LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL (LDOL: P&N) TOOLKIT

Instructions for response to Symptom/Sign Rating

1. This document should be used in conjunction with standardised medication management guidelines and non-pharmacological interventions (refer to pg. 4 *of COSA: P&N*).
2. If no PRN medication is charted, escalate to Medical Officer or Nurse In Charge
3. Reassess symptoms no more than 30 minutes following treatment. If a symptom is not adequately addressed, escalation to a clinical review may be required.
4. Where there has been an escalation, record management and intervention outcomes in the patient's health care record.

Instructions for Psychosocial Assessment – Patient/Parent/Carer/Family Distress

Parent/carer/family emotions in the last days of life can be fluctuating, wide-ranging and intense. Clinicians can assist families by being available when needed. Consider what additional supports may be helpful/available, listen to concerns, reassure and seek advice from social work and/or palliative care if needed.

Prescribed Frequency of Symptom/Sign Assessment and Comfort Observations

COSA: P&N assessments must be performed routinely a minimum of every 4 hours in consideration of expressed needs and wishes of the child/parent/carer. Document each assessment and tick √ when action is completed, date and time that care is provided.

If no action is required, denote N/A after assessment. If any treatment or escalation is initiated more regular assessments should occur. Document in the patient's health care record.

Between the Flags

This form utilises the Between the Flags principles to ensure early recognition and rapid response to emerging symptoms aimed at ensuring the patient is kept comfortable.

Refer to your Clinical Emergency Response System (CERS) protocol for instructions on how to make a call to escalate care for your patient. Alternatively, parents/carers/families can escalate care using the R.E.A.C.H process.

Special Considerations

- The *COSA: P&N* (pg. 3) focuses on nursing interventions and assessments that promote patient comfort e.g. eye care, mouth care, bowel, and bladder monitoring and management.
- Infusion devices and access sites should be monitored according to local policy.

Non-Pharmacological Measures for Symptom Management

Consider non-pharmacological measures in the last days of life to assist in the management of symptoms. Encourage families to create a home like environment to support a therapeutic approach to care.

Document 4. Pain Management Guidance: Last Days of Life: P&N

Provides symptom guidance relating to the non-pharmacological and pharmacological management of pain (Includes an oral/transdermal to subcutaneous opioid conversation table).

Document 5. Nausea and Vomiting Management Guidance: Last Days of Life: P&N

Provides symptom guidance relating to the non-pharmacological and pharmacological management of nausea and vomiting.

Document 6. Breathlessness Management Guidance: Last Days of Life: P&N

Provides symptom guidance relating to the non-pharmacological and pharmacological management of breathlessness. (Includes an oral/transdermal to subcutaneous opioid conversation table).

Prescribing Considerations

- Doses should be titrated to the assessed needs of the individual patient, including frailty and co-morbidities
- If >3 PRN doses are required in the previous 24 hours and symptoms persist, regular medications should be commenced or regular doses increased: see symptom management flowcharts for specific guidance on dose titration for each of the common symptoms.
- The existing intravenous route may be preferred over the subcutaneous route for patients dying in the NICU and ICU setting
- If an opioid is prescribed for pain, the same opioid prescription order may also be used for breathlessness, and vice versa
- LHD policy and procedure must be followed when prescribing and administering medications via a subcutaneous syringe driver

Support can be obtained for a dying paediatric or neonatal patient through the NSW Paediatric Palliative Care services including after-hours advice via any NSW CHILDREN'S HOSPITAL'S SWITCHBOARDs.

LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL (LDOL: P&N) Toolkit Guidance Document

This Guidance Document informs on how to use the *Last Days of Life: Paediatric & Neonatal (LDOL: P&N) Toolkit* and expands on principles when caring for a dying, child, or neonate.
This document accompanies the *LDOL: P&N Comfort Observation and Symptom Assessment Chart (COSA: P&N).*
End of life management is not the stopping of care. Instead, it is the redirection of active management to ensure comfort

About the LDOL: P&N Toolkit

The aim of the ***LDOL: P&N** Toolkit* is to improve the care of a dying patient and their family in the acute care setting by:
- Providing an education framework for clinicians who may care for a child/neonate with a life-limiting condition
- Providing real-time guidance for clinicians who are caring for a dying child/neonate by introducing a suite of clinical documents that support care planning, patient assessment, and management during the last days of life
- Providing a tool that promotes reflective practice after the child/neonate has died

The Toolkit is a guide only and does not replace existing local policies or guidelines.
The information contained in the *Toolkit* provides best practice guidance. However, the information is general and cannot consider all the complexities present at end of life.
For support with the LDOL: P&N Toolkit or advice about the care of a dying child or neonate, assistance is available from the local Specialist Paediatric Palliative Care (SPPC) team or if after-hours, contact SPPC via any of the NSW Children's Hospital's switchboards.
While it is envisaged that this *Toolkit* is a helpful education resource, the *Toolkit* must only be initiated when a patient is in the last days of life and meets the Mandatory Criteria (refer Doc. 1- *Initiating LDOL: P&N Management Plan*)
The patient's attending Admitting Medical Officer must authorise the *Toolkit* initiation.
Refer to the Last Days of Life: Paediatric & Neontal Heti module for further information about how to use the Toolkit.

Location of the LDOL: P&N Toolkit

The ***LDOL: P&N Toolkit*** can be viewed in entirety on the NSW Paediatric Palliative Care (PPC) Programme or Clinical Excellence Commission (CEC) website.
Copies of the LDOL: P&N Information sheets can be printed from the NSW PPC Programme website.
LDOL: P&N documents can be ordered from Stream Solutions (https://www.tollstreamdirect.com/)
It is envisaged that there will be further modifications and developments to this *Toolkit*.
To provide feedback or to enquire further about the development of this Toolkit contact the *LDOL: P&N* Project Officer on 0428 183 290.

Recognising dying

When making decisions about the patient's prognosis, the following signs and considerations should be used in conjunction with clinical judgement, parent/carer/family input, and multidisciplinary discussion.
Patients should have a medical review daily while on the *Toolkit*. Any improvement in the clinical condition that indicates the patient is no longer actively dying should be assessed by the care team to determine the most appropriate management plan.

Indications of dying that may be present include:

- an ongoing deterioration despite indicated clinical care and;

Paediatric	**Neonatal**
Increasing difficulty with swallowing or taking oral medications	Frequent apnoeic and/or bradycardic episodes
Increasingly disinterested in play or other interests/activities	Frequent and prolonged desaturations
Increasingly weak and bed bound	Mottled appearance
Drowsy for extended periods of time	Low tone
Increasingly disinterested in food and fluid	Lethargy or decreased movements
Colour and temperature changes	Temperature instability

- *There are various patterns of death trajectory at the end of life, however, certain signs tend to be present when patients are actively dying that are applicable across the different diagnostic groups for children with life limiting conditions.*
  - *Paediatric patients with non-malignant disease may have had the above signs and symptoms for some time. Malignant conditions may have clearer end of life indications. Care should be taken not to rely on these long-term indicators when determining if a patient is dying. Clinical judgement is crucial.*
  - *In the NICU/ICU setting, signs and symptoms often become more apparent once intensive treatments are ceased and a decision is made to institute care aimed at comfort. The Toolkit is appropriate for one-way extubations when death is expected to occur quickly as it can assist with preemptive planning.*
- ***Additional advice can be sought from the* Specialist Paediatric Palliative Care (SPPC) services. Out of hours support is provided by the SPPC Medical On-Call Service that can be contacted via the hospital switchboards at The Children's Hospital at Westmead, Sydney Children's Hospital, Randwick or John Hunter Children's Hospital, Newcastle.**

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Last Days of Life: P&N - Compass

The **LDOL: P&N Compass** is to help navigate the documents in the Toolkit:

- Each document is numbered to support the Toolkit sequence, e.g. Document 1, Document 2, etc.
- The Compass boxes are colour coded to demonstrate function and purpose. e.g. green boxes (Clinical Documents), blue boxes (Medication Guidance Documents), and the orange box (Information Sheets).

Document 1. Initiating the Last Days of Life Toolkit: P&N – Management Plan

Section: A & B **to be completed by Medical Officer/delegated senior nurse**

The *Initiation of the LDOL: P&N Management Plan* forms part of the patient's health care record

It may be necessary to complete this section in stages (review daily/date accordingly/document in health care record rationale).

While these tools provide a framework for care planning for dying patients, it is the responsibility of the MDT to ensure that the plan of treatment developed is individualised to meet the dying patient/parent/carer's needs and wishes.

Section A

The *Initiation of the LDOL: P&N Management Plan* guide provides a **Mandatory Criteria** to instruct on when it is appropriate to commence the Toolkit.

Considerations:

- Why would you consider the patient is dying within hours to days?
- Is deterioration unexpected or a predictable consequence of a known illness? Is there any treatable problem that has caused this deterioration?
- Who is involved in recognising the patient may be dying? Have discussions occurred between multidisciplinary teams caring for the patient?
- Communication with patient and family – have discussions been held with the patient (if appropriate) and family whereby they have been given an opportunity to ask questions or voice concerns?

If all aspects of the criteria are met, clinicians should identify key components which may affect future care.

These will include if the child is known to the Department of Communities and Justice, is organ or tissue donation possible, is there a reason for a post mortem autopsy, or is it a Coroners Case?

Section B

Initiation of the LDOL: P&N Management Plan assists clinicians in creating a management plan to promote patient comfort, enhance communication, streamline care and empower clinicians to explore and incorporate considerations relating to spiritual, cultural, and religious wishes.

Management Planning

When a patient is dying, high-quality care involves creating a calm environment and a pre-emptive plan which promotes patient comfort.

- PRN Medication should be prescribed to ensure symptoms are managed without delay. Route of administration and ceasing non-beneficial/burdensome medications should be considered.
- Food and fluids (oral, gastric, or medically administered) are generally not well tolerated at the end of life and may cause discomfort, therefore rationalise intake.
- Standard observations (temperature, pulse, BP) should be reconsidered and an assessment of common end-of-life (EOL) symptoms that can be distressing to a patient during EOL should occur (Refer Doc 3 - *LDOL: P&N Anticipatory Prescribing Recommendations).*
- Non-essential investigation and interventions should be ceased to ensure comfort.
- Compassionate psychosocial support of the child and family is critical to 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.

Last Days of Life: P&N TOOLKIT INFORMATION SHEETS

LDOL: P&N Toolkit Information Sheets

Communication between patients/parents/carers and health care providers are important across the span of a child's terminal stage of care, especially in the last days of life.

LDOL: P&N Information Sheets have been developed considering the needs of both clinicians and families. They do not replace the clinical staff's responsibility to communicate with families nor replace existing supports such as social work intervention. Instead, they can be used to support conversations with families.

Often the best support for the child and family is being present and taking time to listen.

N.B. Careful consideration should be given to the relevance and timing of provision for each Information Sheet.
Document: P-Patient, C- Parent/Carer according to who the information sheet(s) have been given.
Document in the patient's health care record if an information sheet has been provided and if follow-up is required.

LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL (LDOL: P&N) TOOLKIT

Document 2. Anticipatory Prescribing Recommendations - Last Days of Life: P&N

The ***LDOL: P&N Anticipatory Prescribing Recommendation*** provides direction on prescribing medicines to ensure there is no delay in treating emerging symptoms that may occur in the dying phase.

All patients in the last days of life should have pre-emptive STARTING PRN medications, prescribed which consider what symptoms may occur according to the patient's illness during the dying process.

This guide includes non-pharmacological ways to manage symptoms as well as the recommended STARTING dose for first-line medications.

Doses are conservative and should be adjusted up or down according to the needs of the individual patient and their clinical condition.

***Anticipatory Prescribing Recommendations* – Page 1.**

Anticipatory Guidance for most common symptoms associated with the end of life;

- Pain
- Nausea & Vomiting
- Breathlessness
- Secretions
- Delirium

Principles of symptom management in last days of life;

- Dying patients are assessed regularly to allow existing and emerging symptoms to be detected, assessed, and treated effectively
- If symptoms are present always consider reversible causes and non-pharmacological measures
- If non-pharmacological measures are ineffective, as required (PRN) medication is given
- If the medication is ineffective, the patient is reassessed and further intervention and/or escalation is implemented to manage the symptom(s) and ensure patient comfort
- The likely cause and management of the symptom(s) are communicated to the parent/carer.

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

If a neonate/child has been prescribed morphine for pain, they do not require an additional dose prescribed for breathlessness.

***Anticipatory Prescribing Recommendation* - Page 2.**

The *Anticipatory Prescribing Recommendation* document provides information about starting doses, titrating medications, routes of medication administration and the use of syringe drivers.

Throughout the documents (in red), it is emphasised that support can be obtained for a dying paediatric or neonatal patient through the NSW SPPC services which include an after-hours advice line.

Non-pharmacological options are provided to assist with symptom prevention and management. Provision of options and choices to child/family/carer will promote a more holistic approach to care.

Document 3. Comfort Observation and Symptom/Sign Assessment: Paediatric and Neonatal (COSA: P&N)

Using the COSA: P&N

This document is designed to promote and monitor the comfort of the dying paediatric or neonatal patient. It takes into account the patient/family/carer needs.

The *Initiating of the LDOL: P& N and COSA: P&N documents* form part of the patient's health care record.

- This form should only be used if the *Initiating Last Days of Life: P&N Management Plan* has been completed and staff are aware of the management plan for this patient.

This chart generally replaces the Standard Paediatric Observation Chart (SPOC)/Standard Neonatal Observation Chart (SNOC) or other flowcharts. However, the COSA: P&N does not preclude their use if there is an agreement between the treating team and parent/carer to assess standard observations.

Instructions for Symptom/Sign Assessment

1. Where possible, base the assessment on the patient's verbal response.
2. For non-verbal/semi-conscious patients, look for visual cues of pain or discomfort and/or discuss with parents/carers.
3. Assess each symptom and document whether Absent/Mild/Moderate/Severe then document 'P' for Patient, 'C' for Parent/Carer, and 'S' for Staff to identify the source of assessment. (N.B. Some symptoms may be difficult to assess for neonates therefore document best response).
4. In case of discrepancy between assessments (e.g. perception of carers and staff, or patient and carers), separately document relevant severity for each assessment with 'P' for Patient, 'C' for Parent/Carer/Family, and 'S' for Staff.
5. N.B. Symptoms are recorded according to the distress experienced by the patient. A symptom may be present, e.g. breathlessness but may not be distressing to the patient.