and decision-making. . **2.4** The person is supported to consider, document and update their future care goals, including in an advance care plan. **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. **2.7** Initial and ongoing discussions informing the care plan are documented and readily available to guide care delivery.

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	2.8 The expectations and preferences of the person, their family and carers for the type and place of care are discussed, negotiated and an agreed plan is documented. **2.9** The care plan is reviewed and updated regularly, based on reassessments of the person's condition, needs and preferences, and in consultation with the person, their family and carers. Changes to the care plan are documented.
3. Caring for others 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	**3.2** The service works with the family and carers to understand their needs and desired level of involvement in care. The potential benefits and risks around assisting with care are discussed with the person, their family and carers and there is ongoing assessment of their willingness and ability to participate in the provision of care.
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	**4.3** Where care cannot be delivered in accordance with the goals and preferences of the person, this is discussed with the person, their family, and carers, and an agreed alternative plan is documented and communicated. **4.4** There are protocols and procedures in place for the escalation of care where required, based on assessed needs.
5. Transitions within and between services Care is integrated across the person's experience to ensure seamless transitions within and between services	**5.3** Care plans demonstrate appropriate actions to support seamless transition between care settings.

National Safety and Quality Health Service Standards, 2ⁿᵈ Edition

Relevant standard	Relevant action (where available) against Essential Component 2

1. Clinical governance
• Patient safety and quality systems
	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
	  c. incorporates information on the diversity of its consumers and higher risk groups into the planning and delivery of care.
	
	1.16 The health service organisation has healthcare record systems that:
	  a. make the healthcare record available to clinicians at the point of care

Relevant standard	Relevant action (where available) against Essential Component 2
• Clinical performance and effectiveness	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 e. integrate multiple information systems, where they are used. **1.20** The health service organisation uses its training systems to: a. assess the competency and training needs of its workforce b. implement a mandatory training program to meet its requirements arising from these standards c. provide access to training to meet its safety and quality training needs d. monitor the workforce's participation in training. **1.21** The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients. **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. **1.24** The health service organisation: a. conducts processes to ensure that clinicians are credentialed, where relevant b. monitors and improves the effectiveness of the credentialing process.
2. Partnering with consumers • Partnering with patients in their own care	**2.4** The health service organisation ensures that its informed consent processes comply with legislation and best practice. **2.6** The health service organisation has processes for clinicians to partner with patients and/or their substitute decision-maker to plan, communicate, set goals, and make decisions about their current and future care. **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.

Relevant standard	Relevant action (where available) against Essential Component 2

• Health literacy
 	
• Partnering with consumers in organisational design and governance
	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.
	
	2.9 Where information for patients, carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review.
	
	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
	  d. information needs for ongoing care are provided on discharge.
	
	2.13 The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs.

3. Preventing and controlling healthcare-associated infection
• Infection prevention and control systems
	3.6 Clinicians assess infection risks and use transmission-based precautions based on the risk of transmission of infectious agents, and consider:
	  a. patients' risks, which are evaluated at referral, on admission or on presentation for care, and re-evaluated when clinically required during care
	  b. whether a patient has a communicable disease, or an existing or a pre-existing colonisation or infection with organisms of local or national significance
	  c. accommodation needs to manage infection risks
	  d. the need to control the environment
	  e. precautions required when the patient is moved within the facility or to external services
	  f. the need for additional environmental cleaning or disinfection
	  g. equipment requirements.

4. Medication safety • Documentation of patient information	**4.5** Clinicians take a best possible medication history, which is documented in the healthcare record on presentation or as early as possible in the episode of care. **4.6** Clinicians review a patient's current medication orders against their best possible medication history and the documented treatment plan and reconcile any discrepancies on presentation and at transitions of care.

Relevant standard	Relevant action (where available) against Essential Component 2
• Continuity of medication management	**4.7** The health service organisation has processes for documenting a patient's history of medicine allergies and adverse drug reactions in the healthcare record on presentation. **4.8** The health service organisation has processes for documenting adverse drug reactions experienced by patients during an episode of care in the healthcare record and in the organisation-wide incident reporting system. **4.10** The health service organisation has processes: a. to perform medication reviews for patients, in line with evidence and best practice b. to prioritise medication reviews, based on a patient's clinical needs and minimising the risk of medication-related problems c. that specify the requirements for documentation of medication reviews, including actions taken as a result. **4.11** The health service organisation has processes to support clinicians to provide patients with information about their individual medicines needs and risks.
5. Comprehensive care • Clinical governance and quality improvement to support comprehensive care • Developing the comprehensive care plan	**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. always identify the clinician with overall accountability for a patient's care. **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. **5.6** Clinicians work collaboratively to plan and deliver comprehensive care. **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 b. that identify the risks of harm in the minimising patient harm criterion.

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	5.8 The health service organisation has processes to routinely ask patients if they identify as being of Aboriginal or Torres Strait Islander origin, and to record this information in administrative and clinical information systems.
	
	5.9 Patients are supported to document clear advance care plans.
	
	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
	   c. to identify social and other circumstances that may compound these risks.
	
	5.11 Clinicians comprehensively assess the conditions and risks identified through the screening process.
	
	5.12 Clinicians document the findings of the screening and clinical assessment processes, including any relevant alerts, in the healthcare record.
	
	5.13 Clinicians use processes for shared decision making to develop and document a comprehensive and individualised plan that:
	   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. starts 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.

• Delivering comprehensive care	**5.14** The workforce, patients, carers and families work in partnership to:
	   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.

Relevant standard	Relevant action (where available) against Essential Component 2

• Minimising patient harm	**5.15** The health service organisation has processes to identify patients who are at the end-of-life that are consistent with the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care.*
	
	5.17 The health service organisation has processes to ensure that current advance care plans:
	   a. can be received from patients
	   b. are documented in the patient's healthcare record.
	
	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.*
	
	5.21 The health service organisation providing services to patients at risk of pressure injuries has systems for pressure injury prevention and wound management that are consistent with best-practice guidelines.
	
	5.22 Clinicians providing care to patients at risk of developing, or with, a pressure injury conduct comprehensive skin inspections in accordance with best-practice time frames and frequency.
	
	5.23 The health service organisation providing services to patients at risk of pressure injuries ensures that:
	   a. patients, carers and families are provided with information about preventing pressure injuries
	   b. equipment, devices and products are used in line with best-practice guidelines to prevent and effectively manage pressure injuries.
	
	5.24 The health service organisation providing services to patients at risk of falls has systems that are consistent with best-practice guidelines for:
	   a. falls prevention
	   b. minimising harm from falls
	   c. post-fall management.
	
	5.25 The health service organisation providing services to patients at risk of falls ensures that equipment, devices and tools are available to promote safe mobility and manage the risks of falls.
	
	5.26 Clinicians providing care to patients at risk of falls provide patients, carers and families with information about reducing falls risks and falls prevention strategies.

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	5.27 The health service organisation that admits patients overnight has systems for the preparation and distribution of food and fluids that include nutrition care plans based on current evidence and best practice.
	
	5.28 The workforce uses the systems for preparation and distribution of food and fluids to:
	  a. meet patients' nutritional needs and requirements
	  b. monitor the nutritional care of patients at risk
	  c. identify, and provide access to, nutritional support for patients who cannot meet their nutritional requirements with food alone
	  d. support patients who require assistance with eating and drinking.
	
	5.29 The health service organisation providing services to patients who have cognitive impairment or are at risk of developing delirium has a system for caring for patients with cognitive impairment to:
	  a. incorporate best-practice strategies for early recognition, prevention, treatment and management of cognitive impairment in the care plan, including the *Delirium Clinical Care Standard*, where relevant
	  b. manage the use of antipsychotics and other psychoactive medicines, in accordance with best practice and legislation.
	
	5.30 Clinicians providing care to patients who have cognitive impairment or are at risk of developing delirium use the system for caring for patients with cognitive impairment to:
	  a. recognise, prevent, treat and manage cognitive impairment
	  b. collaborate with patients, carers and families to understand the patient and implement individualised strategies that minimise any anxiety or distress while they are receiving care.
	
	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 respond to patients who are distressed, have thoughts of self-harm or suicide, or have self-harmed.
	
	5.33 The health service organisation has processes to identify and mitigate situations that may precipitate aggression.
	
	5.34 The health service organisation has processes to support collaboration with patients, carers and families to:
	  a. identify patients at risk of becoming aggressive or violent
	  b. implement de-escalation strategies
	  c. safely manage aggression, and minimise harm to patients, carers, families and the workforce.

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	5.35 Where restraint is clinically necessary to prevent harm, the health service organisation has systems that:
	  a. minimise and, where possible, eliminate the use of restraint
	  b. govern the use of restraint in accordance with legislation
	  c. report use of restraint to the governing body.
	
	5.36 Where seclusion is clinically necessary to prevent harm and is permitted under legislation, the health service organisation has systems that:
	  a. minimise and, where possible, eliminate the use of seclusion
	  b. govern the use of seclusion in accordance with legislation
	  c. report use of seclusion to the governing body.

6. Communicating for safety
• Clinical governance and quality improvement to support effective communication
	6.1 Clinicians use the safety and quality systems from the Clinical Governance Standard when:
	  a. implementing policies and procedures to support effective clinical communication
	  b. managing risks associated with clinical communication
	  c. identifying training requirements for effective and coordinated clinical communication.
	
	6.3 Clinicians use organisational processes from the *Partnering with Consumers Standard* to effectively communicate with patients, carers and families during high-risk situations to:
	  a. actively involve patients in their own care
	  b. meet the patient's information needs
	  c. share decision-making.
	
	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
	  c. critical information emerges or changes about a patient's care, including information on risks.

• Communication at clinical handover	**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 needs of patients, carers and families
	  c. clinicians who are involved in the clinical handover.

Relevant standard	Relevant action (where available) against Essential Component 2
• Communication of critical information	**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 f. ensuring that clinical handover results in the transfer of responsibility and accountability for care. **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. **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.
• Documentation of information	**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 c. changes to the care plan.
8. Recognising and responding to acute deterioration • Detecting and recognising acute deterioration and escalating care	**8.4** The health service organisation has processes for clinicians to detect acute physiological deterioration that require clinicians to: a. document individualised vital sign monitoring plans b. monitor patients as required by their individualised monitoring plan c. graphically document and track changes in agreed observations to detect acute deterioration over time, as appropriate for the patient. **8.5** The health service organisation has processes for clinicians to recognise acute deterioration in mental state that require clinicians to: a. monitor patients at risk of acute deterioration in mental state, including patients at risk of developing delirium b. include the person's known early warning signs of deterioration in mental state in their individualised monitoring plan c. assess possible causes of acute deterioration in mental state, including delirium, when changes in behaviour, cognitive function, perception, physical function or emotional state are observed or reported

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	d. determine the required level of observation e. document and communicate observed or reported changes in mental state. **8.6** The health service organisation has protocols that specify criteria for escalating care, including: 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. **8.7** The health service organisation has processes for patients, carers or families to directly escalate care. **8.8** The health service organisation provides the workforce with mechanisms to escalate care and call for emergency assistance. **8.9** The workforce uses the recognition and response systems to escalate care.

National Consensus Statement (Adult and Paediatric)

Relevant standard	Relevant action (where available) against Essential Component 2
1. Patient and family-centred care Patients/children and families are part of decision making about end-of-life care	**Adult** **1.1** Clinicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end-of-life care aligned with the patient's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations. **1.2** The clinical team should work with the patient, family and carers to identify the substitute decision-maker, family spokesperson or other key contacts that the patient wishes to be involved in discussions about their care. **1.3** In some cultures, mainstream assumptions about death and dying, and about patients and families as decision-makers may not be correct. Culturally appropriate decision-makers should be identified as early as possible so that strategies can be put in place for obtaining their input into discussions about end-of-life care.

Relevant standard	Relevant action (where available) against Essential Component 2
	1.4 Clinicians should seek to understand, and be respectful, sensitive and responsive to the individual preferences and needs of all patients, substitute decision-makers, families and carers. This is regardless of aspects of identity such as culture, religious belief, gender or sexual preference. **1.5** Whenever possible, clinicians should prepare for having conversations about end-of-life care. Necessary preparation may include: • reaching consensus among all of the clinical teams involved in the patient's care about the patient's prognosis and what treatment options are appropriate to recommend • ensuring familiarity with the patient's history and current condition (this may include discussion with key community care providers), their family structure, and cultural needs and preferences • arranging adequate time for uninterrupted discussion • ensuring that patients have access to their regular communication aids • arranging for the appropriate people to be in attendance – ideally, this will include the patient; their substitute decision-maker, carers and family members; the most senior doctor available; the nurse responsible for the patient's care; and other members of the interdisciplinary team, such as interpreters, Aboriginal support workers, chaplains or social workers • ensuring that discussions can be held in an appropriately quiet and private environment. **1.6** The patient, substitute decision-maker, family and carers should be provided with written information on which clinician is responsible for leading and coordinating their care. Whenever possible, this clinician should be directly involved in discussions about the patient's end-of-life care. **1.7** Whenever possible, clinicians should work with patients, families and carers to ensure that key family members, substitute decision-makers and carers are present during end-of-life discussions. This will ensure that consistent messages are given about treatment options, their likelihood of success, risks and prognosis. This is particularly important when patients are in the process of transition to the terminal phase, as conflict and uncertainty among family and carers can result in avoidable suffering.

Relevant standard	Relevant action (where available) against Essential Component 2
	1.8 Clinicians should provide an honest and straightforward summary of their clinical assessment of the situation, what they consider to be appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the patient's condition improving in response to such treatment. Clinicians should be compassionate and sensitive, use plain language, and avoid medical jargon. **1.9** Clinicians should express empathy for the patient's situation. They should allow adequate time for those involved to absorb, process and react to the information they are being given. Multiple discussions may be required. **1.10** End-of-life discussions should routinely include the provision of information about organ and tissue donation for transplantation, in circumstances where donation is possible. These discussions should be conducted with advice from the state or territory DonateLife agency and should preferably be led by clinicians who have attended the core *Family Donation Conversation* workshop. **1.11** Clinicians should check that patients, families and carers have been provided with sufficient support to make decisions. This includes support for patients, substitute decisionmakers, families and carers who have communication difficulties associated with cultural and linguistic diversity, or decision-making difficulties associated with disability, mental illness or cognitive impairment. **1.12** Clinicians should clearly document the content of the discussion and any agreed plan of care in the patient's clinical record. Any unresolved issues that require further follow-up should also be documented, along with a plan for follow-up. **1.13** The content of the discussion and plan of care, including any limitations of medical treatment, should be communicated to all teams involved in the patient's care, including relevant community care providers. **Paediatric** **1.1** The interdisciplinary team should identify who has parental responsibility. **1.3** Clinicians should consider the wishes of the parents as to the extent of involvement of the child in these discussions, while at the same time providing support for the child to be involved as much as possible. **1.4** Clinicians should be respectful, sensitive and responsive to the preferences and needs of individual children and their families, regardless of aspects of identity such as culture, religious belief, gender or sexual preference.

Relevant standard	Relevant action (where available) against Essential Component 2
	1.5 Clinicians, the child and their parents should identify opportunities for proactive and pre-emptive end-of-life care discussions to increase the likelihood of delivering high quality end-of-life care aligned with the child and their parents' values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations. **1.6** Whenever possible, clinicians should prepare for having conversations about end-of-life care. Necessary preparation may include: - reaching consensus among all of the teams involved in the child's care about the prognosis and what treatment options are appropriate to recommend - ensuring familiarity with the child's history and current condition (this may include discussion with key community care providers), their family structure, and cultural needs and preferences arranging adequate time for uninterrupted discussion - arranging adequate time and an appropriate physical environment for uninterrupted discussion ensuring that the child and their parents have access to their regular communication aids - arranging for the appropriate people to be in attendance – depending on the child and parents' individual preferences, this may include the child; their parents and family; the most senior doctor available; the nurse responsible for the child's care; and other members of the interdisciplinary team, such as interpreters, Aboriginal support workers, child life therapists, chaplains and/or social workers - ensuring that discussions can be held in an appropriately quiet and private environment. **1.7** Clinicians should provide parents with written information about which clinician is responsible for leading and coordinating their child's care. Whenever possible, this clinician should be directly involved in discussions about the child's end-of-life care. **1.8** Clinicians should assist parents in communicating information to their child about the outcomes of discussions about end-of-life care. **1.9** Clinicians should work with parents to ensure that key family members are present during end-of-life discussions or that appropriate follow-up meetings are offered. This will ensure that consistent messages are given about treatment options, their likelihood of success, risks and prognosis.

Relevant standard	Relevant action (where available) against Essential Component 2
	1.10 In some cultures, mainstream assumptions about death and dying may not be correct. Clinicians should work with parents to identify as early as possible any culturally appropriate decision-makers to include in discussions about end-of-life care. **1.11** Clinicians should provide an honest and straightforward summary of the clinical assessment findings, appropriate and feasible options for treatment, any risks and potential side effects, and the likelihood of the child's condition improving in response to such treatment. Be compassionate and sensitive, use plain language, and avoid the use of medical jargon. **1.12** Clinicians should express empathy for the child and parents' situation. Allow adequate time for those involved to absorb, process and react to the information they are being given. Multiple opportunities for discussion may be required. **1.13** Clinicians should check that the child and their parents have been provided with sufficient support to make decisions. This includes support for children and parents who have communication difficulties, cultural, spiritual or linguistic needs, or decision-making difficulties associated with disability, mental illness or cognitive impairment. **1.14** Clinicians should clearly document the content of discussions and any agreed plan of care in the patient clinical record. Any unresolved issues that require further follow-up should be documented, along with a plan for follow-up. **1.15** Clinicians should communicate the content of the discussion and plan of care, including any limitations of medical treatment, to all teams involved in the child's care, including relevant community care providers.
2. Teamwork Clinicians work together to provide end-of-life care	**Adult** **2.3** If there is disagreement or ambiguity about the appropriate options for future treatment among members of healthcare teams, the range of views and the reasons for them should be discussed with the patient, substitute decision-maker, family and carers. **Paediatric** **2.3** If members of interdisciplinary teams are unable to reach agreement on appropriate treatment options, or there is ambiguity about options for future treatment, clinicians should discuss the range of views and the reasons for them with the parents and, where appropriate, the child.

Relevant standard	Relevant action (where available) against Essential Component 2
3. Goals of care Clear goals improve the quality of end-of-life care	**Adult** **3.1** The psychosocial, cultural and spiritual needs of patients, families and carers should be assessed, and care should be provided in accordance with their wishes, values and needs. Support should be offered for patients, carers and families who wish to include cultural or religious practices in their care, such as particular foods, singing, ceremonies or healing. **3.2** Patients who are likely to die within the short or medium term should be informed about the process and purpose of advance care planning and asked if they would like to instigate or revisit their advance care plan. **3.3** As part of the advance care planning process, clinicians should ask about, and document, a patient's wishes regarding donation of their organs and tissues for clinical use or research purposes after death where this is clinically appropriate. **3.4** Unnecessary burdens associated with medical treatment should be avoided for dying patients. For example, non-beneficial or unwanted observations, surgical interventions, investigations, medications and treatments should not be prescribed or administered. Where a clinician feels pressured – by the patient, family, carer or another health professional – to provide such interventions, they should seek advice and support from an experienced colleague who is able to assist with a second opinion and sensitive discussion. **3.5** The goals of care, the treatment plan and any limitations of medical treatment for the current admission should be appropriately discussed with the patient, and their substitute decision-maker, family and carers, and clearly documented in the patient clinical record by the treating medical officer or team. This should occur as early as possible in the patient's admission to the health service, and the information should be routinely reviewed and updated throughout the admission. **3.6** The rationale for medical decisions to discontinue or withhold non-beneficial observations, investigations or treatments should be clearly communicated with the patient, family and carers. **3.7** The goals of care, treatment plan and any limitations of medical treatment should be revisited with the patient, substitute decision-maker, family and carers when significant changes in the patient's condition or circumstances occur – for example, when the patient is in transition to the terminal phase. The patient, substitute decision-maker, family and carers should be empowered to request further discussion and a review of the plan at any time.

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	3.14 Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the patient. If feasible, this could include the patient's usual residence, a local hospital, a community or residential aged care facility, or a hospice or other palliative care facility. **Paediatric** **3.1** Clinicians should assess the psychosocial, cultural and spiritual needs of the child. Support should be offered for families who wish to include cultural or religious practices in the care of the child, such as particular foods, singing, ceremonies or healing. **3.2** Clinicians should inform families about the process and purpose of advance care planning. This process should be undertaken using age-appropriate advance care planning documents where available. **3.3** Clinicians should avoid unnecessary burdens associated with medical treatment for dying children. For example, non-beneficial observations, surgical interventions, investigations, medications and treatments should not be prescribed or administered. Where a clinician feels pressured - by the family or another health professional - to provide such interventions, they should seek advice and support from an experienced colleague who is able to assist with a second opinion and sensitive discussion, or seek legal or clinical ethics advice where appropriate. **3.5** Clinicians should revisit the goals of care, treatment plan and any limitations of medical treatment when significant changes in the child's condition, preferences, or circumstances occur – for example, when the child is in transition to the terminal phase. **3.6** Clinicians should clearly communicate the rationale for medical decisions to discontinue or withhold nonbeneficial observations, investigations or treatments to the parents and, where appropriate, the child. **3.7** Clinicians should enable the child and their parents to request further discussion and a review of the goals of care, treatment plan and any limitations of medical treatment at any time. **3.10** Clinicians should support dying children to receive oral food and fluids for as long as they wish. **3.11** Clinicians should manage physical symptoms in alignment with the child and their parents' wishes, and review treatment regularly.

Relevant standard	Relevant action (where available) against Essential Component 2
	3.12 Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the child and their parents. This could include providing appropriate referrals, equipment and support to deliver care in the family home, the child's local hospital, a hospice or other palliative care facility. **3.14** Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the patient. If feasible, this could include the patient's usual residence, a local hospital, a community or residential aged care facility, or a hospice or other palliative care facility. **3.15** Clinicians should support parents and families to care for their dying child and provide information about what to expect during the dying process. **3.16** Clinicians should provide information about organ and tissue donation for transplantation, in circumstances where donation is possible. Discussions should be conducted with advice from the state or territory DonateLife agency. Such discussions should preferably be led by clinicians who have attended the core *Family Donation Conversation* workshop. If families have previously expressed a wish for the child to die at home, they should be informed that choosing organ donation may influence options for the place of death. The process of organ donation should not interfere with the family's wishes for time with their child after death.
4. Using triggers Triggers identify when patients need end-of-life care	**Adult** **4.1** The 'surprise' question should be used by clinicians as a simple screening mechanism to recognise patients who could benefit from end-of-life care interventions. Clinicians should ask themselves: • Would you be surprised if this patient died in the next 12 months? • Would you be surprised if this patient died during this admission, or in the next days or weeks? **Paediatric** **4.1** Clinicians should use the 'surprise' question as a simple screening mechanism to recognise children who may benefit from end-of-life care interventions. Clinicians should ask themselves: • Would you be surprised if this child died as a result of this condition or problem? • Would you be surprised if this child died in the next 12 months? • Would you be surprised if this child died during this admission or in the next days or weeks?

Relevant standard	Relevant action (where available) against Essential Component 2
5. Responding to concerns Clinicians get help to rapidly respond to patient suffering	**Adult** **5.6** To avoid after-hours decisions to limit medical treatment or stop non-beneficial treatments, pre-emptive planning should be undertaken by the team with overall responsibility for the patient's care. When after-hours decision-making is required as a result of sudden or unexpected deterioration in the patient's condition, the patient should be followed up by the responsible team as soon as possible.
10. Supporting systems Systems align with NSQHS Standards to improve outcomes	**Adult** **10.1** Systems should be in place to support clinicians to work with patients, families and carers to receive, prepare, review or update advance care plans and directives, according to the wishes of the patient. These systems should align with NSQHS *Standard 1: Governance for safety and quality in health service organisations* and *Standard 9: Recognising and responding to clinical deterioration in acute health care*. **Paediatric** **10.1** The health service organisation should ensure that systems are in place to support clinicians to work with children and their families to receive, prepare, review or update age-appropriate advance care plans, according to the wishes of the child and their family. These systems should align with *NSQHS Standard 1: Governance for safety and quality in health service organisations* and *Standard 9: Recognising and responding to clinical deterioration in acute health care.*

Standards for General Practice (RACGP), 5th Edition

Relevant standard	Relevant action (where available) against Essential Component 2
Core Standard 1: Communication and patient participation	**1.3** Informed patient decisions
Core Standard 2: Rights and needs of patients	**2.1** Respectful and culturally appropriate 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 2
1. Consumer dignity and choice	
2. Ongoing assessment and planning with consumers	
3. Feedback and complaints	

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

Relevant standard	Relevant action (where available) against Essential Component 2
1. Care is person centred	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.
2. There is recognition and support for families and carers	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 families and carers to be involved in planning and providing care, and to access the services they need to carry out this role.

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

Relevant standard	Relevant action (where available) against Essential Component 2
Key action 4: Care planning	Care planning establishes the care goals and needs of the person, their family and carers. Individuals should be involved as much as possible in their care planning, to ensure their preferences and needs are reflected. Recognising variation in community and cultural preferences and expectations of care will help to support a person-centred approach for all. Multicultural health and Aboriginal health professionals can provide cultural guidance and support and, where applicable, be part of the multidisciplinary team. **Action:** Processes are in place to ensure that following comprehensive assessment of people with life-limiting illnesses, the person and their family and carers are actively involved in discussions and decisions regarding immediate care needs and advance care planning. Appropriate documentation must reflect these decisions.

Relevant standard	Relevant action (where available) against Essential Component 2
Key action 5: Open and respectful communication	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. **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.
Key action 8: Place of death	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/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/carer's needs is important. **Action:** Processes are in place for identified and embedded local pathways which support people to: • 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. Regular assessment of the appropriateness of the preferred setting is also encouraged.