

GUIDE

Palliative Care Network

Planning and Organising End of Life Care

A Guide for Clinical Model Development



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Purpose

The purpose of this document is to provide guidance and direction for clinicians and service planners to plan and organise end of life care locally. It suggests a range of actions, tools and considerations primarily targeting non-specialist palliative care providers, such as those working in aged care, oncology, surgical care or in the management of chronic and complex illnesses.

All health professionals should be competent in providing care to people who are approaching and reaching the end of their life, their families and carers. Safe and effective quality care at the end of life is a continuation of quality care for any population of patients.

Specialist palliative care services are sometimes necessary to support and complement the care provided across all care settings. These specialist services provide care for patients with complex or unstable symptoms or meet other high level needs associated with a life-limiting illness. Figure 1 illustrates needs-based referral or shared-care arrangements based on the patient, family or carer’s assessment of complexity of need.

This document guides both early and late interventions to improve the quality of care during this most vulnerable stage of their journey.

Based on the ten Essential Components of Care within the Palliative and End of Life Care Blueprint for Improvement (‘The Blueprint’), this guide supports services to apply the Blueprint for planning and for organising end of life care locally.

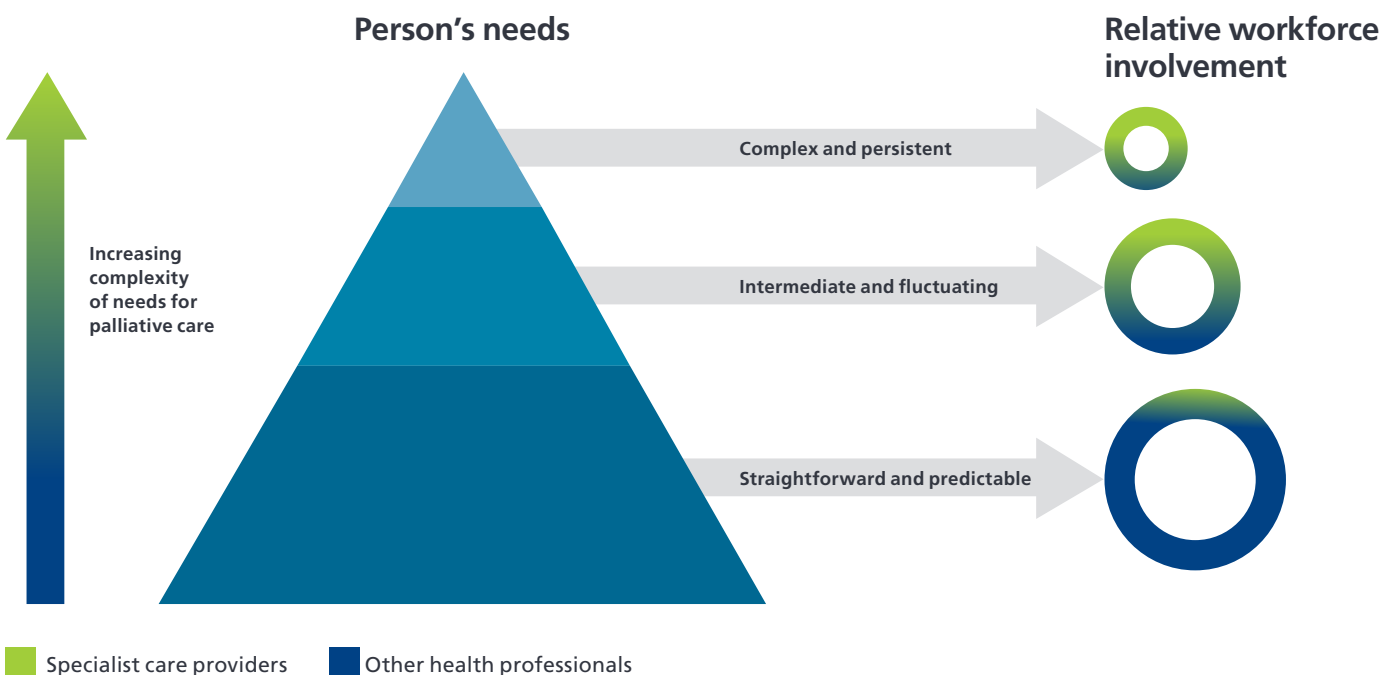
These essential components of care should be present in any service committed to the delivery of high quality, patient and family focussed care for those approaching the end of life.

The provision of end of life care must be seen as an integral component of care planning rather than something separate or additional. Integration of actions to meet needs as people approach and reach the end of life must be incorporated along the patient journey.

Vision

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

Figure 1: Alignment of need for specialist palliative care against workforce capability



Source: Adapted from Palliative Care Australia, Palliative Care Service Development Guidelines, January 2018

How to use this guide

- 1** The following sections provide extracts from the Blueprint that are particularly relevant to the development of clinical models of care and some suggested actions linked to the ten essential components that could be incorporated into the model of care to ensure that end of life care needs are addressed.
- 2** Teams developing models of care should review the suggested actions and consider how they may be customised to the specific patient population or need.
- 3** Integration of end of life care into the model of care should be seamless and consistent with the appropriate points along the patient journey.
- 4** Consider using the [Where are we at? checklist](#) to help discuss and identify local strategies to achieve the 10 Essential Components of Care. Ideally, this check list can be used as a group planning tool with a mix of stakeholders.

Background

The Blueprint is a flexible guide for health services and Local Health Districts to construct their own localised models of care for the delivery of palliative and end of life care.

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

The Blueprint is informed by research-based evidence and consultations with more than 1200 clinicians, service managers, researchers, consumers, their families and carers. Detailed findings of this process can be found in the Diagnostic Report to Inform the Model for Palliative and End of Life Care Service Provision (ACI, 2014).

Key learnings

There were [12 Key Learnings](#) that helped shape the Blueprint. Some of them related to the need for system level realignment to meet the needs of people approaching and reaching the end of their life and others recognised existing barriers and constraints to the delivery of high quality care. The three key learnings in the box are particularly relevant to inform the inclusion of end of life actions into any model of care.

Key learning 1

People's needs change

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.

Key learning 4

Many people fall through the gaps

Care to people approaching and reaching the end of life is often fragmented and under-utilised by identified population groups or clinical cohorts.

These include but are not limited to:

- Aboriginal people
- people of culturally and linguistically diverse backgrounds
- people under the age of 65
- people with non-cancer diagnosis such as motor neurone disease
- people who live alone
- people living with dementia.

Key learning 5

Not every patient journey is the same

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.

Principles

There are six principles that provide the foundation for the Blueprint's essential components.

Principle 1 Care is patient, carer and family centred.

Principle 2 Care is provided on the basis of need.

Principle 3 Patients, carers and families have access to local and networked services to meet their needs.

Principle 4 Care is evidence based, safe and effective.

Principle 5 Care is integrated and coordinated.

Principle 6 Care is equitable.

Key messages

- Safe and effective quality care at the end of life is a continuation of quality clinical care for any population of patients.
- Everyone has a role to play in providing care to people as they approach and reach the end of life, their family and carers.
- Discussions about end of life issues and planning for care can be difficult, but are necessary to ensure person-centred care.
- Early recognition that a person may be approaching and reaching the end of their life provides clinicians, patients and their families the opportunity to establish their goals of care and to plan for their changing care demands into their future.
- Specialist palliative care services are sometimes necessary to support and complement the care provided across all care settings. Access should be based on assessed need.
- Care providers across all settings should know when and how to access specialist palliative care services. This can often require the development of documented shared care arrangements.

Incorporating actions to improve end of life care in a Model of Care

Below are some suggested actions aligned to the [Blueprint's Essential Components](#) that may be appropriate to the development or modification of a model of care. Each action would need to be reviewed in the context of the particular patient population and their needs. The following information should be used as a starting point for discussion, modification, and integration.

Essential components

1. Informing community expectations and perceptions on death and dying

- Ensure that all patient education material relevant to the patient population for your model of care includes information about end of life. This may include information about access to care, information to assist advance care planning and information on raising issues of concern with the care team.
- Identify and incorporate opportunities to raise awareness of advance care planning and other elements of end of life care.

When facing the end of life, we are naturally scared. Our problem is that too many of our decisions are based on this fear, or on a lack of information or misinformation, which often results in devastating physical, emotional and financial consequences for the patient and family alike.

– Tani Bahti, RN, CT CHPN

2. Discussions about palliative and end of life care and planning for future goals and needs

- It is suggested that discussions about palliative and end of life care occur early – for example, as people enter into the last year or so of their life.
- Consider the incorporation of specific tools to support health professionals in the early identification of patients nearing the end of life (for example SPICT, Surprise Question, AMBER). These tools can be found on the ACI Blueprint website.
- Incorporate specific actions to ensure that goals are defined, appropriately documented and reviewed.

It starts with the day they come in. Firstly, opening up the conversation even though it's a difficult time ... the conversation has to start straight away. We talk about their life, their stories, their history ... which are then coordinated into our care plans.

– Registered Nurse, Rural Residential Aged Care Facility

3. Access to care providers across all settings who are skilled and competent in caring for people requiring palliative and end of life care

- Include in workforce development initiatives/strategies, specific actions to improve end of life care practices – specifically assessment and care planning, symptom management, provision of psychological and family support, loss and grief.
- Introduce review of end of life into mortality review processes, incorporate care of the dying audits in evaluation components of the model.
- Incorporate referral pathways and triggers into the model of care that are based on assessment of need and that identify patients who may benefit from access to specialist palliative care services.
- Incorporate referral criteria, processes and requirements for ensuring access to care, including out-of-hours medical care.

We need to be alongside people. Not coming in and consulting and going away – but doing things with them. Do clinics with them, show them what it means to have difficult conversations, demonstrate that it's everyone's business – increasing the standard across the system.

– Metropolitan Specialist Palliative Care Service

4. There is early recognition that a person may be approaching the end of life (i.e. last year of life)

- Consider the incorporation of specific tools to support health professionals in the early identification of patients nearing the end of life (for example SPICT, Surprise Question, AMBER). These tools can be found on the ACI Blueprint website.
- Incorporate specific actions to progress and expand the uptake of advance care planning and other necessary documentation (for example, wills and medical enduring power of attorney) at points in the care journey that are relevant and sensitive to the needs of the population.
- Medications are reviewed to ensure appropriate to end of life goals – non-essential medications are ceased.

If we can give them a heads-up warning that they might be approaching the last 12 months of their life, that then gives them and their carers the opportunity to make the sorts of plans to reset their goals that they may not otherwise think about.

– General Practitioner

5. Care is based on assessed needs of the patient, carer and family

Review and incorporate as appropriate specific assessments that focus on needs known to commonly occur as people approach and reach the end of life. Needs may include equipment to ensure care and a safe home environment; care that is delivered in accordance with their cultural, spiritual and other values; management of pain and other symptoms, including psychosocial needs; and assistance in grief and bereavement.

- For Aboriginal patients, carers and families consider partnerships with Aboriginal Community Controlled Health Services and Aboriginal Health Workers.
- Incorporate actions that maximise opportunities for patient choice through early identification and documentation of care goals, regular and routine review of the goals of care and modification in accordance with patient and family wishes.
- Identify the need for support for families and carers and incorporate specific actions to address their discrete needs.
- Information is provided on financial and other benefits to support patient and carers.

Patients' needs can change every time that you see them and same with family needs, so everytime we meet with the patient we'll do an assessment – whether it be in the hospital or the community or an aged care facility.

– Specialist Palliative Care Nurse

6. Seamless transitions across all care settings

- Clear communication and clinical tools are agreed to support optimal, safe clinical handover. Consider the use of multi-disciplinary case conferences.
- Formalise referral and patient file access arrangements (including transfer of care planning).
- Involve patients, carers and families in decisions regarding transfer and referral.

Discharge planning is so important. It should start when people walk through the door of the hospital.

– Metropolitan Specialist Palliative Care Service

7. Access to specialist palliative care when needs are complex

- Care providers across all settings should be able to identify local specialist palliative care providers and know when and how to access them.
- Consider what mechanisms should be in place to support shared care arrangements with specialist palliative care providers.

They got me the bed, walker, shower stool and oxygen – things I wouldn't have been able to arrange myself. Without the specialist palliative care service I don't know how you'd get all this.

– Consumer

8. Quality care during the last days of life

To ensure that quality care in the last days of life is safe, effective, responsive and appropriate, the model of care should have mechanisms to ensure that:

- 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
- there is information and support for patients, carers and family members
- care plans continue to be implemented and reviewed
- preventable transfers of patients who are imminently dying are avoided
- tools and resources within the [Clinical Excellence Commission Last Days of Life Toolkit](#) are considered
- NSW Ambulance Authorised Palliative Care Plans are in place to support paramedic decision making.

In the last week they put the catheter in so I could administer his medications. They wrote down all the details and I added notes to help me. It was very important they could lay that out for me – because when you're in shock, you're going on raw feelings.

– Carer

9. Supporting people through loss and grief

- Identify bereavement services appropriate to the patient population needs.
- Establish formal processes to refer carers and family members who may need or seek support.
- Ensure that appropriate information and resources are available to carers and family members about grief and bereavement support.

Bereavement counselling closes the loop for family members.

– Intensivist

10. Quality care is supported through access to reliable, timely clinical information and data

Ensure that data and information systems capture data elements related to end of life care, including:

- patient outcomes
- carer and family experiences
- care coordination and integration.

Having access to an electronic medical record for patients when they are going between one care setting and another, improves care. It improves communication...

– Specialist Palliative Care Nurse