

# Palliative care model of care

A local initiative of the Justice Health and Forensic Mental Health  
Network

May 2023

END OF LIFE AND PALLIATIVE CARE NETWORK

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<b>Title</b>	Local initiative: Palliative care model of care, Justice Health and Forensic Mental Health Network		
<b>Published</b>	May 2023		
<b>Next review</b>	2028		
<b>Produced by</b>	End of Life and Palliative Care Network		
<b>Preferred citation</b>	NSW Agency for Clinical Innovation. NSW Palliative Care Model of Care. Sydney: ACI; 2023.		
TRIM ACI/D23/1187	SHPN (ACI) 230188	ISBN 978-1-76023-459-1	ACI_7430

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# Justice Health and Forensic Mental Health Network

## Introduction

The Justice Health and Forensic Mental Health Network (Justice Health) is part of NSW Health and provides healthcare to adults and young people in contact with the criminal justice and forensic mental health systems in NSW. Each year, Justice Health staff care for more than 30,000 patients in correctional centres, youth justice centres, courts, police cells, inpatient settings and in the community. Twenty-five percent of patients identify as Aboriginal, which is a significant overrepresentation compared with 3.4% in the wider NSW community. Justice Health:

- provides multidisciplinary health services to patients, including primary care, drug and alcohol, mental health, population health, women's and midwifery care, oral health, Aboriginal health, youth health, and a range of allied health services
- forms a vital component of the NSW public health system through its support of a highly vulnerable patient population whose health needs are often numerous and more complex than those of the wider community
- is positioned with a unique opportunity to respond to the health needs of these individuals who commonly have had minimal contact with mainstream health services in the community.

## Palliative care model at Justice Health

### Overview

Justice Health provides palliative and end of life care to patients. In 2019, the Ministry of Health provided palliative care flexible funding to Justice Health to review and analyse palliative care. Following this, Justice Health established palliative care specific roles, evidence-based best practice guidelines and a sustainable model of care for palliative care and end of life care provision to patients in correctional settings. These guidelines and model of care are available on Justice Health's intranet site.

The clinical lead of Justice Health's palliative care service is the Clinical Director of Primary Care.

The palliative care service is made up of:

- nurse practitioner (1.0 FTE)
- Aboriginal health worker (1.0 FTE)
- occupational therapist (0.6 FTE)
- social worker (0.4 FTE)
- visiting medical officer (VMO) from Prince of Wales Hospital (0.1 FTE).

## Settings of care

- Justice Health's palliative care service provides support to patients referred from facilities throughout NSW. Justice Health provides inpatient end of life care in two settings: Long Bay Hospital, which is situated in the Long Bay Correctional Complex, and through transfer of care to another NSW Health inpatient setting. Patient preference and staff capacity to provide safe and comfortable care are considered when deciding the appropriate setting.
- Escalation and after hours arrangements are in place; these vary depending on the location of the patient.

## Referrals

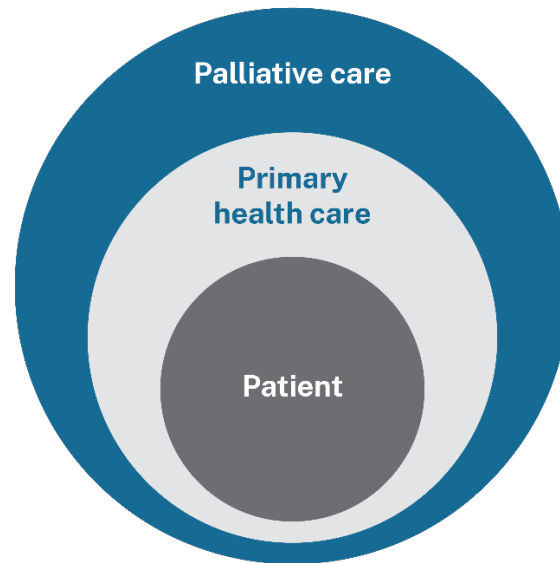
To be referred to the palliative care service, patients must have a life-limiting illness and require specialist support. Patients are generally referred for the following reasons:

- palliative symptom management (e.g. pain, shortness of breath, nausea, vomiting, fatigue, anxiety or crisis)
- recent clinical deterioration
- recent functional decline
- known to a palliative care service external to Justice Health
- end of life care
- complex advance care planning support
- staff wanting palliative care guidance for a patient
- meets [SPICT identifiers](#).

Referrals to the multidisciplinary team are made through the PAS (Patient Administration System). This referral should be accompanied by a phone call or email to the palliative care service. Palliative care is not provided to patients who do not have a diagnosed life-limiting illness and/or do not have unmet care needs.

## Services

The palliative care model of care is delivered collaboratively by Justice Health to ensure care is holistic and person-centred to meet the physical, emotional, social, cultural and spiritual needs of the patients. The model of care is a standard approach for clinical safety of patients, and variances should be documented.



Primary healthcare is at the core of palliative care and is provided by nurses and general practitioners (GPs). Justice Health directly employs a primary healthcare team, including full-time and part-time GPs who cover the 50 Justice Health health centres/clinics in correctional facilities across NSW. Patients who need a primary health appointment first see the primary health nurse, who escalates to the GP as required. A palliative care VMO or staff specialist is also on staff one day per fortnight at the Long Bay Correctional Complex, with additional phone support available, if required.

Justice Health is committed to providing appropriate patient-centred care. This is facilitated through a staged primary health assessment process that commences with a reception screening assessment (RSA). The RSA usually occurs when the patient arrives at a reception centre upon entry into custody. In the Long Bay Hospital inpatient setting, all patients must receive a comprehensive medical assessment within 24 hours of admission and all patients should have a comprehensive assessment by the hospital multidisciplinary team within 48 hours of admission, wherever possible, depending on the availability of relevant staff. This is in accordance with Network Policy 1.037 Long Bay Hospital Admission Policy (Referral, Admission and Assessment).

Through the primary health assessment, patients can be referred and escalated to the palliative care service. Further assessments are undertaken in a planned and coordinated manner based on assessed need, with follow-up appointments arranged for those patients who are identified as at risk of developing or currently diagnosed with an acute or chronic condition. Additional primary health assessments should also be considered and initiated before referral to the palliative care service based upon each patient's individual needs. These assessments may include:

- Falls Risk Assessment and Management Plan (FRAMP)
- Pain Management Plan
- Pressure injury risk screening and assessment.

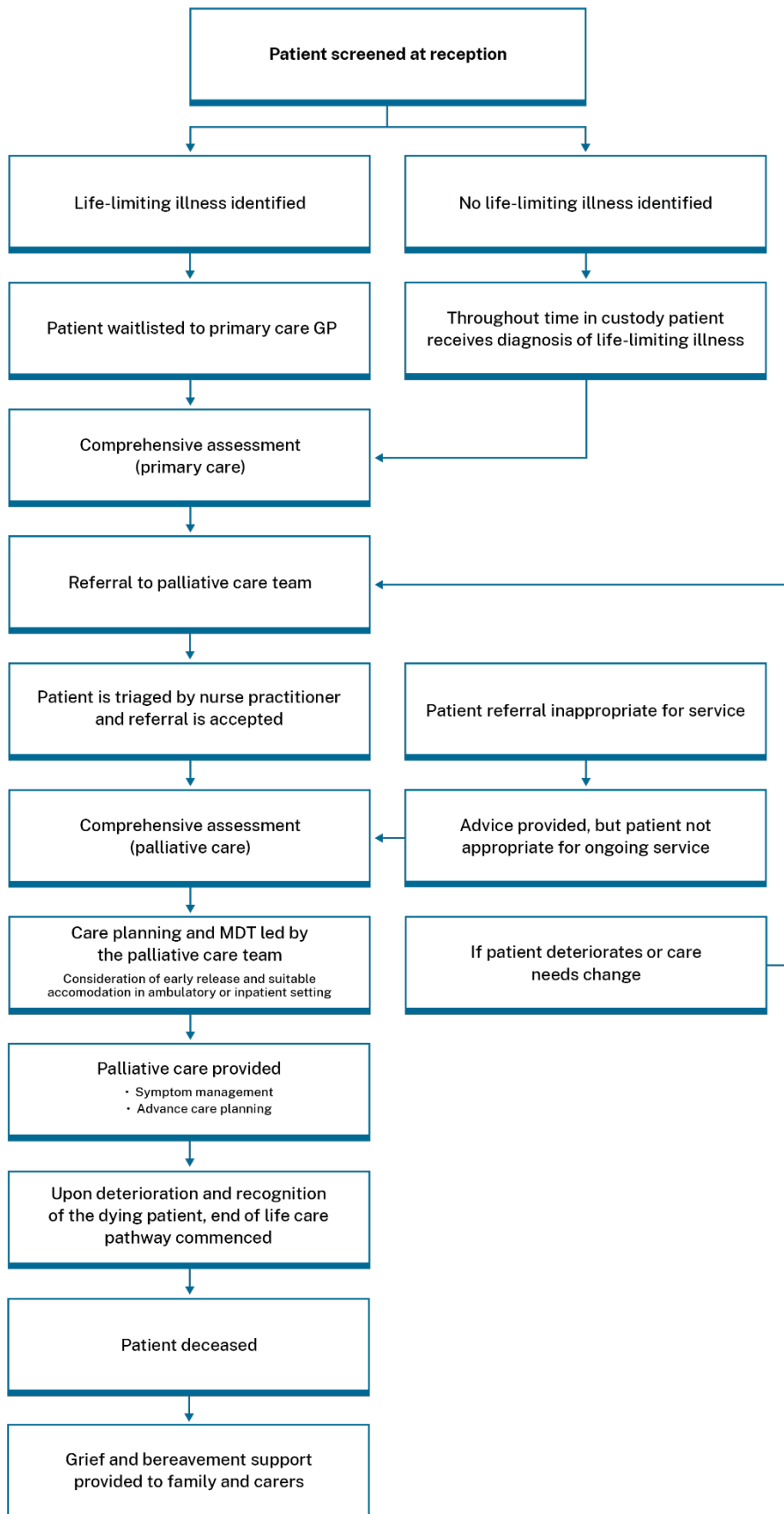
All assessments are completed by Justice Health's multidisciplinary team.

## Referral to palliative care

- Once a patient has been referred to Justice Health's palliative care service, a comprehensive assessment is conducted.
- The multidisciplinary team reviews all information from primary health assessments and holistically assess each patient to identify their individual needs. This can vary widely, dependent on illness and goals of care.
- An initial palliative care assessment is undertaken, capturing the following:
  - Essential assessments – all palliative patients:
    - Palliative Care Nurse Practitioner Assessment
    - Psychosocial Assessment Tool
    - Aboriginal Health Considerations Tool (for Aboriginal and Torres Strait Islander patients)
  - Additional assessments – based on clinical need of palliative patients:
    - PCOC Symptom Assessment Scale ([SAS](#))
    - Australia-modified Karnofsky Performance Status ([AKPS](#)) Scale
    - PCOC Palliative Care [Phases](#)
    - [Barthel](#) ADL Index
    - Waterlow Pressure Ulcer [Prevention/Treatment](#) Policy.
- Use of additional palliative care assessment tools will vary based on the clinical judgement of what is appropriate and relevant for each patient. These may be used to support ongoing needs of patients. Not all tools are required for all patients.
- To ensure culturally appropriate and responsive care for Aboriginal patients, the Palliative Care Aboriginal Health Worker can work with the patient, family and/or carers to inform the palliative care team, and internal and external care providers about the patient's specific needs.
- The team uses the palliative care patient summary sheet to support palliative care provision. Review of the patient and summary sheet is triggered through initial assessment, review at the multidisciplinary team meeting, movement or deterioration and progression to comfort care.

Figure 1 illustrates the Justice Health Palliative Care Referral Clinical Pathway.

**Figure 1: Justice Health Palliative Care Referral Clinical Pathway**





## Benefits of the model

### Primary health model of care

Justice Health patients receive care via a primary health model. Benefits of primary health as the foundation of the Justice Health palliative care model of care include:

- The focus of care is person-centred
- Care takes a multidisciplinary approach
- There is increased collaboration with external care providers
- Specialist palliative care support is provided, which is not dependent on a particular care setting
- Advance care planning is facilitated by the specialist palliative care team, which ensures patient involvement is decision-making.

In addition, patients may receive care from other Justice Health clinicians and specialties, including:

- dietitian
- speech pathologist
- physiotherapist
- cancer care nurse
- Integrated Care Service (ICS)
- drug and alcohol, population health and custodial mental health teams.

The palliative care service works closely with external care providers, including:

- Palliative Care Staff Specialist (Prince of Wales Hospital Visiting Medical Officer to Long Bay Hospital)
- Corrective Services NSW (CSNSW) services and programs officers
- CSNSW Chaplaincy Services.

Care provision is based on each patient's individual needs. Goals of patient care vary but can include comfort measures, wishes not to be moved between correctional centres or to a tertiary hospital, and support for early release.

Practical support is provided with supporting next of kin navigate Corrective Services visitation processes, and getting access to appropriate equipment for comfort and mobility support. After the patient has died, and where visitation is not possible, Justice Health team can arrange video calls with next of kin and family member to provide follow-up bereavement care.

## Patient and carer experience

Patients and their family members provided feedback throughout the project's consultation, diagnostic and evaluation phases. The project officer developing the new palliative care model of care invited six patients or bereaved family members who were interested in sharing their experience participate in the creation of the model of care by providing feedback on what interventions helped and when.

Some common themes that emerged from the interviews:

- A resounding agreement that being diagnosed or having a loved one diagnosed with a life-limiting illness in prison is very isolating
- Patients feel supported by the care provided by Justice Health and empowered by having some control over their care planning decisions
- Family members are grateful to have a consistent, centralised contact point in the palliative care service from which to seek information and guidance as they navigate challenging health and corrective processes.

## Staff experience

While provision of palliative care to patients in their care is not new for Justice Health Network, the establishment of a specific palliative care team provides additional support to all Justice Health staff in delivering high-quality, patient-centred care. The creation of the palliative care model of care, supporting clinical tools, referral pathways and service information further equips, supports and guides staff to understand and deliver palliative care within Justice Health.

Staff can find information on Justice Health intranet page and are also encouraged to contact the palliative care team with any queries or to discuss a patient of concern.

## Next steps

The palliative care model of care has followed clinical redesign methodology and is working towards sustainability. Further evaluation is being resourced to support the ongoing quality improvement of the model. Changes will be evaluated 12 months post implementation to ensure compliance, improved palliative care provision and patient outcomes, while also regularly reviewing the evidence base for currency. Justice Health is a partner of the National Palliative Care in Prisons Project and will continue its support and participation to build an evidence-based gold standard framework for palliative care service provision in correctional settings.

## Appendix

### Alignment of the Palliative Care Model of Care with the [Clinical Principles for End of Life and Palliative Care Guideline](#)

Key action area		Evidence of alignment
1. Screening and identification	✓	Use of SPICT tool
2. Triage	✓	Reception Screening Assessment on intake to the service
3. Comprehensive assessment	✓	A staged primary health assessment by the specialist team across multiple appointments
4. Care planning	✓	A comprehensive care plan is developed and documented on the patient's health record
5. Open and respectful communication	✓	Coordinated care via a primary health model A consistent, centralised contact point for family and carers to seek information and support
6. Symptom management	✓	Comprehensive care plan is regularly reviewed and any palliative symptoms are monitored and addressed by the specialist team (including a Staff Specialist and Nurse Practitioner) as required
7. 24/7 Access to support	✓	Strong partnerships with local health districts (LHDs) ensure equitable access to after-hours services for <a href="#">Justice Health</a> patients. <a href="#">Justice Health</a> links with LHDs as required, based on the patient's care needs or preferences, with a variety of localised processes. While there are service level agreements in place between individual health centres and LHDs, these are for all health issues, not just specific to palliative care
8. Place of death	✓	Patient preference is considered and a transfer of care to a NSW Health inpatient or Long Bay Hospital is facilitated, if possible. There are some procedures that cannot be managed at Long Bay Hospital, including intubation and setting up a syringe driver (for security reasons). If the patient requires these procedures, they will be moved to a tertiary hospital nearby. The nurse unit manager of their health centre will escalate the need for additional support and coordinate the patient's care with the LHD and specialist palliative care team.  <a href="#">Justice Health</a> support patients to die as close to home (and country) as possible. If a patient is released from custody, release planning and transfer of care is undertaken in partnership with LHDs and Corrective Services NSW.

		In the last 5 years, an average of 11.6 patients a year have had an expected (i.e. not sudden) death in custody.
<b>9. Grief and bereavement support</b>	✓	<b>Justice Health</b> provides follow-up bereavement care to next of kin and family members via the palliative care team's social worker and transitional nurse practitioner. Generally, bereavement follow-up is provided via phone for six to eight weeks. If ongoing support is required, the palliative care team will facilitate access and refer for additional community supports.

## Acknowledgements

Josie Cullen, Project Officer Palliative Care, Clinical Improvement Unit

Shaun Connolly, Nurse Manager Operations, Access and Demand Management

Paul Grimmond, Network Director, Nursing and Midwifery Services

Dr Joanne Grimsdale, Deputy Clinical Director, Primary Care

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