

# **Palliative and End of Life Care**

## **A Blueprint for Improvement**

**A Progress Report**  
**From the ACI Palliative Care Network Executive Committee**  
**November 2014**



**Palliative and End of Life Care –A Blueprint for Improvement (‘the Blueprint’) has been developed to provide a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers.**

The Blueprint is for everybody in NSW. It emphasises the need for an integrated approach to care whereby relationships between specialist palliative care providers and care providers across all settings of care are fostered. It seeks to enhance networks of support, to build skills and competence in providing care to those approaching and reaching the end of their lives across all care settings and seeks to better support patients, families and carers along the way.

This online resource aims to guide services and Local Health Districts in constructing their own, localised models of care. The website will be dynamic and updated as new resources and evidence develop. It emphasises that everyone can have a role to play in supporting or providing care to people approaching and reaching the end of life.

This progress report outlines the key features of the Blueprint. These include:

- Vision
- Principles
- Essential Component and Intended Beneficial Outcomes
- Enablers

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The Blueprint has five key elements – vision, principles, intended outcomes, essential components and enablers (Diagram 1).

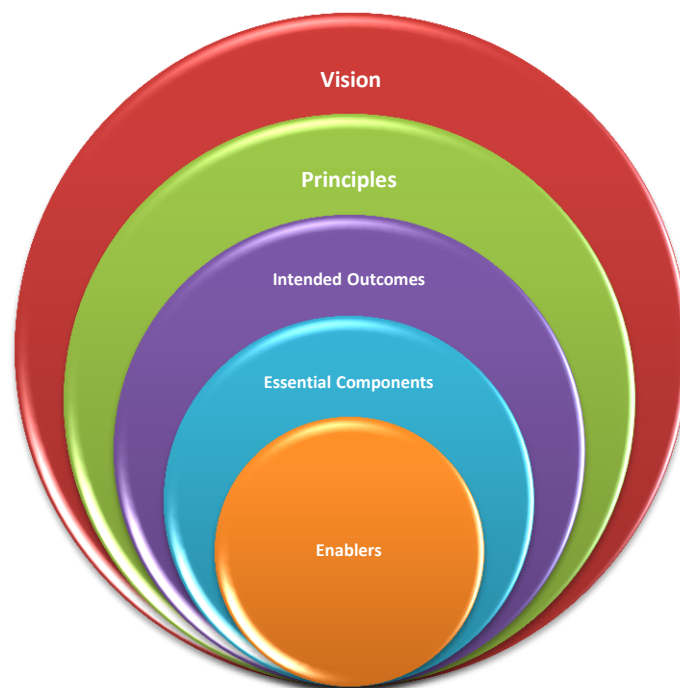


Diagram 1: Palliative and End of Life Care; A Blueprint for Improvement

### Understanding the Elements of the Blueprint.

The following table provides a brief description of the purpose of each of the elements of the Blueprint.

<b><i>Vision</i></b>	The vision statement broadly identifies what we want to achieve. Our vision is aspirational.
<b><i>Principles</i></b>	The principles are the rules, beliefs and ideas that underpin the Blueprint.
<b><i>Intended Outcomes</i></b>	The Intended Outcomes are statements describing the anticipated and desirable results of implementing the Blueprint.
<b><i>Essential Components</i></b>	These essential components should be present in any service committed to the delivery of high quality, patient and family focused care for those who are approaching the end of life.  There may be a number of ways that an essential component can be delivered.
<b><i>Enablers</i></b>	The local forces or environmental factors that contribute to successfully using this Blueprint.

# Vision

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**To ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life.**

## Principles

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The following principles have been informed by research-based evidence, *the ACI Framework for the Statewide Model for Palliative and End of Life Care Service Provision* outcomes from the consultations and diagnostic work undertaken by the ACI Palliative Care Network and key policies and guidelines.

### **Principle 1 Patient, carer and family centred care**

*What does this mean for the patient, carer and family?*

Patients, carers, families have a key role in contributing to decisions about care and are considered as ‘partners’ in the provision of health care. This means that care is ‘respectful of, and responsive to, the preferences, needs and values of [patients, carers and family members]’ (ACSQHC, 2013). Patient, carer and family centred care requires that they be actively involved in all aspects of care, including care planning and setting holistic goals of care.

*Why are we proposing this as a principle for our Blueprint?*

Patient, carer and family centred care is a historical cornerstone of palliative and end of life care. Evidence has shown that this approach can lead to improved quality of life in terms of physical and psychosocial measures (Temel, J.S. et al. 2010). The first Standard of the PCA Standards for providing quality palliative care for all Australians (PCA, 2005) reads: “*Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families’ needs and wishes are acknowledged and guide decision making and care planning*”. The ten National Safety and Quality Health Service (NSQHSS) Standards articulated by the Australian Commission on Safety and Quality in Health Care (ACSQHC, 2011) includes “Partnering with Consumers’ (Standard 2) . The broad aim of Standard 2 is to improve safety and quality outcomes for patients.

Patient centred care describes how a healthcare system meets people’s expectations regarding respect for people and their wishes, communication between health workers and patients. Core elements of patient-centred care have been identified as education and shared knowledge; involvement of family and friends, collaboration and team management; sensitivity to non-medical and spiritual dimensions of care; respect for patient needs and preferences and the free flow and accessibility of information (Shaller, 2007).

Research has demonstrated the link between patient-centred care and a reduction in the number of test orders and other referrals, greater patient satisfaction and greater patient enablement.

## **Principle 2**

### **Care is provided on the basis of need**

*What does this mean for the patient, carer and family?*

Needs based care ensures patients, carers and families have equitable access to services based on effective assessment. This requires that services be available to meet the needs of both patients and their families and carers. In a needs-based care model, care is assessed and tailored to the unique needs of the patients, carer and family. Needs based care ensures that the individual needs of the patient, their family and carer are the basis on which services are provided, rather than for example on the basis of diagnosis, age or geography. Assessment of need as people approach and reach the end of life is central to delivering person-centred, holistic care.

*Why are we proposing this as a principle for our Blueprint?*

A key learning in our consultations is that “People’s needs change.” The needs of the patient, family and carer during their end of life journey vary over time and care settings. In order for services to be responsive, coordinated and flexible in meeting these changing needs, there needs to be space and frequent opportunity for patients, carers and families to describe their changing needs over time and to reassess care plans and goals of care.

The NSW Government Plan to increase access to palliative care 2012 – 2016 acknowledged gaps in both specialist and primary care services for people approaching and reaching the end of life. The Plan also acknowledged gaps in assessment skills and referral process needed for an integrated, networked approach to care. Ensuring that all clinical staff have the skills to undertake assessment of holistic needs as people in their care approach and reach the end of life is the primary mechanism to ensure that people get the right care in the right place at the right time. Needs-based assessment drives effective referral and clinical handover.

Primary care providers in particular, reported limited access to training and less access to continuing education required to provide quality care to people as they approach and reach the end of life. Professional education, formalised networking and shared care arrangements were viewed by many as key ways to improve care into the future.

## **Principle 3**

### **Patients, carers and families have access to local and networked services to meet their needs.**

*What does this mean for the patient, carer and family?*

Gaps in both specialist and primary care services for people approaching and reaching the end of life in NSW means that sometimes patients, carers and families have to travel long distances to receive the care they need. All people need to be able to access the level and type of care required to address their needs within a reasonable distance to where they live.

People approaching and reaching the end of their life need access to local primary care, needs based access to level one specialist palliative care

services and networked access to Level 2 and 3 services based on assessed need.

The principle of care as close to home as possible means that people have access to reasonable services and supports required to meet their needs and satisfy their desire, if that is the case, to remain at home. Where this is not possible or desired, care systems should be oriented to provide care as close to home as is practical, safe and desired. This can include a residential aged care facility or a relative's home.

Decisions about how close to home care is possible start with a detailed understanding of the patients and their families and carers wishes combined with good clinical judgement and decision-making about safe and practical options. As always in a patient centred model of care these options need to be negotiated and agreed with patients and their families

*Why are we proposing this as a principle for our Blueprint?*

NSW residents experience limited access to specialist palliative care services as well as primary care providers with expertise in providing care to people as they approach and reach the end of their lives. This is documented in both the NSW Government Plan to increase access to palliative care 2012 – 2016 and the ACI PEO LC Diagnostic Report. Limited access to both local and networked services to meet their needs is particularly apparent for people living in rural and remote areas of NSW.

#### **Principle 4**

#### **Care is evidence-based, safe and effective**

*What does this mean for the patient, carer and family?*

The care experienced by patients, carers and families meets the Australian Safety and Quality Goals for Health Care (ACSQHC, 2012). This means that

- people receive health care without experiencing preventable harm;
- people receive appropriate evidence-based care;
- there are effective partnerships between consumers and healthcare providers and organisations at all levels of healthcare provision, planning and evaluation.

Evidence-based practice (EBP) is an approach to care that encourages clinicians to use the best available evidence in combination with the individual patient's circumstances and preferences in clinical practice (Caresearch, 2014). The approach also highlights the need to draw on knowledge from past clinical experience in addition to best external evidence. As systems of care mature and engage a wider group of people with an interest in improving care for people approaching or reaching the end of life, the need to have access to up-to-date literature, research-based evidence and specialist palliative care knowledge and expertise is critical. As palliative and end of life care is multidisciplinary and spans across jurisdictions, the literature and evidence base can be vast.



*Why are we proposing this as a principle for our Blueprint?*

The vision for our Blueprint is that all NSW residents have access to quality care based on assessed need as they approach and reach the end of life. Ensuring that care provided is in accordance with best practice recommendations, is organised for quality and is driven by the collection and reflection of appropriate and meaningful clinical data are all necessary components of quality systems. Quality and safety in palliative and end of life care is eroded when there are gaps in resourcing and support available to those providing such care.

## **Principle 5**

## **Care is integrated and co-ordinated**

*What does this mean for the patient, carer and family?*

Integrated care is seamless care. It enables patients, carers and families to be central to their own care planning and to receive the right care in the right places at the right times.

Integrated care is “the provision of seamless, effective and efficient care that responds to all of a person’s health needs, across physical and mental health in partnership with the individual, their carers and family. It means developing a system of care and support that is based around the needs of the individual [the carer and family], provides the right care at the right time and makes sure dollars go to the most effective way of delivering healthcare for the people of NSW” (NSW Ministry of Health).

A distinction can be drawn between real integration, in which organisations merge their services, and virtual integration, in which providers work together through networks and alliances (Kings Fund, 2011). This is particularly relevant for people approaching and reaching the end of life, where networked arrangements are required among primary care and specialist palliative care services.

*Why are we proposing this as a principle for our Blueprint?*

A key goal of the NSW Government Plan to increase access to palliative care 2012 – 2016 is to work towards better integration of primary care, aged care and specialist palliative care across the state to improve access for all people approaching and reaching the end of life, their families and carers. Integrated services contribute to coordinated, timely and flexible care for patients, families and carers.

The Guide to Palliative Care Service Development: A Population based approach developed by Palliative Care Australia (2005) outlined a plan for providing equitable access to care for people approaching and reaching the end of life in the context of ‘efficient, effective and ethical use of resources’ (PCA, 2005: 5). Based on the National Palliative Care Strategy back in 2000, the guide suggests a networked approach to care involving primary health care providers and specialist palliative care services. Importantly, the guide recognises that not all people will need or desire the same type of access to specialist palliative care. Many people can have their needs met through their existing and ongoing relationship with their primary care practitioner or multidisciplinary health service. This includes other medical specialists and general practitioners for example. This approach sees specialist palliative care services as having a focus for serving populations

with complex care needs as well as providing support and guidance for a range of care providers across all care settings.

Both health providers and consumers at times described health services as being siloed in their care and in the systems they use to support that care. This results in care that is delayed and or fragmented and not supported with timely, transferrable data that works across agencies and jurisdictions. The PEOLC Diagnostic Report emphasised how the needs of patients, families and carers change over time, requiring flexible and integrated approaches to care.

## Principle 6

## Care is equitable

*What does this mean for the patient, carer and family?*

We know that some population groups and clinical cohorts do not have equitable access to care or experience care that is sub-optimal and/or culturally unsafe or inappropriate.

Equity in relation to health care means that patients, carers and families have equal access to available care for equal need; equal utilisation for equal need and equal quality of care for all. (Whitehead, 1992).

*Why are we proposing this as a principle for our Blueprint?*

The Diagnostic Report found that care to people approaching and reaching the end of life is often fragmented and under-utilised by identified population groups or clinical cohorts. These included Aboriginal people; people under the age of 65; people who live alone; people of culturally and linguistically diverse backgrounds; people with a non-cancer diagnosis, people living with dementia and people living with a disability.

There is a growing body of evidence indicating that given a choice, patients would prefer to die at home or as close to home as possible. However, a lack of services to support that care means that many people die in acute care settings or for people in rural and remote areas, death occurs far from their local community. A lack of after-hour support services particularly inhibits carers and family members' ability to provide home care.

A key learning within the Diagnostic Report noted that although most patients prefer to be cared for as close to home as possible, services required to provide such care are limited and often inflexible. The report also noted that people living in rural and remote areas experience additional barriers to receiving quality care at the end of life, and rely on local, innovative strategies to help overcome these. Limited formalised arrangements for after-hours care and support from GPs and other care providers compound the difficulties in providing care as close to home as possible for people in rural and remote NSW.

## Essential Components and Intended Outcomes

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### Essential Components

These essential components should be present in any service committed to the delivery of high quality, patient and family focused care for those who are approaching the end of life. The Intended Outcomes are statements describing the anticipated and desirable results of implementing the Blueprint.

Within each component a range of resources will be available to support flexible, localised implementation. Key performance indicators for successful implementation will be developed for each of the essential components.

Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ Communities will have an increased understanding of the need for and benefits of quality care for people approaching and reaching the end of their life</li> <li>▪ Through community engagement and awareness raising, death and dying will be more openly discussed by more people outside of crisis events</li> <li>▪ An increase in forward planning will be evidenced by the appointment of enduring guardians, the completion of Advance Care Plans, Directives and other legal instruments</li> <li>▪ There are increased opportunities for earlier and ongoing conversations about end of life issues with health care providers</li> <li>▪ Communities increasingly recognise the limitations of active treatments when approaching the end of life and consider quality of life in discussing their goals of care</li> <li>▪ Death is considered a natural event and will be increasingly destigmatised</li> <li>▪ Community volunteer programs are supported and well-recognised for their contributions</li> </ul>	<p>Dying is a shared and unavoidable consequence of living.</p> <p>Inadequate community awareness of death and dying can result in a lack of acceptance of death generally, and a delay in planning for and transitioning to the final phase of life.</p> <p>Consumers themselves have identified that a lack of knowledge of end of life care options and services can take a significant toll on patients and their families. There are additional barriers for culturally and linguistically diverse and Aboriginal clients. (HPCSA, 2013)</p> <p>In 2012, The Australian Senate Community Affairs Committee called for improvement in "...the provision and timeliness of information to palliative care patients, their carers and families. Processes should be put in place to ensure that patients, their carers and families are provided with the right amount of information, in the right format, at the right time and that a 'show bag' approach be avoided" (ASCA, 2012: xi ).</p> <p>The impact of caring for someone at the end of life can have a profound effect on family members, friends, health professionals and aged care workers. For families, understanding the physical nature of the dying process provides important contextual information that helps avoid crisis-induced decisions at critical moments, particularly during the last days of life. However, caring for those who are dying can also serve to:</p> <ul style="list-style-type: none"> <li>- deepen the bonds within families</li> <li>- build communities across neighbourhoods; strengthen friendships and</li> </ul>

	<p>collegial networks</p> <ul style="list-style-type: none"><li>- foster compassion and resilience</li><li>- enhance respect for health and life</li><li>- reduce community anxiety about death. (SA Health, 2009)</li></ul> <p>Building capacity in, and opportunities for, volunteers in palliative and end of life care contexts can generate multiple benefits across communities</p>
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<b>Intended Beneficial Outcome</b>	<b>Why is this an Essential Component? Evidence for Inclusion</b>
<ul style="list-style-type: none"> <li>▪ Patients, families and carers are well-informed about their illness and treatment options</li> <li>▪ Goals for patient, family and carer are defined and appropriately documented</li> <li>▪ Care providers across all settings are skilled in engaging with patients, families and carers on end of life discussions and setting goals of care</li> <li>▪ Advance care planning is undertaken and documented</li> <li>▪ Advance care plans are regularly reviewed</li> <li>▪ Preferred place of care and death is articulated and documented</li> <li>▪ There is enhanced community awareness, understanding and ability to engage in conversations regarding end of life</li> </ul>	<p>Discussions about end of life issues and planning for care can be difficult for clinicians to initiate. These discussions are multifaceted and take into consideration a range of goals.</p> <p>Research on end of life decision-making has identified six major types of patient goals: to be cured; to live longer; to improve or maintain function / quality of life; to be comfortable; to achieve life goals; and to provide support for family / caregiver (Kaldjian et al, 2008).</p> <p>There is also evidence that advance care planning positively impacts on the quality of end-of-life care. Complex advance care planning interventions involving multiple conversations and planning tools over time may be more effective in meeting patients' preferences than written documents alone (Brinkman-Stoppelenburg et al 2014).</p>

Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ Patients and families have access to care in a setting appropriate to their needs</li> <li>▪ Care providers understand the unique contribution they make to the care of people who may be approaching or reaching the end of life, and are supported to fulfil that potential</li> <li>▪ Care providers have access to the resources and supports required to achieve high quality outcomes.</li> <li>▪ Care providers are supported through the development and dissemination of clinical practice guidelines and pathways</li> <li>▪ Preventable hospital admissions are reduced</li> <li>▪ Specialist palliative care providers are structured and resourced to support other services caring for people approaching and reaching the end of life</li> <li>▪ Skills in caring for people approaching and reaching the end of life are core competencies for all health, aged and community care workers</li> <li>▪ Support and resourcing for the development of new collaboration initiatives</li> <li>▪ Non-beneficial or burdensome care is minimised</li> </ul>	<p>Care providers across all settings can play a key role to improve outcomes and experiences for people approaching the end of life, their families and carers (NSW Ministry of Health, 2012). To do this they need access to appropriate education, development opportunities and to be appropriately resourced. (PCA, 2010).</p> <p>There is now a compendium of resources available to support care for people approaching the end of life across all care settings. The use of these resources should be optimised.</p>

Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ Clinical staff are able to identify those people who may benefit from integrated care as they approach the end of life</li> <li>▪ Standardised screening tools are available and used</li> <li>▪ People have an opportunity through early recognition to benefit from enhanced care models</li> <li>▪ Conversations about goals of care commence earlier to optimise opportunities to align care to those goals.</li> <li>▪ There are earlier opportunities for advance care planning</li> <li>▪ Negotiated goals of care guide service provision to prioritise quality of life for patients, their families and carers</li> <li>▪ Liaisons and partnerships are built with other services to provide multidisciplinary and cross-sectoral care</li> <li>▪ Liaison and coordination with other specialists occur</li> <li>▪ Patients, carers and families are informed and educated about the expected course of the patient's illness and can plan for that</li> <li>▪ Earlier involvement of specialist palliative care services based on assessed need can improve quality of life, potentially improve survival and reduce distress for patients, their carers and families</li> </ul>	<p>Earlier recognition that a person may be approaching the end of their life provides both clinicians and patients and their families opportunities to establish their goals of care and to plan for their changing care demands into their future. This also allows for earlier consideration of approaches to care that focus on improved quality of life. Improved satisfaction with care, quality of life, physical and psychological symptoms and health service utilisation are all documented benefits of this approach to care (El-Jawahri et al, 2011; van der Steen et al, 2014; Temel et al, 2010; Zimmerman et al, 2014).</p> <p>Earlier recognition also increases capacity to improve support to carers and families, especially where the patient's goals of care include remaining at home.</p>



Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ All people receive timely, quality care in the appropriate setting, in accordance with their assessed needs and in consultation with them, their families and carers.</li> <li>▪ Care is delivered in accordance with quality and safety standards</li> <li>▪ All people are assessed using common assessment tools that identify needs particular to their end of life care</li> <li>▪ Cultural, spiritual and other values of patients, their families and carers are respected</li> <li>▪ Partnerships with Aboriginal stakeholders (including Aboriginal Community Controlled Health Services) are fostered to address the health needs and interests of Aboriginal people</li> <li>▪ Patients' pain and/or other physical symptoms will be effectively controlled</li> <li>▪ Psycho-social and spiritual support is available and offered</li> <li>▪ Access to grief and bereavement support is available and offered</li> <li>▪ Patients, families and carers are provided with appropriate equipment to ensure a safe home environment</li> </ul>	<p>Care should be based on the assessed needs of people approaching the end of life, their carers and families, rather than on diagnosis, age or prognosis.</p> <p>Working to address these assessed needs can support people and their families to remain in their preferred place of care for as long as possible.</p> <p>Ensuring that care is provided on the basis of assessed need, rather than diagnosis or prognosis ensures that health and social resources are used efficiently and effectively.</p> <p>Ensuring that all people who are at risk of unmet needs as they approach the end of life receive care in accordance with the use of validated assessment tools improves patient outcomes and experience.</p> <p>The NSW Government Plan to increase access to palliative care 2012 – 2016 (NSW Ministry of Health, 2012) highlights that “Gaps in assessment skills and referral processes often mean that the recognition that a person is dying does not occur until very late in their life, leaving them and their family and carers very little time to come to terms with the approaching death and denying them the time to consider options such as dying at home.”</p> <p>The delivery of needs based care reduces unnecessary burden and distress on both patient and their carers and families</p>

Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ People are able to receive care aligned with their goals as they transition between settings of care (ie hospital, home, aged care)</li> <li>▪ Care is well coordinated and support is provided to patients, carers and families to assist in navigating health and community care systems</li> <li>▪ Care providers across all settings have an understanding of their unique roles and are skilled in providing care to people as they approach and reach the end of their lives</li> <li>▪ Clinical handover of care is optimal and supported by clear communication and clinical tools</li> <li>▪ Changes in care requirements are identified and responded to appropriately</li> <li>▪ Formalised referral and access arrangements support the patient’s transitions of care</li> <li>▪ Clinical information to support seamless care is available at the point of care</li> <li>▪ Transfer of care occurs in consultation with patients, families, carers and care providers across all settings</li> </ul>	<p>As they approach and reach the end of life people, their families and carers are required to navigate increasingly complicated care systems to address their needs.</p> <p>The Diagnostic Report to inform this Blueprint found that current patient journeys are often poorly coordinated. This is particularly true for people with advanced chronic disease who have multiple comorbidities and a much slower and more unpredictable trajectory of functional decline (ACI, 2013). The Report also found that the needs of the patient, family and carer during their end of life journey vary over time and care setting. Services need to be responsive, coordinated and flexible in meeting these changing needs.</p> <p>It has been demonstrated that navigation support and/or care coordination improves clinical outcomes and the experience and satisfaction of patients, families and carers.</p> <p>The ACI Fact of Death Analysis (ACI, 2013) found that in NSW, people who were in their last year of life and were hospitalised between 2011 – 2012 experienced frequent hospitalisations, being admitted on an average of 4 occasions with an average length of stay (ALOS) of 10 days (compared to the overall ALOS in hospital of 4 days).</p> <p>This cohort utilised approximately 984 000 bed days at an estimated cost of over \$900 million. (ACI, 2013). There is evidence that community palliative care teams are effective at reducing acute care use and hospital deaths (Seow et al 2014).</p> <p>Acute care settings, particularly Emergency Departments, cannot always provide the best outcomes or experiences for people approaching the end of life. Emergency Departments can be distressing, and the needs of people approaching</p>

the end of life are often incompatible with the principles of Emergency Medicine (Forrero et al, 2012).

We also know that nationally, 76% of residents of aged care facilities have high care needs (AIHW, 2012) and approximately 24% of residents will require a hospital transfer (AIHW, 2010).

A key action area of the NSW Government Plan to increase access to palliative care 2012 – 2016 (NSW Ministry of Health, 2012) is to drive greater integration across primary, aged, acute care and specialist palliative care services across the state.

Understanding patient journeys and designing care to improve their outcomes and experience ensures that we deliver person centred care.

<b>Intended Beneficial Outcome</b>	<b>Why is this an Essential Component? Evidence for Inclusion</b>
<ul style="list-style-type: none"> <li>▪ All people in NSW have access to services and health professionals that have the necessary skills and expertise to meet their needs</li> <li>▪ A networked approach to care (referral, education, data and research) connects specialist palliative care services with other care providers across all care settings</li> <li>▪ Best available evidence informs clinical practice</li> <li>▪ Care providers across all settings know when and how to access specialist palliative care services</li> <li>▪ Shared care arrangements are fostered between specialist palliative care providers and other care providers across all settings</li> <li>▪ Unplanned hospital admissions are reduced</li> <li>▪ Specialist palliative care services are resourced to provide networked support across the system</li> <li>▪ Ongoing access to specialist palliative care services is based on regular assessment of need and adapts to these accordingly</li> </ul>	<p>Providing strategic links between specialist palliative care services and other care providers across all settings ensures that all people can access the level of care appropriate to their needs.</p> <p>Specialist palliative care services support and complement the care provided across all settings, and are an essential component of a high quality and safe system of care for people who are approaching and reaching the end of their life. These specialist palliative care services provide care for patients with complex or unstable symptoms or meet other high level needs associated with a life-limiting illness (Palliative Care Australia, 2005). Ensuring that all people in NSW have access to this level of care through timely, coordinated and formal relationships and integrated processes is an essential component of any model for service provision.</p> <p>Specialist palliative care services have a role in research and in knowledge generation and dissemination (NSW Health, 2007) and require funding and support to make this contribution to support overall improvement in the quality of service delivery and outcomes.</p>

Intended Beneficial Outcome	Why is this an Essential Component? Evidence for Inclusion
<ul style="list-style-type: none"> <li>▪ Timely recognition of the imminently dying person occurs</li> <li>▪ Quality care in the last days of life is safe, effective, responsive and appropriate</li> <li>▪ Care is provided in the most appropriate environment as close to home as possible in accordance with the needs of patients and in consultation with them, their families and carers</li> <li>▪ Patients, families and carers are provided with information and support</li> <li>▪ Care plans are developed, implemented and reviewed regularly to support people who are imminently dying, their families and carers</li> <li>▪ Preventable transfer of patients who are imminently dying is avoided</li> <li>▪ Patients and care providers across all settings have access to 24-hour-a-day, 7-day-a-week support</li> </ul>	<p>Health care workers should be skilled in recognising the imminently dying patient and responding safely and appropriately to the particular needs of that person, their carers and families. They should also have the skills to explain clearly and sensitively that a person may be imminently dying to that person, their family and carers, in a way that is appropriate to their circumstances.</p> <p>Being unaware that a loved one may be imminently dying can compound the distress and subsequent grief felt by families and carers, after what they may perceive to have been the sudden death of their loved one (LACDP, 2014).</p> <p>Timely recognition that a person may be imminently dying and clear communication of that possibility enables goals of care to be discussed and a plan of care developed, implemented and reviewed so care can be responsive to the changing needs and preferences of the patient, their family and carer.</p> <p>Resourcing should ensure that safe and high quality care can be provided across all care settings and that regular communication between the patient, their family and carers occurs.</p>

<b>Intended Beneficial Outcome</b>	<b>Why is this an Essential Component? Evidence for Inclusion</b>
<ul style="list-style-type: none"> <li>▪ Grief and bereavement support is available</li> <li>▪ Family members, carers and significant others are supported as they grieve</li> <li>▪ Care providers across all settings are supported and resourced to support carers and families through their loss and grief</li> <li>▪ Bereavement services are recognised as an essential component of care to family and carers</li> <li>▪ Bereavement services are resourced and are a routine part of palliative and end of life care</li> <li>▪ There are models and guidelines to support best practice in bereavement services including bereavement risk assessments</li> </ul>	<p>Grief is a normal and inevitable response to loss, and can affect every part of a person’s life (ACGB, 2014). Grief and bereavement support encompasses the “entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one” (Christ et al, 2003).</p> <p>To deliver the highest standard of care there is a requirement to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.</p>

<b>Intended Beneficial Outcome</b>	<b>Why is this an Essential Component? Evidence for Inclusion</b>
<ul style="list-style-type: none"> <li>▪ Access to and use of high quality patient-level data informs efforts to improve patient experiences and outcomes</li> <li>▪ Access to and use of high quality service-level data informs efforts to improve care coordination and integration</li> <li>▪ Access to and use of high quality system-level data informs efforts to improve funding models, planning and policy development</li> <li>▪ Medical records are electronically integrated and available across all care settings at point of care throughout NSW</li> <li>▪ Clinical information is available at the point of care in all care settings</li> <li>▪ Access to and use of high quality data supports effective benchmarking and service evaluation</li> <li>▪ Access to and use of high quality data enhances quality improvement outcomes and research</li> </ul>	<p>Access to and use of high quality, timely and transferrable data can contribute to improved patient experiences and outcomes.</p> <p>A key objective of this Blueprint is to enable patients, families and carers to have seamless journeys through the often complicated care systems required to meet their needs.</p> <p>“Collecting and analysing data are central to the function of quality improvement in any health service” (Victorian Quality Council, 2008). Healthcare data collected using standardised assessment tools and compared with benchmarks can have impacts not only on decisions about the care of individual patients, but also on outcomes at a population level.</p> <p>Quality improvement initiatives at a service or jurisdiction level depend on understanding and utilising reliable data to solve “the right problem in the right way...Data not only enables us to accurately identify problems, it also assists to prioritise quality improvement initiatives and enables objective assessment of whether change and improvement have indeed occurred” (ibid).</p>

# Enablers

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The following enablers are forces or environmental factors that contribute to successfully using this Blueprint.

## **Terminology used within the Blueprint is clearly articulated and understood**

- In order to achieve a shared understanding of terms, we all need to be diligent about defining the way we are using the words and avoid using euphemisms.

## **There is local ownership and engagement**

- This Blueprint is designed to be used as a resource for local development and implementation. This requires localised leadership and participation in the development of services.

## **Local needs and assets are recognised**

- There is no single model of care for people approaching and reaching the end of their lives. Planning arrangements need to take advantage of local needs as well as assets within the community. Building on the skills of local residents, organisations and networks can lead to stronger and more sustainable program.

## **Collaborative governance arrangements are fostered**

- Providing care to people approaching and reaching the end of their lives across all care settings firstly requires a commitment to work better together. It requires a mix of stakeholders (often extending beyond health services) to take a shared responsibility in developing an integrated system of care.

## **There is access to specialist palliative care knowledge and expertise**

- Specialist palliative care services are an essential component of a high quality and safe system of care for people who are approaching and reaching the end of their life. These services can be leveraged on to guide, build capacity and drive integration within local communities.

## **There is access to education, practice training and ongoing professional development**

- Education on the provision of care to people as they approach and reach the end of their lives is essential for all health professionals. This includes:
  - Undergraduate and post graduate students;
  - New health professionals;
  - Medical specialists in other fields;
  - Primary care providers; and
  - Specialist palliative care providers.

## **Re-engagement of health professionals across all care settings occurs**

- All health professionals need to better understand the essential and unique contributions they can make. Providing care to people approaching and reaching the end of their life, their families and carers is everybody's business.



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