Clinical Principles for End of Life and Palliative Care

Summary	This Guideline is relevant to all clinical services within NSW Health that provide care and support to people with life-limiting or severe advancing illness, their families and carers. It identifies the clinical principles that underpin the delivery of high quality, accessible and appropriate end of life and palliative care for people in NSW. It includes the key actions to be undertaken by NSW Health services and their partner organisations to meet the priorities identified in the NSW Health End of Life and Palliative Care Framework 2019-2024
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CLINICAL PRINCIPLES FOR END OF LIFE AND PALLIATIVE CARE

GUIDELINE SUMMARY

This Guideline outlines the clinical principles and key actions that will support good quality, evidence-informed practice and improvement in the provision of end of life and palliative care (EoLPC) in NSW. This Guideline aligns with the *NSW Health End of Life and Palliative Care Framework 2019-2024* ([the Framework](#)).

The key actions described in this Guideline have been identified as meaningful, measurable and achievable priority actions that can be implemented locally to drive state-wide, coordinated efforts to address the priority areas of the Framework.

KEY PRINCIPLES

The objectives of this Guideline are to identify overarching key principles which guide provision of EoLPC, identify key actions which will contribute to achieving the state-wide priorities of the Framework and communicate expectations regarding alignment with published 'standards' for the delivery of EoLPC to all people across NSW.

All NSW Health services providing EoLPC are to ensure they have evidence-informed, locally developed model/s of care that meet the needs of their community and, at a minimum:

- address the five priority areas of the Framework
- incorporate the nine key actions from this Guideline
    - o Screening and identification
    - o Triage
    - o Comprehensive assessment
    - o Care planning
    - o Open and respectful communication
    - o Symptom management
    - o 24/7 access to support
    - o Place of death
    - o Grief and bereavement support.
- ensures reference with applicable nationally agreed standards for the provision of EoLPC
- ensures use of appropriate, evidence-based tools and resources
- articulates pathways to ensure access is available to multidisciplinary services
- integrates the use of clinically appropriate virtual care modalities to support the provision of integrated care
- improves equitable access for priority and underserved populations.

USE OF THE GUIDELINE

NSW Local Health Districts (Districts) and Specialty Health Networks (Networks) are responsible for ensuring their services and facilities meet the requirements of this Guideline. It is recommended that local governance mechanisms are in place to oversee the implementation of the Guideline.

All staff and services who provide end of life care and/or palliative care (includes, but is not restricted to, specialist palliative care services) are to be aware of this Guideline and actively participate in its implementation.

This Guideline is applicable across all care settings including community settings, non-admitted settings, admitted settings, or other settings in which NSW Health services are providing care. It is relevant to all people (neonates, infants, children, adolescents, young adults, adults and older adults) who have a life-limiting illness or are identified as approaching the end of life.

Districts and Networks are to use this Guideline to:

- develop, implement and monitor strategies aligned to the key actions specified in this Guideline

- understand the expectations of NSW Health regarding alignment with relevant nationally agreed standards for EoLPC

- ensure locally developed model/s of care reflect appropriate, evidence-informed tools and resources

- assist in meeting accreditation requirements.

REVISION HISTORY

Version	Approved by	Amendment notes
September-2021 (GL2021_016)	Deputy Secretary, Health System Strategy and Planning	Initial Document

ATTACHMENTS

1. Clinical Principles for end of life and palliative care: Guideline

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1   BACKGROUND

The [NSW Health End of Life and Palliative Care Framework 2019-2024](#) (the Framework) identifies the vision and direction for end of life and palliative care (EoLPC) in NSW. It aims to create a renewed drive for people and services to work together in providing accessible, high quality EoLPC. This includes working in partnership with people receiving care, as well as their families and carers.

Five priority areas were identified during the Framework development and consultation process:

1. Care is person-centred.
2. There is recognition and support for families and carers.
3. There is access to care providers across all settings who are skilled and competent in EoLPC.
4. Care is well coordinated and integrated.
5. Access to quality care is equitable.

These priority areas are to be the focus of quality improvement activities.

1.1   Scope of Delivery

The delivery of EoLPC outlined in this Guideline is relevant to all people who have a life-limiting illness, or are identified as approaching and reaching the end of life, including:

- neonates, infants and children
- adolescents and young adults
- adults and older adults.

This includes, but is not limited to, people living with:

- congenital disorders, conditions or disease
- neurodegenerative or neuromuscular diseases
- frailty, multiple comorbidities and/or dementia
- a diagnosis of advanced cancer
- end-stage chronic disease.

This is inclusive of support for their family and carers.

All NSW Health services providing EoLPC should ensure they have evidence-informed, locally developed model/s of care that meet the needs of their community, and that at a minimum:

- addresses the five priority areas of the Framework
- incorporates the nine key actions in this Guideline
- ensures reference with applicable nationally agreed standards for the provision of EoLPC:

- o **All services**: *National Safety and Quality Health Service Standards*, Australian Commission on Safety and Quality in Health care; with noting of Standard 5: Comprehensive Care Standard with EoLPC.
- o **Specialist palliative care services**: *National Palliative Care Standards* (5th edition), Palliative Care Australia.

- ensures use of appropriate, evidence-based tools and resources, such as those included in the *Palliative and End of Life Care - A Blueprint for Improvement.*

- articulates pathways to ensure access is available to multidisciplinary services

- integrates the use of clinically appropriate virtual care modalities to support the provision of integrated care that is accessible across the nine key actions for service delivery

- improves equitable access for priority and underserved populations, such as Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse (CALD) backgrounds, people with disabilities, people experiencing homelessness, people in long-term institutional care (including being incarcerated), people who identify as lesbian, gay, bisexual, transgender, queer, intersex, or asexual (LGBTQIA+), refugees or veterans.

1.2 Evidence Review

The suitability of identified clinical cohorts as benefiting from palliative interventions was reinforced by a rapid review of palliative care cohorts as part of the Guideline development process.

The rapid review centred around non-cancer populations and was conducted via a search of PubMed from 2015 onwards, to build on an existing 2016 systematic review of palliative care populations.

- Search string: *(palliative care[mh] OR palliat*[tiab] OR hospices[mh])*.

- Inclusion criteria: English language clinical trials, reviews and systematic reviews investigating palliative care in non-cancer populations.

- Exclusion criteria: cancer-only cohorts, specific medical interventions and published protocols.

- Findings: 53 papers were identified for inclusion.

1.3 Key Definitions

Advance care planning

Advance care planning involves individuals thinking about what care they would like should they find themselves in a position where they cannot make or communicate decisions about their treatment or care. It can include the individual talking with family, carers and/or health professionals, developing an Advance Care Plan, appointing an Enduring Guardian and making an Advance Care Directive. An Advance Care Plan can be made by the individual or together with people that they trust and/or who are important to them. Where the individual is not able to make decisions, the Advance Care Plan can

be made by their family with a health professional. An Advance Care Plan is not a legal document.

Advance Care Directive

An Advance Care Directive is a way an individual can document what health care treatments they would like to have or refuse, should they find themselves in a position where they are unable to make or communicate decisions about their treatment and care. An Advance Care Directive in NSW can be spoken or written, there is not a specific form. An Advance Care Directive can only be made by an adult with decision-making capacity and if it is valid, it must be followed. Health professionals and Persons Responsible have no authority to override a valid Advance Care Directive.

Bereavement care

The care and services offered to family members, carers and friends in response to the death of a loved one.

End of life

This refers to the timeframe an individual is clearly approaching the end of their life and is living with/impaired by a life-limiting illness. This includes

- the patient's last weeks or days of life, when deterioration is irreversible; and
- when a patient is likely to die in the next 12 months.

End of life care

The care delivered to improve the quality of life for people who have a life-limiting illness, as well as their families and carers. End of life care ensures the appropriate support and palliative care needs are provided to the person, so they live as well as possible until their death. It recognises end of life care is the responsibility of everybody.

Life-limiting illness or condition

An illness or condition where it can be expected the person will die prematurely as a direct consequence of the specific illness. This term can be used for people expected to die in the near future, and for those who may live for many years with a chronic illness or condition before dying.

Modalities

The mode of care provision or delivery. This includes face-to-face services or virtual care modalities, including (but not limited to) telephone (audio), video conferencing (audio-visual), store and forward (email), remote monitoring (other) and the use of apps and mobile equipment.

Palliative care

Improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Specialist palliative care

Care given to patients with complex, unstable symptoms or high needs by either medical, nursing or allied health professionals who have formal specialist palliative care qualifications and often work exclusively within interdisciplinary teams with other palliative care health professionals. Specialist palliative care services can provide direct care to people and their families, as well as provide education and advice to other clinicians providing end of life care. Not all people with a life-limiting illness require specialist palliative care services.

Virtual care

Any interaction between people and/or members of their care team occurring remotely, using any forms of communication or information technologies with the aim of facilitating or maximising the quality and effectiveness of person-centred care.

2   CARE DELIVERY

All services should be able to demonstrate that the key actions outlined in this Guideline are provided in the delivery of end of life and palliative care (EoLPC).

2.1   Service level processes

All services should be able to demonstrate that methods, strategies and/or processes are in place to implement the key actions, such as local model/s of care, or standard operating procedures, policies or guidelines. Where appropriate, these should facilitate collaborative approaches with other relevant services for common issues. This will assist in a more consistent, equitable and sustainable EoLPC.

2.2   Governance and quality improvement

All services should ensure the provision of EoLPC is supported by appropriate governance processes and mechanisms within the Local Health District (Districts) and Specialty Health Network (Networks). There must be agreed leadership and accountability, which is underpinned by appropriate policies and procedures, and supports implementation of this Guideline.

It is recommended that a multidisciplinary group, such as an End of Life Committee or equivalent, is in place to support governance. These governance committees are to take responsibility for the development of a clear approach for EoLPC governance and quality improvement for their organisation. This will ensure consistent and equitable provision of EoLPC across the Districts / Networks, as well as facilitate ongoing monitoring, evaluation and quality improvement processes.

Local review and quality improvement processes are to be implemented, including participating in the death review process established by the Clinical Excellence Commission for all deaths in NSW Health hospitals.

Palliative care services may also choose to participate in the Palliative Care Outcomes Collaborative (PCOC) benchmarking program as a mechanism to support local quality improvement.

2.3   Data, monitoring and evaluation

All services are to collect and monitor data to determine the quality of EoLPC provided and to guide improvements in local model/s of care and their implementation in practice. Districts and Networks should contribute to local and state monitoring and reporting activities.

3   NINE KEY ACTIONS

This Guideline sets out the following nine key actions to ensure the provision of EoLPC addresses the priority areas of the published Framework.

Figure 1: Relationship between key actions
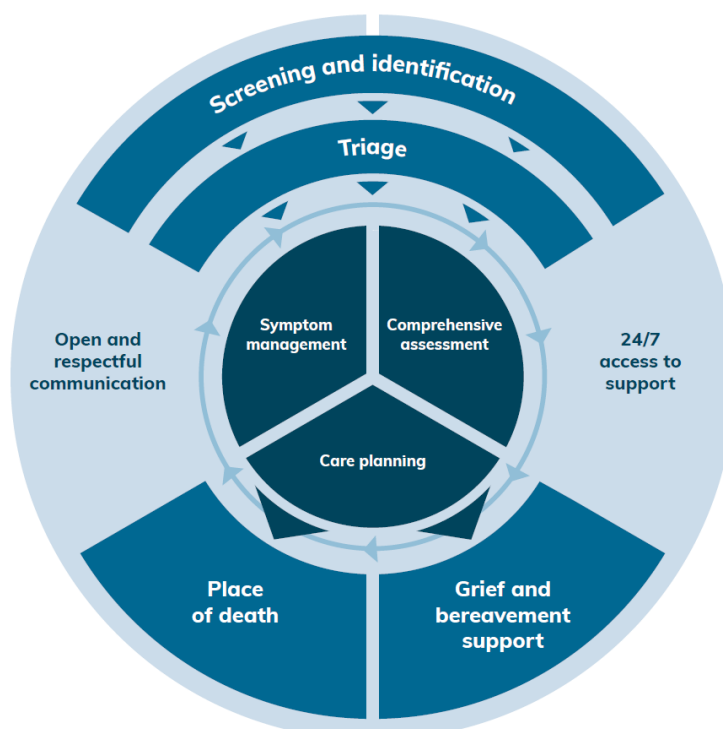
The optimisation and integration of appropriate virtual care modalities can support the provision of access to EoLPC across the nine key actions. Virtual care does not aim to replace face-to-face services; rather, it extends access to care and the opportunities to be responsive to people, their families and carers, and health care provider's needs.

Various tools and resources are available to support implementation of the key actions, as well as examples of care delivery highlighting the processes discussed in each of the key actions. These can be found via the Agency for Clinical Innovation website *Palliative and End of Life Care - A Blueprint for Improvement* (Blueprint). As new or updated materials are identified as relevant for provision of EoLPC in NSW these will be added to the online space.

3.1   Screening and Identification

Undertaking screening and identification with recognised tools ensures detection of people who have potentially unmet end of life and/or palliative care needs. The screening and identification process also recognises and identifies populations that face barriers in accessing and using services because of geographic location, age, religion, sexual orientation, gender identity, disability, racial and ethnic background, or communication difficulties.

Action
Processes are in place to identify those people who are approaching and reaching the end of their life.

Considerations and resources
Use of available tools supports and screening enables early identification of people with end of life and/or palliative care needs. Examples of useful tools include *AMBER Care Bundle*, *Supportive and Palliative Care Indicators Tool* (SPICT™) and the "*Surprise Question*".

Evidence
Screening and early identification of care needs is important to allow for shared care planning with the person, their family and carers. Early identification of care needs also ensures timely access to appropriate EoLPC services.

3.2   Triage

Triage improves timely and appropriate access to multidisciplinary care for the person, their family and carers.

Action
Processes are in place to facilitate timely referral and access for further and thorough end of life and/or palliative care needs assessment, including by specialist palliative care services, when indicated.

Considerations and resources
Establishing integrated and multidisciplinary care pathways, inclusive of (but not limited to) general practitioners, NSW Ambulance and strategic partners (e.g. residential aged care facilities), ensures timely assessment, treatment, referrals and transfers of care.

Evidence
Optimal triage facilitates the right care being provided to the right person, at the right time, by the right service or health professional.

3.3   Comprehensive Assessment

Comprehensive assessment enables the evaluation of physical, environmental, social, cultural, emotional, psychosocial and spiritual needs. Comprehensive assessment can also determine the need for inclusion of an Aboriginal liaison officer or palliative care Aboriginal health worker, as required, or the use of the Health Care Interpreter Service.

Action
Processes are in place to ensure comprehensive, culturally appropriate and holistic assessment is undertaken for all people identified as having end of life and/or palliative care needs.

Considerations and resources:
Holistic assessment should be multidisciplinary and occur through a combination of dedicated services or specified referral pathways to existing services, as appropriate. This may require virtual care access where resources are limited.

Assessment is to include use of a validated symptom assessment tool, distress screening tool, and a screening/assessment tool for identification of carer needs, availability and capability.

Examples of assessment tools include *Resource Utilisation Groups-Activities of Daily Living* (RUG-ADL), *Australia-modified Karnofsky Performance Status* (AMKPS), *Symptom Assessment Scale* (SAS) and *Palliative Care Problem Severity Score* (PCPSS).

Evidence
Comprehensive assessment is important to facilitate identification of all EoLPC needs for the person, their family and carers throughout their experience.

3.4   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/carers are actively involved in discussions and decisions regarding immediate care needs and advance care planning. Appropriate documentation must reflect these decisions.

Considerations and resources
Advance care plans must be readily available for current and future care providers, including during unplanned and out-of-hours care (including formal documents, such as advance care directives).

Advance care planning information and resources are available on the NSW Health website and tools such as the *End of Life electronic medical record (eMR) solution* can improve shared care planning across multiple settings.

Care plans need to be communicated with the person's general practitioner and original referrer.

Processes must be in place to ensure periodic reassessment of patient and family/carer needs, as these needs may change over time. This includes the provision of relevant health literate information.

Evidence
Care planning is important to support meeting the goals and needs of the person with life-limiting illness, their family and carers.

3.5 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 EoLPC. 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.

Considerations and resources

Communication training tools, such as eLearning module *SHAPE End of Life Conversations* and *Teach-back*, can be used for EoLPC discussions and planning, including discussing advance care directives and *NSW Ambulance Authorised Palliative Care Plans*.

Evidence

Open and respectful communication is important to improve the experience of the person with life-limiting illness, their family and carers.

3.6 Symptom Management

Timely and effective best practice symptom management is fundamental in the provision of quality EoLPC and must include engagement between primary health care/general practitioners, EoLPC specialists and multidisciplinary team members.

Action

Clear processes are in place to ensure there is provision of optimal, best practice physical, spiritual and psychological symptom management, as agreed by care providers, the person with the life-limiting illness, their family and carers. Processes are in place to review, respond and escalate if required, including case conferencing modalities.

Considerations and resources

Matters regarding appropriate medication use, non-pharmacological considerations and rationalising treatments is important.

Useful resources can be found on the NSW Clinical Excellence Commission website, which includes the *Last Days of Life toolkit*, *Medication prescribing for symptom management – Anticipatory Prescribing Guide* and *Symptom Management Flowcharts*.

Evidence

Appropriate symptom management is crucial to the health outcomes and experience of the person receiving care, their family and carers.

3.7 24/7 access to support

Access to support 24 hours, seven days' a week (i.e. 24/7) delivers timely appropriate care interventions and builds partnerships in decision-making with the person, their family

and carers. Providing access to urgent clinical advice, medications (prescribing and supply) and support in the after-hours period will support people to be cared for in their preferred place and provide a point of contact for individuals, their family and carers.

Action

Processes are in place to ensure all people receiving EoLPC, as well as their family and carers, have access to appropriate support 24/7, and are informed of how to access this support. In the after-hours period, mechanisms are in place to provide urgent clinical advice and support for people receiving care at home. People have clear information and instructions about how to access this advice.

Considerations and resources:

In the after-hours period, mechanisms are in place to provide urgent clinical advice and support for people receiving care at home.

This include the *NSW Palliative Care After Hours Helpline* and a local after-hours telephone support and advice line or after-hours home visiting, where available.

Evidence

Access to supportive care and advice outside of business hours aims to support high quality provision of care and reduce the burden on families, carers and clinicians in stressful and unfamiliar situations.

3.8   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.

Considerations and resources

Assessment of the person's needs, preferences and values; family and carer capacity to provide care; and availability of an appropriate and safe environment, services, resources and equipment to provide care should be undertaken.

Risk screening/assessment needs to be considered and issues addressed for any children or other vulnerable people living in the household.

Facilitate/refer to appropriate in-home support programs and ensure liaison with the person's general practitioner/primary health care regarding their role and availability in after-hours care.

Aboriginal liaison officers or palliative care Aboriginal health workers may assist with enabling Aboriginal people to be supported to die on 'Country', where possible and if desired. Multicultural health workers can provide advice on cultural considerations and requirements, including burial timeframes.

Evidence
Assessment of needs and planning for place of death is important in respecting the wishes of the person with life-limiting illness, their family and carers.

3.9   Grief and Bereavement Support

Grief and bereavement support assists with the multifaceted aspects of loss that are associated with death, such as emotional, financial and practical challenges. Support includes responding to needs around 'sorry business' practices for Aboriginal families and carers, and specific cultural needs.

Action
Processes are in place to ensure the person and their family/carers are provided with grief and bereavement support throughout the care continuum, and processes are in place for the screening of all carers for bereavement risk.

Processes are in place to provide bereavement information and support in response to the needs of families and carers, at the time and after a death. Where risks or higher needs are identified, access to additional care planning, support and referrals are provided, including where the person was cared for outside of specialist palliative care.

Considerations and resources
Either at the time of, or soon after death, families and carers of all deceased people are to be given information regarding grief and bereavement, and where indicated through a screening process, referral to appropriate bereavement support undertaken.

The Australian Centre for Grief and Bereavement has online resources for grief. Beyond Blue provides confidential counselling services 24 hours a day, 7 days a week. Griefline provides telephone and online counselling services. Headspace is the national youth mental health foundation. They can help young people who are going through a tough time.

Evidence
it is important to provide access to grief and bereavement information and support for family, carers and significant others to help the immediate and future impacts of loss on the person, their family and carers at all stages of EoLPC.

4   ADDITIONAL CONSIDERATIONS

The following areas are important for consideration in conjunction with the key actions.

Primary Health Care is a central part of community health services in NSW. EoLPC is best managed when it is integrated with, and provided in partnership with, the person's general practitioner and primary health care practice.

Strong partnerships are required between Districts and *Justice Health and Forensic Mental Health Network (JHFMHN)* in order to ensure equitable access for this population and meet the identified key actions of 24/7 access to support, place of death, and grief and bereavement support.

NSW Ambulance delivers emergency response services to the community, including through partnering with providers as an integrated part of a wider system. For many people in need of health support, NSW Ambulance is the first point of contact into the NSW Health system. Strong partnership and collaboration with providers to enable local pathways which support people to die in the place of their choosing, where it is safe and feasible to do so, is an important role of NSW Ambulance.

Provision of *culturally safe practices* include actions which recognise and respect the cultural identities of others, and safely meet their needs, expectations and rights. Whereas culturally unsafe practices diminish, demean or disempower the cultural identity and wellbeing of an individual. Cultural safety therefore considers an environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault challenge or denial of their identity, of who they are and what they need. It is about shared respect, meaning, knowledge and experience.

Cultural competence is also a vital element within the provision of EoLPC practices. Cultural competence is the ability to participate ethically and effectively in personal and professional intercultural settings. It requires being aware of one's own cultural values and world view, and their implications for making respectful, reflective and reasoned choices, including the capacity to imagine and collaborate across cultural boundaries. Acquiring the knowledge, skills and experience necessary to operate effectively and ethically in multicultural environments is crucial.

5 RESOURCES

[National Safety and Quality Health Service Standards](#) are applicable to all services. They provide a nationally consistent statement of the level of care people can expect from health care organisations. These standards provide guidance over a range of relevant areas and are used in accreditation of health services. In particular, Standard 5 includes actions regarding [comprehensive care at the end of life,](#) directly relevant to end of life care.

More information can be found in relevant National Consensus Statements around comprehensive end of life care:

- *[National Consensus Statement: Essential elements for safe and high quality end-of-life care](#)*

- *[National Consensus Statement: Essential elements for safe and high quality paediatric end-of-life care](#)*

National Palliative Care Standards ([5th edition](#)) have been developed to be used by specialist palliative care services to support the delivery of high-quality palliative care for

the person receiving care, their family and carers. These standards clearly articulate and promote a vision for compassionate and appropriate specialist palliative care.

The Palliative and End of Life Care – A Blueprint for Improvement provides a guide for health services in NSW to meet the needs of people approaching and reaching the end of life, their families and carers. It can be implemented across all settings of care and sectors. The Blueprint tools and resources will support implementation of the key actions outlined in this guideline.

NSW Health Policy Directives which can provide guidance regarding aspects of EoLPC include:

(PD2020_018)	Recognition and Management of Patients who are deteriorating
(PD2014_030)	Using Resuscitation Plans in End of Life Decisions
(GL2021_004)	End of Life Care and Decision-Making