

# LAST DAYS OF LIFE TOOLKIT

## PRACTICE GUIDELINE<sup>®</sup>

### DOCUMENT SUMMARY/KEY POINTS

- The Last Days of Life Toolkit: Paediatric & Neonatal (LDOL: P&N) provides best practice guidance to clinicians who may or are caring for a dying child or neonate in the last days of their life
- The guideline may not encompass all the complexities relevant to end of life in the neonatal or paediatric intensive care setting in SCHN. Variation from the guideline for individual practice may be considered by Admitting Medical Officer in neonatal or paediatric intensive care.
- The Toolkit promotes a standardised, equitable, and safe approach to end of life care. This standardised approach enables care to be individualised to the needs of the child so that a high level of care regardless of the clinician's experience, the patient's location, ethnicity, religion, or social status.
- The LDOL: P&N is specific to care of the dying child/neonate and their family when cared for in an acute care setting (hospital or hospice).
- Documents developed for the *Toolkit* include:
  - [LDOL: P&N Compass](#)
  - [Initiating the LDOL P&N](#),
  - [Anticipatory Prescribing Guide](#),
  - [Pain Medication Guidance Document](#) ,
  - [Breathlessness Medication Guidance Document](#)
  - [Nausea and Vomiting Medication Guidance Document](#)
  - [Comfort Observation and Symptom Assessment Chart \(COSA: P&N\)](#)
  - [LDOL: P&N Guidance document](#)
  - Thirteen [Information Sheets](#) are available to support communication.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> December 2022	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Clinical Nurse Consultant	<b>Area/Dept:</b> Paediatric Palliative Care

- SCHN staff should consider completing the *LDOL: P&N* HETI Module prior to using the Toolkit
- Specialist Paediatric Palliative Care Services are available to support in the care of a dying patient and the use of the LDOL: P&N Toolkit.

**This Clinical Guideline does not replace local existing policies or guidelines but should be used as an additional resource.**

## CHANGE SUMMARY

- N/A – New document

## READ ACKNOWLEDGEMENT

- SCHN Specialist Paediatric Palliative Care (SPPC) staff
- All SCHN clinical staff who are involved in providing end of life care to patients in the acute care setting

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## Definitions

The following definitions will be used for this document.

**Carer** - A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged<sup>2</sup>

**Paediatric or Child** - a person greater than 4 weeks up to 18 years

**Clinician** - A healthcare provider, trained as a health professional. Clinicians include registered and nonregistered practitioners, or members of a team of health professionals providing health care who spend the majority of their time providing direct clinical care<sup>3</sup>.

**Dying** - The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as 'actively dying'<sup>1</sup>

**Family** - Those who are closest to the patient in knowledge, care and affection. This may include parents, siblings, grandparents, aunts, uncles, cousins and friends. May also include 'carers'<sup>4</sup>.

**Goals of care** - The aims for a child's medical treatment, as agreed between the child, their parents, family and the healthcare team. Goals of care will change over time, particularly as the child enters the terminal phase. Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying child. The child's goals of care may also include non-medical goals – for example, returning home or reaching a particular milestone, such as participating in a family event<sup>1</sup>.

**Last days of life** - hours or days before death, often referred to as imminently dying

**Neonate** - baby four weeks corrected or under

**Parent/s** - The person or persons identified by law as having parental responsibility for the child<sup>1</sup>.

**Patient** - The primary recipient of care<sup>1</sup>

**Resuscitation orders/plans** - A Resuscitation/Allow a Natural Death Plan is a medically authorised order to use or withhold resuscitation measures. It also documents other aspects of treatment relevant at end of life<sup>1</sup>.

**Specialist Paediatric Palliative Care Service (SPPC)** - Level 3 tertiary services specialising in paediatric palliative care <sup>1</sup>

**Terminal phase** - The hours, days or, occasionally, weeks, when a patient's death is imminent. This is sometimes referred to as the period when a patient is actively dying<sup>1</sup>.

## Abbreviations

AH	After Hours
AMO	Admitting Medical Officer
BH	Business Hours
LDOL	Last Days of Life
LDOL:P&N	Last Days of Life: Paediatric & Neonatal
MDT	Multidisciplinary Team
NSW PPC AH Medical On-Call	NSW Paediatric Palliative Care After Hours Medical On-Call
PPC	Paediatric Palliative Care
SCHN	Sydney Children's Hospitals Network
SPPC	Specialist Paediatric Palliative Care
Toolkit	Last Days of Life: Paediatric & Neonatal Toolkit

## Supporting High Level Policy and Guideline Documents

**This Clinical Guideline does not replace existing policies but should be used as an additional resource.**

Other considerations relating to end of life care;

- [NSW Health End of Life and Palliative Care Framework 2019-24](#)
- [National Consensus Statement: Essential Elements for Safe and High Quality Paediatric End of Life Care](#)
- End of Life & Palliative Care <https://aci.health.nsw.gov.au/palliative-care-blueprint>
  - SCHN [Palliative Care for Inpatients](#)
  - SCHN [Death of a Child Policy](#)

Acknowledgement in the development of this guideline to: End of Life Care for Neonates Clinical Guideline - HNEkidshealth

## Introduction

The death rate of children in Australia has been decreasing over the years<sup>5</sup>. Of those children who die, most will die in hospitals<sup>6</sup>. The consequence of fewer deaths is a lack of expertise and comfort in caring for a child in the terminal phase of life<sup>7,8</sup>. Many clinicians feel ill equipped to recognise dying, the death process, symptom management and post-death care<sup>9</sup>. A standardised approach to care enables a child to receive a high standard of care regardless of clinician experience or care location. For clinicians experienced in end-of-life care, a standardised approach confirms and provides reassurance that nothing has been missed. This guideline will aid clinicians to use the Last Days of Life: Paediatric and Neonatal (LDOL: P&N) Toolkit when caring for a dying child or neonate in the last hours to days of life when cared for in an acute care facility or hospice within the Sydney Children's Hospitals Network (SCHN).

This guideline does not replace local policies but should consider circumstances, culture and practices<sup>10</sup>.

## Recognising Dying and Focus on Comfort Care

The decision to focus on comfort care and not the maintenance of life can occur over a period of time, after an unexpected clinical deterioration or as a part of a planned redirection of care. Prognostication can be difficult with a child or neonate but recognising when a patient is approaching the end-of-life is essential to delivering appropriate, compassionate, and timely end-of-life care<sup>1</sup>.

Signs and symptoms commonly seen in a paediatric or neonatal patient when actively dying are documented in the LDOL: P&N Guidance document. However, the trajectory of death is sometimes difficult to predict. For example, some children will have an underlying condition that mimics many signs displayed by a dying patient well before death is imminent. Conversely, death may occur quickly after a decision has been made to de-escalate active intervention to maintain life, omitting any of the symptoms and signs of death.

## Document 1: Initiating the Last Days of Life: Paediatric & Neonatal Management Plan

### Section A: Commencement of the LDOL: P&N Management Plan

#### Mandatory criteria

The mandatory criteria in the Toolkit enable clinicians to identify a patient who will benefit from a comfort care approach. The patient must be comprehensively assessed to be dying, with death expected within days to meet the Toolkit criteria. Prior to commencing the Toolkit, the most senior medical officer or nurse must sign and date that the LDOL: P&N mandatory criteria has been satisfied.

- **Criteria 1, 2 & 3:** The Admitting Medical Officer (AMO) and/or ICU Staff Specialist has assessed and agreed that the patient is in the last days of life and the focus of patient's care will be comfort.
- **Criteria 4 & 5:** Communication and End of Life Planning

- Communication between patients/parents/carers and clinicians is vital across the span of a child's terminal stage of care, especially when dying is recognised and the patient is believed to be in the last days of life. A family meeting is recommended to ensure the family understands that death is likely within days thereby allowing a chance to ask questions, and the clinicians can explore what is important to the family<sup>4</sup>. Depending on the needs and wishes of the child and parent/carer, other key people in their life may be involved in these discussions. Planning should ensure the child's best interests are at the centre of all decisions. Developing trust and a respectful partnership between the family and treating team is integral in providing quality end of life care<sup>10</sup>.

- **Criteria 6: Medical Goals of Care and Decision Making**

The LDOL: P&N Toolkit focuses on care aimed at comfort and not for care aimed at prolonging life. A resuscitation plan or similar must be documented prior to commencement of the Toolkit. See criteria & refer SCHN Electronic Resuscitation Plan & Advanced Care Planning Policy (in draft).

*For support around goals of care discussion and decision making contact SCHN PPC services (SCH or CHW) within Business Hours (BH) or if After Hours (AH), the NSW PPC AH Medical On-Call service is available via any of the NSW Children's Hospital's switchboards.*

## **Communication**

**Interpreter:** The quality of care and outcomes can be hindered if a language or other communication barrier exists. The use of interpreting services or other communication aids should be considered. Interpreters – [Standard Procedures for Working with Health Care Interpreters](#)

When an interpreter is used, a pre-meeting between the interpreter and clinicians to discuss terminology and topics is a way to support the interpreter and enhance understanding for the family<sup>11</sup>.

- **Patient Clinicians/ Teams:** For communication to be effective, processes should be in place to support the interface between different services and teams. Many patients, particularly those with complex requirements, are known to numerous clinicians in the hospital and community. Consideration should be given to the importance of these connections and the need to contact to inform that the patient is actively dying. Notify GP, AMO and relevant consulting specialist teams involved in the patient's care. This may include the Obstetrician for babies in the neonatal intensive care unit.

Some families, especially those who have spent extended periods in hospital, may wish for clinicians/hospital staff from other areas to be informed that their child is in the last days of their life.

**Specialist Paediatric Palliative Care Service:** The *Toolkit* triggers clinicians to consider a referral to a SPPC service. Specialist PPC services are available to support clinicians when caring for a dying paediatric or neonatal patient. Assistance may include; symptom management, medication guidance, communication strategies, memory making and general care needs. A referral may involve meeting the family (if appropriate) or providing phone advice to clinicians.



## **Other important considerations**

- **The appropriate setting for end-of-life care:** When planning the location for end-of-life care, it is important to respect patient/parent/carer preference while considering where it is possible and appropriate. Specialist PPC services advocate for end-of-life care to occur in the location of child/family's choice which may include home, hospice, tertiary hospital, local hospital or community care facility. Within that, in a hospital setting, preference may be for a particular ward in the hospital or wish to spend time outside. Considerations include: being comfortable e.g., availability of medications, equipment and does the family have support if parent/care request for their child to go home, is there a need for a post mortem examination, and is the possibility that the patient might die in transit deemed an acceptable risk. It is also important to determine if there is adequate nursing staff on the ward to ensure proactive care. Where possible, the patient and family should have 1:1 nursing support.

Location of care options should be explored and facilitated where clinically practical and possible. [Palliative Care at Home- Support by Specialist Paediatric Palliative Care Service.](#)

**Single Room:** Privacy is generally considered important for a family at the end of life. Ideally, a single room will be made available to the family however this is not always possible. Regardless of the availability of a single room, patients/parents/carers should be given the option to adapt the environment to promote comfort to their family (e.g., blankets, familiar toys, lighting, sounds).

Be aware that some families in single rooms may feel isolated and that 'privacy' can make them fearful that help is not quickly available. Explore what is important to the family<sup>12</sup>.

- **Organ and tissue donation:** Talk to the donation team about what is possible if this is important to the family. They are contactable 24/7 via the hospital switchboard.
- **Post Mortem Examination:** The Medical Officer caring for the family must assess the need for an autopsy and make a recommendation to the family accordingly. Clinicians caring for a dying patient should be aware if an autopsy will be or has been requested. Determining if there are time restrictions around this procedure and any special care requirements should be pre-emptively planned. [Frequently asked questions on post mortem examinations in NSW](#)
- **Department of Community Justice:** Some expected deaths may still require notification to the coroner.

Refer to [Coroners Cases and the Coroners Act 2009](#)

Some patients may have an alternate coroner notification pathway for a paediatric palliative care death. This process takes time and is not possible for all patients. For more information, contact the SCHN SPPC service.



## Section B: LDOL: P&N Management Plan

The LDOL: P&N prompts clinicians to have a timely conversation about crucial aspects of care so that the child's (where appropriate)/ parent/carers' wishes can be explored with an overarching aim of comfort<sup>1</sup>.

It may be necessary to complete planning in stages as the patient's condition changes. While prompts in the Toolkit provide a framework, it is the responsibility of the Multidisciplinary Team (MDT) to ensure that the management plan is individualised to meet the dying patient's, parent carer's needs and wishes.

### Area of Assessment

- **Medications:** A review of the patient's medication is imperative to ensure current and emerging symptoms are managed. Clinicians should involve the patient (if applicable) /parent/carer in decisions and rationale about ceasing or prescribing medicines. Consider rationalising non-essential/non-beneficial medications, pre-emptive prescribing for potential symptoms, and review medication administration routes to take into account changing circumstances (inability to tolerate enteral route or tissing of intravenous lines). Refer to the LDOL: P&N Anticipatory Prescribing Guide to assist with prescribing medicines for new and emerging symptoms. Page two of the LDOL: P&N Anticipatory Prescribing Guide lists non-pharmacological ways to manage symptoms and promote comfort.
- **Food and fluids:** Oral, gastric, or medically administered nutrition and fluids are generally not well tolerated at the end of life and may cause the patient to be uncomfortable. While evidence in the literature is lacking, there are some indications that excess secretions, agitation, nausea, breathlessness, and oedema/fluid overload may be experienced by a dying patient<sup>13</sup>. Medically provided nutrition and hydration at the end of life is often an emotive topic that may raise concerns with parents/carers and health care professionals. Therefore, an individualised approach that considers patient comfort and parental/carers' views is recommended<sup>14</sup>.
- **Investigations/Interventions:** Non-essential interventions should be discussed with the family and ceased if deemed non-beneficial or burdensome to the patient.
- **Observations:** Standard Paediatric Observations Chart (SPOC) /Standard Neonatal Observation Chart (SNOC) promotes early identification of a deteriorating patient to escalate treatment<sup>15</sup>. When deterioration is expected, these observations become less valuable and may be deemed intrusive for the patient and become upsetting to the family.

Alternatively, bereaved parents/carers frequently comment on the comfort of their dying child, which makes it a robust measure of quality care. The *COSA: P&N* chart provides tailored, individualised symptom and comfort assessment and management for patients when their death is expected<sup>16</sup>.

The *COSA: P&N* does not preclude the SPOC/SNOC use if there is an agreement between the treating team and parent/carer to assess standard observations.

- **De-escalation of monitors:** The use of monitors at the end of life is usually not recommended and can cause distress to those at the bedside witnessing deterioration. Despite this, parents/carers may prefer monitoring to be continued. Monitoring therefore should be negotiated according to benefit vs burden.

## **Comfort Assessment Planning**

- **Cultural/Spiritual/Religious considerations:** Compassionate psychosocial support of the child and family is critical to the end of life care. Every family will have different needs. The Toolkit prompts discussion and documentation of family wishes, including the family's spiritual, cultural, and religious wishes, environmental considerations, and memory-making. It is important to be guided by the family<sup>17</sup>.
- **Environmental considerations**
  - **Visiting hours:** Patient/parent/carer preference for visitors will vary and should be negotiated to keep in mind the family's wishes and the ward's ability to manage these wishes. This may involve ward staff screening visitors or providing a 'guest book' to leave a message because the family does not want visitors. Alternately, some families may wish to have many visitors with whom to share this experience, and the ward will need to explore possibilities. In some circumstances, there may be conflict, or the family dynamics may need to be managed to prevent a negative impact on patient care or threat to staff.
  - **Overnight:** Determine options available and discuss preferences with family.
  - **Home-like Environment:** consider environment ways to de-medicalise the environment. Creating a home-like environment can create a positive distraction, which has been shown to increase caregivers' satisfaction and improve the overall comfort and wellbeing of the patient and family. Improving the ambient environment involves the using familiar objects, lighting, sound, and temperature<sup>18</sup>.
  - **Memory/Legacy Making:** The memories of their time spent with their child will take many forms for families. Memories involve both tangible and intangible forms. Tangible are the creations of memories such as a handprint, footprint, photos, or locks of hair, or other physical mementos. In contrast, intangible memories incorporate significant moments or experiences. A religious ceremony such as a baptism, reading a book to a child, celebrating a birthday early, taking a child outside are all potential ways to create memories<sup>19</sup>.

For the baby, Neonatal Palliative Care guidelines frequently emphasise the importance of parents/carers being given the opportunity to parent. Time spent before and after death promotes memories that affirm their baby's existence and the affirmation of parenthood, which is believed to impact the parent's experience of loss. In addition to tangible memories, bathing, kangaroo cuddles or being given the opportunity to put a baby to the breast are some options<sup>20,21</sup>.

For children and adolescents, legacy-making promotes the feeling that they will not be forgotten and are loved. Children, regardless of age, may wish to attend to unfinished business, delegate who will be given particular objects, draw pictures, write letters, songs or create videos<sup>22</sup>.

Clinicians should compassionately explore some of these options and provide opportunities for memory and legacy-making. Not all parents/carers will want photos, handprints or other tangible memories of their child dying, and their wishes should be respected. The Toolkit prompts the acknowledgment that memory/legacy-making has been discussed. Conversations and wishes should be documented in the patient's medical records.

The personalised approach is important, and communication between clinicians is imperative so that the family does not become burdened by the same conversations. Understanding how parents/carers experience memory-making is crucial to providing support<sup>21</sup>.

### **Information sheets:**

Compassionate, psychosocial support of the child and family is critical to the end of life care. Every family will have different needs, communication styles, and beliefs. Some families will want to know what to expect, while others will not ask questions as what is ahead is too difficult to contemplate. The Toolkit provides information sheets to help prepare healthcare professionals for common queries or information frequently requested by parents/carers/patients. The information sheets can also be given to parents/carers to help support conversations but should not replace discussions.

### **Last Days of Life PAEDIATRIC & NEONATAL Information Sheets**

- [Information sheets: A guide for health professionals \(2.8MB pdf\)](#)
- [Asking questions can help \(324kb pdf\)](#)
- [What happens in the last days of life \(341kb pdf\)](#)
- [Medicines in the last days of life \(339kb pdf\)](#)
- [Taking your child home to die \(328kb pdf\)](#)
- [Supporting someone who is caring for a dying child \(334kb pdf\)](#)
- [Siblings and the last days of life \(344kb pdf\)](#)
- [When a child dies at home \(326kb pdf\)](#)
- [When a child dies in hospital \(326 kb pdf\)](#)
- [Arranging a funeral for a child or adolescent \(336kb pdf\)](#)
- [Arranging a funeral for a baby \(331kb pdf\)](#)
- [Managing lactation and breastfeeding \(325kb pdf\)](#)
- [Understanding your grief \(333kb pdf\)](#)

## Document 3: Comfort Observation and Symptom Assessment (COSA: P&N)

Once the patient has been recognised as dying and the patient (if appropriate) parent/carer has a clear understanding of the plan, the Comfort Observation and Assessment Chart can be commenced.

### **Between the Flags Response & Comfort Observation Symptom Assessment**

Quality end-of-life care ensures the patient is kept comfortable. Comfort should be monitored and symptoms of discomfort should be recognised early and addressed. The *COSA: P&N* has been designed in the same style as the SNOC/SPOC, to monitor observations and trigger an appropriate response to abnormal observations (in this case patient discomfort) and prompt an escalation. The Clinical Review in this circumstance reminds further non-pharmacological and pharmacological interventions should be considered, an increase of surveillance on symptoms, and an escalation to the nurse in charge to help direct what extra level of support may be required.

- **Daily Review:** The Toolkit recommends a daily review of the patient to determine if it is still appropriate to remain on the Toolkit. This section is in recognition that prognostication in neonates and children is difficult. Sometimes patients do better than expected (their condition stabilises or improves), and it might be appropriate to cease the Toolkit. For others, the dying phase may occur over a longer than expected timeframe. If the patient is still deemed imminently dying, the Toolkit should continue.
- **Variation to Frequency of Observations:** While rare, there may be occasions when it is in the best interests of the patient and family for the frequency of the observations to be changed. For example, a variation may be warranted if the patient's symptoms are controlled, and the parents/carers request not to be disturbed overnight. A variation and rationale are to be documented by the most senior available doctor or nurse.

### **Comfort Assessment and Management**

While an individualised approach to care is important, some core care considerations will promote patient comfort. These include skincare, mouth care, eye care, bladder care, and bowel care. Where a device is in situ (IV or S/C), this should also be monitored to ensure that it is not causing discomfort to the patient. The Toolkit prompts regular (at least four hourly or more frequently if required) assessment and management. The Toolkit does not replace other policies guiding the administration of medications.

### **Non-Pharmacological Measures for Symptom Management**

The Toolkit provides non-pharmacological suggestions to improve patient comfort, parent/carers' perception of what is important for their child, and a more holistic approach to care.

## LDOL: P&N Guidance Document

A LDOL: P&N Guidance Document accompanies the COSA: P&N document. The Guidance Document informs on triggers to recognise that a child or neonate is potentially approaching the end of life and expands on principles relating to end-of-life care mentioned in the Toolkit.

## Medication Management Documents

Support can be obtained for a dying paediatric or neonatal patient by contacting SCHN PPC services (SCH or CHW) within BH or if AH, advice can be obtained through the *NSW PPC AH Medical On-Call service* which is available via any of the NSW Children's Hospital's switchboards. Specialist PPC support includes advice on symptom management and medication guidance.

## Document 2: Anticipatory Prescribing Recommendations for In-Patient Setting

Anticipatory Prescribing Recommendations for in-patient setting document guides how to prescribe starting dose medications for the frequently experienced end of life symptoms. These include pain, nausea/vomiting, breathlessness, excess secretions, confusion, delirium, and restlessness.

Many children and neonates may already be prescribed an opioid or benzodiazepine before reaching the dying phase of their illness, especially in the ICU or oncology setting making Anticipatory Prescribing Recommendations doses less applicable.

Dosing guidance for escalating Pain, Nausea & Vomiting or Breathlessness symptoms can be found in documents 4, 5 and 6.

Non-pharmacological symptom management should be considered and has been contained in this document.

Patient groups who experienced symptoms prior to the end of life phase, such as pain in oncology patients, may require higher dosages. Review the patient's medication history when prescribing. This document does not replace clinical judgment or local policy.

Pre-emptive prescribing prevents the delay in the treatment of symptoms<sup>17</sup>.

## Document 4: Management of Pain

The Management of Pain Document guides how to prescribe starting dose medications and escalating requirements for the symptom of pain. Non-pharmacological pain management should be considered and has been included in this document. Pre-emptive prescribing prevents the delay in the treatment of pain.

This document includes an oral/transdermal to subcutaneous opioid conversation table.

## Document 5: Management of Nausea/Vomiting

Management of Nausea/Vomiting document guides how to prescribe starting dose medications and escalating requirements for nausea/vomiting. Non-pharmacological nausea/vomiting management should be considered and is included in this document. Pre-emptive prescribing prevents the delay in the treatment of nausea/vomiting.

## Document 6: Management of Breathlessness

Management of Breathlessness document guides how to prescribe starting dose medications and escalating requirements for the symptom of breathlessness. Non-pharmacological breathlessness management should be considered and has been included in this document. Pre-emptive prescribing prevents the delay in the treatment of breathlessness. This document includes an oral/transdermal to subcutaneous opioid conversation table.

## After the Death of a Child or Neonate

- [SCHN Death of a Child Policy](#)

### Other:

- [SCHN Palliative Care Bereavement Support Practice Guideline](#)
- [Employee Assistance Program Policy](#)

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