NSW GOVERNMENT | Health

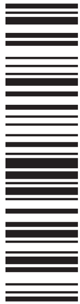
Last Days of Life Paediatric & Neonatal

Facility:

FAMILY NAME	MRN
GIVEN NAME	☐ MALE ☐ FEMALE
D.O.B. _______ / _______ / _______	M.O.
ADDRESS	
LOCATION / WARD	
COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE	

Document 3

LAST DAYS OF LIFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N)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Using the Comfort Observation and Symptom/Sign Assessment: Paediatric and Neonatal (COSA: P&N)

The purpose of the COSA: P&N is to ensure the comfort of the patient.

This form should only be used if the *Initiating Last Days of Life: Paediatric & Neonatal (LDOL: P&N) Management Plan* (Doc. 1) has been completed

- Staff should ensure the patient meets the *LDOL: P&N* mandatory criteria
- Staff should be familiar with the patient's management plan

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

***Refer to the *LDOL: P&N Guidance* document for a detailed explanation of *COSA: P&N*.

Between the Flags Response

An essential aspect of end of life care is maintaining the comfort of the patient.

Non-pharmacological and pharmacological measures are used to prevent and treat symptoms.

This form utilises the Between the Flags principles to ensure early recognition and rapid response to emerging symptoms to ensure 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.

Blue Zone Response

IF THE PATIENT HAS ANY BLUE ZONE OBSERVATIONS YOU MUST:

1. Initiate appropriate clinical care, comfort management and consider non-pharmacological measures
2. Increase the frequency of symptom assessment and comfort observations
3. Manage symptoms in consultation with the NURSE IN CHARGE
4. If symptoms persist, even if assessed as mild – escalation is required

You can make a call to escalate the care at any time if worried or unsure, use your clinical judgement.

Yellow Zone Response

IF THE PATIENT HAS ANY YELLOW ZONE OBSERVATIONS YOU MUST:

1. Initiate appropriate clinical care
2. Consult promptly with the NURSE IN CHARGE to decide whether a CLINICAL REVIEW (or other CERS) call should be made
3. Repeat and increase the frequency of symptom assessment and comfort observations as indicated by the patient's condition

When escalating care, consider the following:

- Report all Yellow Zone criteria
- Has the patient not responded to treatment as expected? Are symptoms persisting?
- Does the patient require any additional intervention to relieve their symptoms?

**All clinicians who review the patient should be aware of family wishes and goals of care

If required, seek advice from local Specialist Paediatric Palliative Care team or **IF AFTER HOURS CONTACT SPECIALIST PAEDIATRIC PALLIATIVE CARE VIA ANY NSW CHILDREN'S HOSPITAL'S SWITCHBOARDs.**

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Any symptom which causes discomfort requires an intervention; persistent or severe symptoms require escalation.
Document observations a minimum of every 4 hours routinely or more frequently if a symptom is present.
Symptoms should be reassessed **within 30 minutes** following an action.
Refer to pharmacological and non-pharmacological guidance documents.
Document letter (**P**- Patient, **C**-Parent/Carer, **S**-Staff) in box below to identify the source of assessment.
Some symptoms experienced by neonates may be difficult to assess, therefore document most appropriate response.
Some signs and symptoms associated with end of life may be present but do not cause distress for the patient.

	Date															
	Time															
Pain	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
Distress related to Breathlessness	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
Distress related to Respiratory Secretions	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
Nausea/ Vomiting/ Positing	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
	Tick ☐ if Vomit/posit															
Restlessness/ Agitation/ Delirium	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
Other Symptom ______ (Specify) e.g. seizures	Severe															
	Moderate															
	Mild															
	Absent/Sleeping/No apparent distress															
Action initiated to manage a symptom? If No (N) or if Yes (Y) document intervention type Pharmacological (P), Non-Pharmacological (N-P). Document details in health care record																
Initial																
Daily review for appropriateness to remain on *LDOL: P&N Toolkit* (✓ & initial) (Most senior available doctor or nurse)																

Variations to frequency of observations (most senior available doctor or nurse).

Frequency required				
Name/Signature (Designation)				
Date/Time Document rationale in health care record				

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Instructions for Comfort Assessment and Management

1. Assess and manage comfort care a minimum of every 4 hours in consideration of needs of the child/neonate and wishes of the child/parent/carer
2. Document each care need and tick ✓ when action completed - Note N/A if after assessment no action required

If Further Action Required – document reasons and actions in patient's health care record

Date															
Time															

Section		Item													
Skin care	Assess	Skin intact & clean													
	Action	Cleanse/moisturise/nappy care													
		Pressure relieving mattress													
		Turn and reposition as indicated													
		Manual handling equipment/aids													
		Wound care													
Device	Assess	Infusions and site monitoring (Follow local Policies & Guidelines)													
	Action	Note presence of device: Pump (P)/ Syringe driver (SD)													
		Document site location & type: Intravenous (IV)/Subcutaneous (subcut)													
Mouth care	Assess	Mouth/lips clean and moist													
	Action	Provide mouth care													
Eye care	Assess	Eyes are clean and moist (escalate a review if redness/irritation/discharge present)													
	Action	Clean with Normal Saline													
Bladder care	Assess	Urinary: Patient clean/comfortable (consider retention or incontinence)													
	Action	Document urine output 'PU"													
		Bladder Management													
Bowel care	Assess	Bowels: Patient clean/comfortable (consider constipation or diarrhoea)													
	Action	Documented Bowel movements "BO"													
		Bowel/Stoma management													

3. Psychosocial needs should be assessed once per shift (including Spiritual/Cultural/Religious)

Families will require psychosocial support in the last days of life but needs will vary depending on family. These assessments do not necessarily require a discussion with patient/parent/carer.
Refer to other clinical documentation and/or discuss with Nurse In Charge to ensure there is a support plan available.
Some considerations; LDOL: P&N Information sheets given to parent/carer, procedures explained, new concerns identified, assess physical needs (nutrition), person significant to the family contacted (if requested by family), referral to social work, palliative care or other allied health, Aboriginal Liaison Officer, Pastoral Care contacted, and rituals facilitated as requested.

Assess and tick ✓ when action completed - Note N/A if after assessment no action required

Section		Item													
Psychosocial support needs	Assess	Patient support needs													
	Action														
	Assess	Parent/carer support needs													
	Action														
	Assess	Sibling support needed													
	Action														
		Initials													

The child, parent/carer/family may have specific requests relating to end of life and after death care.
Please document, date and initial these requests.

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GENERAL NON-PHARMACOLOGICAL SYMPTOM MANAGEMENT SUGGESTIONS IN THE LAST DAYS OF LIFE

Environmental comfort measures may include;
- decrease room lighting, stimulation and noise (low volume music may be helpful e.g., favourite songs)
- promoting the presence of parents/carers/significant others
- promoting reassuring touch i.e. kangaroo cuddles/gentle massage
- rationalise visitors
- the addition of familiar objects e.g. favourite toys/pillows/blankets/smells/books/electronics
- specific strategies for neonates may include bathing, pacifiers, feeding, and kangaroo cuddles

These strategies must be appropriate to the cognitive/developmental age of the patient and their clinical condition.

PAIN

Consider and manage causes of pain such as constipation and urinary retention or symptoms which may present as pain such as distress related to anxiety and fear.
Review general non-pharmacological symptom management suggestions (above).
Non-pharmacological measures:
- Ensure a comfortable position; consider repositioning and pressure relieving mattress

NAUSEA/VOMITING

Nausea/Vomiting can have multiple and contributing causes (i.e. constipation, raised intracranial pressure and psychological).
Non-pharmacological measures:
- Consider patient comfort- reduce/stop artificial and oral nutrition replacing with regular effective mouth care/sips of water/ice if appropriate
- Remove strong odours
- Minimise movement
- Provision of tissues and vomit bag within easy reach
- Cool cloth, increase airflow

BREATHLESSNESS

Breathlessness may be present and is often associated with increasing anxiety for the patient and may be distressing for the parent/carer/family
Non-pharmacological measures:
- Reassure the patient and parent/carer/family when necessary and maintain a calm environment with an explanation of cause and management
- Position to maximise comfort and airway
- Increase room airflow (e.g. fan)
- Decisions around the use of supplemental oxygen may be complex; refer to local guidelines

RESTLESSNESS/AGITATION/DELIRIUM

Agitation/Delirium/Terminal restlessness can be distressing for the patient/parents/carers/family. Non-pharmacological measures should be considered before medications are introduced e.g. exclude constipation or urinary retention (manage appropriately if present).
- Assess for emotional, psychological and existential distress; address appropriately if present.

Non-pharmacological measures:
- Promote a calm and safe environment (Review general non-pharmacological symptom management suggestions (as per above))
- Speak calmly, clearly and encourage patient to express their thoughts and feelings (if appropriate)
- Gentle, reassuring touch (holding their hand, massage) as tolerated

RESPIRATORY TRACT SECRETIONS

Respiratory tract secretions may be present and can be a normal part of the dying process; they are not distressing to the patient, but often are for the parents/carers/family.
Non-pharmacological measures:
- Reassure parents/carers/family with explanation of the symptom cause and measures used to relieve secretions
- Position patient to encourage postural drainage and comfort
- Initiation or continuation of medical fluids (IV/NG/gastrostomy) and nutrition can contribute to excess secretions
- Provide mouth care and consider background music to decrease focus on breathing and promote relaxing environment

Oral suctioning may be appropriate but deep suctioning is NOT RECOMMENDED and can be distressing to the patient.

PARENT/CARER/FAMILY DISTRESS

Parent/carer/family emotions in the last days of life can be fluctuating, wide-ranging and intense.
Reassure the parent/carer/family and if concerns escalate or you require additional assistance consider referral to Social Worker, Aboriginal Health Liaison Officer, Specialist Paediatric Palliative Care Service and/or Chaplain.

PATIENT EMOTIONAL DISTRESS

Consider comfort measures and environmental factors listed above.

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