Clinical Guideline

End of Life Care for Neonates

Sites where Clinical Guideline applies	All Newborn Service sites in HNELHD
This Clinical Guideline applies to:	
1. Adults	No
2. Children up to 16 years	No
3. Neonates – less than 29 days	Yes WHaM approval 23 July 2021
Target audience	Clinicians in neonatal units in HNELHD
Description	Provides information for neonatal clinicians regarding end of life care for infants, as well as support for families

Go to Guideline

Keywords	Neonate, newborn, infant, NICU, SCU, end of life, death, dying, re-direction, redirection of care, withdrawal, palliative, palliation, resuscitation
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Replaces existing document?	Yes
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Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics:

- NSW Health Policy Directive PD2020_011 Verification of Death and Medical Certificate of Cause of Death
- NSW Health Policy Directive PD2010_054 Coroners Cases and the Coroners Act 2009
- NSW Health Policy Directive PD2012_069 Health Care Records – Documentation and Management
- HNELHD Policy Compliance Procedure PD2015_040:PCP 3 Care of the Deceased: Coroner's Case
- HNELHD Policy Compliance Procedure PD 2015_040:PCP 2 and PD2010_054:PCP 2 Care of the Deceased: NON Coroner's Case

Position responsible for Clinical Guideline Governance and authorised by	Dr Paul Craven, Executive Director, Children, Young People and Families Services
Clinical Guideline contact officer	Jo Davis, CNC, Newborn Services, JHCH
Contact details	Jo.davis1@health.nsw.gov.au
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Note: Over time links in this document may cease working. Where this occurs please source the document in the PPG Directory at: http://ppg.hne.health.nsw.gov.au/

PURPOSE AND RISKS

This document has been developed to provide support and guidance to the health clinician to provide high quality, safe and timely care for infants who are at end of life.

The risks are:

- *Poor symptom management*
- *Lack of choice and autonomy for the bereaved family*
- *Poor social, emotional and practical support of the bereaved family*

The risks are minimised by:

- *Clinicians having knowledge of available resources to support families through the end of their infant's life, bereavement support strategies and information*
- *Staff being familiar with Last Days of Life: Paediatric & Neonatal Toolkit and comfortable in its use*
- *Keeping the infant comfortable, and the family supported*
- *Keeping families informed of their choices and aware of trajectory of end of life*

Any unplanned event resulting in, or with the potential for injury, damage or other loss to infants/staff/family as a result of this procedure must be reported through the Incident Management System and managed in accordance with the NSW Health Policy Directive PD2020_020: Incident Management Policy.

*It is mandatory for staff to follow relevant: "Five moments of hand hygiene", infection control, moving safely/safe manual handling, documentation practices and to use HAIDET for patient/carer communication: **H**and hygiene **A**cknowledge, **I**ntroduce, **D**uration, **E**xplanation, **T**hank you or closing comment.*

Risk Category: *Clinical Care & Patient Safety*

CLINICAL PROCEDURE SAFETY LEVEL

Every clinician involved in the procedure is responsible for ensuring the processes for clinical procedure safety are followed. The following level applies to this procedure (click on the link for more information):

Level 1 procedure

CONTENT

END OF LIFE CARE SUMMARY POINTS

- A standardised approach to end of life care contributes to improvements in safety, effectiveness, and overall satisfaction of families with their experience. Communication is key in providing effective care
- Tools such as the Last Days of Life Toolkit, assist the health professional in redirecting care activities to those that are in line with the dying patient
- End of life care must incorporate physical aspects such as individual symptom/pain control as well as emotional aspects such as time and space for grief and memory making, as desired by the family
- Families must be afforded choice throughout end of life care over aspects such as location, privacy, spirituality and decision making. Choices that are important to families must, therefore, be important to health professionals managing their care

GUIDELINE

While not requiring mandatory compliance, staff must have sound reasons for not implementing standards or practices set out within guidelines issued by HNE Health, or for measuring consistent variance in practice.

Introduction

Dying infants are cared for in a variety of settings including Neonatal Intensive Care Units (NICU), Special Care Units (SCU) and Maternity Units. Having a standardised approach to end of life care contributes to improvement in safety, effectiveness and the overall experience of families. Care should always be tailored to the individual needs and wishes of the family, and therefore communication is essential in all decisions surrounding care.

Principles of a ‘good death’ include:

- Families having reasonable control of how the death will occur
- Pain and other symptoms are controlled and managed

- Families are afforded dignity and privacy, and are provided with necessary information and expertise
- Families have access to any spiritual or emotional support they require
- Families have time to say ‘goodbye’ and arrange things important to them
- Families have choice over location, with quality care provided

Having to face decisions about whether and how one's infant may die is a very difficult situation for any parent. Many parents prefer decisions to be made in a shared decision-making model involving both parents and health care professionals. Some require decision making to be heavily guided by health care professionals who hold both medical expertise, and in-depth knowledge of the family, their cultural and social values.
All parents need clear, unbiased and sensitively delivered information about the choices before them when considering their goals at the end of their infant’s life.

Communication with Families Top

Communication and clear explanation to families is key to providing quality care throughout the last days of life (LDOL).

Unexpected Clinical Deterioration Top

When an infant has a critical clinical deterioration and appears to be entering the dying phase, a meeting with the family should be arranged urgently. Ideally this should be led by the most senior medical staff member in collaboration with the in-charge nurse/team leader (TL) and nurse caring for the infant. The discussion should aim to cover:

- The clinical situation
- Discussion of the likelihood of the infant dying in the next hours/days and why it can be difficult to predict
- Identifying who are important people the family wish to share information with
- Discussion of the family’s priorities for their infant’s care

Planned Redirection of Care Top

Palliative care is offered to infants after extensive discussion with families in conditions where intensive therapy is not in the infant’s best interests. Situations may include extreme prematurity, severe neurological injury or extensive congenital abnormalities.

The Royal College of Paediatrics and Child Health (UK) outlines 5 circumstances under which withholding or withdrawing curative medical treatment may be considered:

- The child has been diagnosed as brain dead according to standard criteria
- Permanent vegetative state. These children have 'a permanent and irreversible lack of awareness of themselves and their surroundings and no ability to interact at any level with those around them’
- 'No chance situation' - life-sustaining treatment simply delays death without providing other benefits in terms of relief of suffering
- 'No purpose' situation - the child may be able to survive with treatment but the degree of mental or physical impairment would be so great that it would be unreasonable to ask the child to bear it
- The 'unbearable' situation - in the face of progressive, irreversible illness, the burden of further treatment is more than can be borne

A meeting should be arranged at a time suitable to the family. Consideration to the following must be made by clinicians;

- Privacy (e.g. a private/quiet space or room)
- Communication strategy (e.g. interpreter, social work or extended family/support needs)
- Cultural needs (e.g. Indigenous families may wish to have other family members present for such conversations, or the Aboriginal Liaison Officer)

The discussion should be led by the most senior medical staff member in collaboration with the in-charge nurse/TL and nurse caring for the infant. The discussion should aim to cover:

- The clinical situation
- Options for decision-making as well as a recommendation of the best option for the infant under current circumstances including reasons based on medical, experiential or moral factors
- Plan of care, including respiratory support, pain relief, comfort care, fluids, oral or enteral feeding and sedation
- Spiritual and cultural needs
- Place of death consideration
- Consideration of criteria for coroner's case

There should be detailed documentation of the conversation with the family, including noting who was present, information given, family understanding of the information, family concerns and choices expressed, goals for care, and preference for location of death.

Pregnancy Palliative Care and Birth
When a foetus is diagnosed with a life-threatening condition, no matter how early or late in the pregnancy, palliative care may be offered/recommended before birth occurs.
Expectant parents grieving for the loss of an infant they may never know require consistent and empathic support. Parents should be supported and encouraged to make 'family memories' during the remainder of the pregnancy and make detailed plans for the birth, and for the infant's life, even if very limited in length. This may include choosing who is present for birth and hours that follow, as well as religious considerations.
This approach supports families through the rest of the pregnancy, through decision-making before and after **birth**, and through their grief.

Caring for Indigenous Infants and their Families at End of Life

Top

Approximately 12% of all Indigenous infants born in NSW are born in the Hunter New England Local Health District (HNELHD). Where an Indigenous infant is dying, or has died, there may be specific cultural considerations to be factored in to the end of life care provided to the family.

- Many Indigenous parents prefer to consult extensively with their extended family about end of life care choices, and this can take some time. The process should not be rushed.
- Staff should anticipate a large number of visitors to see the infant/family. Such a gathering is a mark of respect for the infant and their family and prepares the infant for the next stage of their life journey. Consider arranging a larger meeting space, and factor in adjustments to visiting hours as appropriate.
- Occasionally the terms 'dying' and 'death' can make people uncomfortable and in this case alternative terms such as 'finishing up' or 'not going to get better' may be culturally appropriate. Discuss with family members their preference in terms.
- Depending upon beliefs of the community, the mourning period or 'sorry business' may last days, weeks or even months.

Indigenous families often have some customary practices that should take place before, during and after the death of their infant. Aboriginal and Torres Strait Islander people have beliefs that support

the notion that where people die is where the spirit will stay, if not enabled to move on. Smoking ceremonies, which Indigenous families believe assists with the journey of the spirit and is healing for the family, or painting the infant's face with ochre as a link to their heritage and ancestry should be encouraged. Some practices are considered sacred and may not be discussed outside of their community.

Sometimes women have needed to travel away from their home to give birth to their infant in a larger health facility for medical reasons. Birthing 'off-country' and away from ancestral homelands can create emotional and spiritual difficulties for the mother and infant. These families should be offered opportunity to bring ochre from country to paint the infant with, or take their placenta home (where possible) to bury on country as the placenta is believed to carry the infant's spirit and the birth is then 'recognised' by mother earth. If the placenta has already been disposed of, part of the umbilical cord can also be offered.
The time of death is very traumatic for family and friends of the deceased infant and may elicit strong reactions. Family members may cry loudly, dance or sing to call the spirit home, or they may become very quiet. It is important for staff to be culturally responsive and understanding.

After death has occurred, it is respectful to cease using the infant's name - for some families they believe that using the name of the infant will call their spirit back and prevent safe passage to the spirit world. However, for some families using the name is not a concern.

Other cultures

Top

Cultural tradition and religious practices may vary even within the same community and so it is important to discuss specific choices with the family and facilitate their wishes as much as is feasible. Some families from other cultural backgrounds will need ongoing spiritual and psychological support before, during and after the baby's death.
Families may be hesitant in discussing their cultural needs with healthcare staff, so a conducive environment is needed during discussion on end of life care choices.

Recognition of Dying

Top

Recognising dying can be difficult. The recognition that an infant is likely to die within hours to days should be made after a discussion between a senior Medical Officers, Neonatal Nurse Practitioners (NNP) and nursing staff caring for the patient. If there is uncertainty, further opinion should be sought. Some infants may improve unexpectedly: - the plan for care must then be reconsidered and explained to the family and wider team.

There are often patterns of the death trajectory at the end of life (apart from when there are precipitous, unexpected fatal events) and certain signs/symptoms tend to be present when infants are actively dying. These can include temperature instability, changes in circulation leading to cool peripheries (mottled appearance), changes in breathing patterns (frequent and prolonged apnoea, shallow breathing) or restlessness/lethargy. The infant may become non-responsive to touch or stimulation.

It may be appropriate to consider organ or tissue donation at this point in care. Information regarding the program and eligibility are contained within the Organ and Tissue Donation in the NICU guideline.

Initiating Last Days of Life Management Plan

Top

LDOL Management Plan Paediatric & Neonatal (see Appendix 2)

Section A: Mandatory Criteria for Commencement of Last Days of Life Management

The patient has been comprehensively assessed to be dying, with death anticipated within next 7 days, and;

- Patient's condition and management are aimed at comfort care only, and,
- Reversible causes for deterioration have been considered and treatment is inappropriate, and,
- The family have been informed that the infant is in their last days of life, and,
- The family's current or previously expressed wishes regarding end of life care have been considered, and,
- A NSW Health Resuscitation Plan; paediatric or equivalent documentation has been completed, including a decision that cardiopulmonary resuscitation (CPR) and other acute measures are inappropriate (see Appendix 5). A plan must be completed as per NSW Health *Advance Planning for Quality Care at End of Life: Action Plan*

Where the answers to all of the above criteria are 'yes', the senior medical officer or Nurse Practitioner signs and dates the document. Communication of the redirection of care should be provided to those Allied Health staff or consulting teams that have been involved in the infant's care.

Section B: Assessment and Management Planning

This section provides some prompts/guidance on what areas of assessment should be covered to meet the needs of the infant and the family. These include conducting a review of existing medications and the necessity of them, food and fluids, observation frequency and other interventions or investigations.
Once a clear plan has been proposed, and the family are in agreement, the Comfort Observation & Symptom Assessment: Paediatric & Neonatal Chart should be commenced.

Comfort Observation and Symptom Assessment (COSA)

Top

COSA Paediatric & Neonatal (P&N) Chart (see Appendix 3)

Comfort Assessment Planning (page 1)

Top

In this section, assessment of cultural, spiritual and religious considerations is made. The family may have special needs or preferences (such as rituals, ceremonies, baptism) and these should be documented clearly and facilitated wherever possible.
All care preferences should be discussed, appropriately documented and facilitated as appropriate. Other considerations include the following.

Location of care
Some families may wish for their infant to be taken outside, to their local hospital, or even home for their last days of life. The logistics of arranging transfers and the associated transport should be explored, and facilitated where reasonable and practical.

Visitors
Some families may have large numbers of visitors they wish to be in attendance, or a specific list of visitors to be permitted to see the infant. This should be explored with the family, and suitable

arrangements made. This may include transferring the family into a larger room (where available) to accommodate visitors without disrupting other patients and families.

Overnight Arrangements
Where end of life care continues over a period of days, arrangements for the family should be considered for overnight where the infant is remaining in hospital.

Memory/Legacy Making
Family preferences for this are also important considerations. Include siblings wherever possible. Suggestions may include:

- Bathing the infant
- Dressing the infant in clothing of their choice
- Hand/foot prints
- Photography (*where available*; Heartfelt Photography https://www.heartfelt.org.au)
- Finger print jewellery (*where available)*
- Collecting locks of hair
- SIDS and Kids hand and foot plaster casting service (*where available*) this can only be offered for infants from 28 weeks gestation, and success is dependent on infant's skin integrity. Casting is completed after an infant has died. Check with the Social Worker before offering, as service may be limited due to SIDS & Kids staffing/policy at the time.
- Memory Box; this can be prepared as a memento for the family. This box may contain a memorial card to display a lock of the infant's hair as well as hand and foot prints, hospital identification (ID) bands, hospital name cards, Personal Health Record (PHR) (also known as 'blue book') and any other memento the family wish to keep from the infant's care in hospital e.g. cord clamp or monitoring etc. Additional memorial cards can be collected if required for separated parents or grandparents. There should be a variety of boxes available, including boxes specifically for indigenous infants and families. These may include clothing or blankets selected by families that are printed with Indigenous art or patterns, and other items collected with Indigenous significance. Some families may wish to keep the clothing the infant has been dressed in, and so it may be useful to prepare several sets.
- Purple Butterfly Sticker – where the infant may be from a multiple pregnancy, and there are surviving siblings, a purple butterfly sticker can be placed next to the surviving infant's cot card on their bed. To read more, see **Appendix 7.**

Symptom Assessment (page 2) Top

This section outlines frequency of assessment (minimum 4th hourly), and areas of assessment including pain, distress related to breathlessness, distress related to secretions, vomiting, and agitation or restlessness. The nurse enters 'C' for carer or 'S' for staff to identify the source of assessment. Each symptom is assessed as either absent, mild, moderate or severe. Symptom management should be escalated to senior staff if assessments are in the blue or yellow zones.

Comfort Observation (page 3) Top

This is performed by assessing the comfort and emotional wellbeing of the infant and family at least once per shift. If concerns are highlighted, measures to address these should be documented. Further documentation of whether the measures were effective should be recorded. At the bottom of this page is a list of LODL Information Sheets. Careful consideration should be given to the relevance and timing of providing these sheets to the family. Only the relevant sheets

should be given when the family require more information, and when the family is considered 'ready' for further written material. Social Workers can assist in this consideration.

Non Pharmacological Measures and Escalation Criteria (page 4) Top

As part of patient assessment of symptoms and comfort, the use of non-pharmacological measures may ease discomfort without requiring medication intervention.
The COSA P&N chart has been designed as a 'track and trigger' tool to provide guidance as to when escalation is required. The blue and yellow zones have associated responses outlined at the bottom of this page.

There should be a daily medical review of the infant's clinical condition, including a discussion between the family, the multidisciplinary team regarding symptoms and treatments over preceding 24 hours

Care after Death in Hospital Top

Care of an infant and their family doesn't end when the infant dies. There are aspects of care still to be undertaken, as well as the immediate and sometimes longer term support of the family. Clinicians must evaluate whether the death is reportable to the Coroner prior attending to the body of the infant (see Special Considerations - Coroners Case).

Initial Care Top

- Family should be encouraged to spend as much time as they wish with their infant. They may wish to take further photos, and cuddle him/her. They may wish to leave the hospital and return later and this should be facilitated wherever possible
- Staff should be aware of how to ensure timely verification and certification of death. Once the infant is certified as deceased, the date and time are recorded in the patient notes and a Medical Certificate Cause of Death (MCCD) is completed
- MCCD should only be completed after consultation with a Neonatologist or Paediatrician, unless it is not within 28 days (Form B)
- An Attending Practitioner's Cremation Certificate should also be completed
- The date and time of death are recorded into the notes, and admission book and entered onto relevant databases (*where applicable*)
- Parents should be informed that they will need to complete Birth Registration Statement. This form is given to them after birth, a Social Worker can assist if required
- The Social Worker will discuss arranging a funeral with the family as appropriate. The parents may be given a package of information, (LIGHT Package), for them to read over at a time that is convenient. Parents should also be directed to the Notes and Claim for Bereavement Payment of Parental Leave Pay and Family Assistance form the back page of which is completed by a medical officer before it can be submitted
- Non-coronial autopsy can be discussed and offered to the family by the medical officer. If consented, complete the following documents:
    - Authority for Post Mortem Examination; signed by parent/s
    - Authority for Post Mortem Examination; requires authorisation by Designated Officer
    - Autopsy Request Form
    - Medical Certificate Cause of Death
    - Attending Practitioner's Cremation Certificate
    - Referral to the NSW Perinatal Post-Mortem Service which offers family-focused care and consultation by NSW Health Pathology Service. The perinatal pathologist

will connect with the family to explain the tests involved and answer questions they may have. (See appendix

- There are a number of services that need to be notified by in-charge nurse/TL:
  - Notify the postnatal ward if the mother is still an inpatient
  - Notify local Child & Family Health Centre
  - Notify SWISH hearing screening team
  - Notify unit administration team/ward clerk, or Bed Allocations if after hours
  - Notify Referring Hospital if mother or infant has been transferred for care
- There are a number of services that need to be notified by medical officer:
  - Paediatrician involved in the care of the infant had been transferred for care
  - Family's general practitioner (GP)
  - Obstetric staff involved in the antenatal care and birth of the infant
- Collect test requirements as necessary (Newborn bloodspot screen (NBS), muscle biopsy, other blood samples etc.)
- Healthcare records; multidisciplinary team notes are completed prior to the healthcare records leaving the unit

Ongoing Care

Top

Some families may choose to spend significant periods of time with their infant after death. Where this seems likely, families can be offered use of a 'cool cot' to ensure that the body does not deteriorate rapidly prior to being moved to the mortuary. NSW Health guidelines indicate that a body should not be out of refrigeration for longer than 8 hours in a 24 hour period.

- Specific cultural or religious wishes and needs of the family must be considered before staff begin to prepare the body in any way for transfer to the mortuary.
- When the family are ready for the infant to be transferred to the mortuary, the following can be attended to (with parent participation where requested):
  - The infant's weight, length and head circumference are recorded in the medical record and in the PHR/'blue book'
  - The PHR/'blue book' is placed into the Memory Box
  - Ensure two ID bands clearly stating the infant's name, Date of Birth (DOB), sex and Medical Record Number (MRN) are placed on the infant's limbs
  - Cover any wounds with a waterproof dressing
  - Ensure the infant is dressed in the clothing the parents have requested
  - Place a completed Mortuary Tag (NSW Health mandated plastic tag NH606642) (see Appendix 4) with cloth tape around a limb
  - The infant is wrapped in a blanket or sheet and placed into the infant body bag, and a second Mortuary Tag is placed onto the outside of the bag, using either tape or a rubber band and attaching to handle. Ensure the infant is transported face upwards.
  - The infant is then placed into a 'papoose' or similar which can be used to transport the infant to the mortuary. If parents are present and wish to carry the infant to the mortuary, this should be facilitated
  - Staff notify a wardsperson for transfer to the mortuary
  - Staff must check Death Certificate +/- Cremation Certificate are complete, placed into the medical record and sent with the body to the mortuary. The infant's medical records will be scanned into the Digital Medical Record (DMR) in the following days
  - The infant's ID bands are checked by the wardsperson to correspond with the mortuary tags prior to leaving the unit

Special Considerations - Coroners Case

Top

The death of an infant is reportable to the coroner if:

- The infant died in circumstances where the death was not the reasonably expected outcome of a health related procedure
- The cause of death is unknown and the medical officer is unable to complete a death certificate
- In relation to section 24 of the Coroners Act, where in some circumstances previous reports to the Department of Community and Justice (DCJ) might influence the decision to assign a death as a coronial death. However, in some situations and following consultation between the Medical Practitioners, Police and the Coroner, a decision to dispense with a post mortem may be made if the reports are not related to the current death
- If there is uncertainty about whether the death should be reported, the NSW Health Duty Pathologist should be contacted. The contact details are located on the Coronial Checklist

Parent consent is not required for a coronial post-mortem examination -
However, agreement should be sought from the parents in relation to retention of body parts for purposes other than the examination, as well as wishes around return or disposal of body parts

When a death occurs that does meet the criteria for a Coroners Case, the following must be adhered to:

- Do not remove any medical devices or equipment from the body
- Contact Local Police station. Notify them of coronial death and await arrival.
- In the meantime, a copy of *SMR010.510 – Report of Death of a Patient to the Coroner (Form A)* must be completed and then faxed or emailed to the Police Local Area Command in a timely manner
- The family must be advised that the facility has notified Police and that the death has been reported to the Coroner
- The Medical Officer must be present when Police arrive to formally identify the deceased to the Police
- A death certificate must not be issued
- The infant cannot be washed, even if the surface of the skin is soiled. All surface contamination must be observed and assessed by the Forensic Pathologist. Leave the infant clothed in whatever they were dressed in at the time of death
- Do not change or replace the identification bands
- Complete NSW Health mandated plastic tag *NH606642 Mortuary Tag* (see Appendix 4) and using cloth tape attach to wrist or ankle of the infant. Complete a second tag and this is attached to the body bag after two staff members verify the infant's identity by confirming that ID bands, mortuary tags and clinical notes accompanying the infant correlate. The infant is then placed into the bag, and it is zipped up, tag placed on the outside
- The nurse or midwife, accompanied by the Police Officer, then takes the infant to the mortuary. There, the Police will place their tag on the body bag to ensure that the body remains in the state it was when transferred to their care. The Police tag can only be removed by the Forensic Pathologist
- The Medical Record must be provided to the mortuary with the body. Mortuary staff will have the record scanned by the Clinical Information Department (CID) at earliest convenience.

- The CID will make all appropriate scans of the record. Where this cannot be facilitated within 24 hours, the hospital Operational Manager can authorise staff to make photocopies of the healthcare record

Note; photocopies of the healthcare record must **not be made without the appropriate approval by the Operational Manager of the hospital*

Returning to Visit

Top

Parents are welcome to return to the hospital to spend more time with their infant.
Parents should be asked to notify the in-charge nurse/TL of their impending visit to allow time to retrieve the infant from the mortuary and have it prepared for viewing. The longest time a body can be left unrefrigerated is 8 hours. The infant can be brought to an appropriate setting within the unit several times but must have a period of refrigeration between those times if the stay is of a long duration. A 'cool cot' can also be used during these visits. To organise for the infant to return to the unit, a wardsperson is contacted to escort the staff member to the mortuary, signing the body in out of the mortuary register.

Taking the Infant Out Of the Hospital after Death

Top

There may be some circumstances where the family request to leave the hospital with the infant after death. Some families may want to travel to significant places or they may wish to take the infant to their home. Where these considerations are important to the family, they should be encouraged and facilitated.
The family are able to take the infant out of the hospital after death providing the death was within last five days and the overall journey is less than 8 hours. Firstly, the body is signed out of the mortuary by staff. A letter from the medical officer must accompany the infant's body, stating date and time of death and that the hospital is aware of the body being moved.

Bereavement

Top

Grief is universal and crosses all cultures and religions. Spiritual, religious and cultural beliefs can play a significant role in the lives of families whose infants are seriously ill or dying. Showing consideration for cultural, religious and spiritual beliefs helps families cope with the death of a loved one. Failing to carry out expected cultural rituals can lead to unresolved feeling of loss for family members. Religious and spiritual beliefs can influence decision making about active treatment as well as end of life decisions.
Throughout the end of life period, consideration of religious and spiritual needs should take place. This may require an interdisciplinary team including doctors, nurses, chaplains, social workers, and members of the community or parish to provide supportive listening and dialogue for families to comfortably express their religious or spiritual wishes.

Family Follow Up

Top

Social Workers keep a bereavement register and provide telephone follow up with parents over the initial days and months following the death of their infant. A bereavement meeting with the medical officer and the social worker is offered to parents approximately 6 weeks later. Families are welcome to return to the hospital for this meeting, or in some circumstances, the medical officer may visit the family at their home.

Staff Support

Top

Staff involved in end-of-life care will often share in the family's grief and loss and feelings of sorrow and helplessness can be felt. These emotions are normal human responses but in the workplace

can lead to compassion fatigue and disenfranchised grief, the hidden grief often downplayed in the clinical setting. Opportunities for staff to speak openly about their grief and to work through their feelings in a safe environment should be provided. These can include:

- Facilitated team debriefings
- Mentorship and collegial support particularly from more experienced staff
- One-on-one debriefing by senior colleague, social work
- Employee Assistance Program (EAP)

It is important to note, for complex and long term cases where death of the patient is anticipated, the debriefing and support process can be introduced well before the death occurs, during the palliative care or treatment process.

IMPLEMENTATION PLAN

The clinical guideline will be:

- Circulated to General Managers and Cluster Managers.
- Circulated to the clinicians via the Tiered Neonatal Network/Newborn Services, Children, Young People and Families Services and the Women's Health and Maternity Network.
- Made available on the intranet (PPG) and HNEKids website.
- Presented at facility/unit meetings and tabled for staff to action.

MONITORING AND AUDITING PLAN

- The person or leadership team who has approved the clinical guideline is responsible for ensuring timely and effective review of the guideline.
- Evaluation will require a review of the most current evidence as well as consideration of the experience of HNELHD staff in the implementation of the clinical guideline.
- Data derived from incidents, monitoring and evaluation should inform the review of the clinical guideline either as required or scheduled.
- Implementation, education support and monitoring compliance be completed by local Clinical Educators and Managers.
- Amendments to the guideline will be ratified by the Manager and Head of Newborn Services & WHaM Network (where applicable) prior to final sign off by Children, Young People and Families Services.

CONSULTATION WITH KEY STAKEHOLDERS

AUTHOR: Justine Parsons, Nurse Educator, NICU JHCH

REVIEWERS: Jo Davis, CNC Newborn Services, JHCH
Jennifier Casey, CNS, NICU, JHCH
Dr Joanne McIntosh, Neonatologist, NICU, JHCH
Kristy Chesworth, Nurse Manger, NICU, JHCH
Dr Koert De Waal, Neonatalogist, NICU, JHCH
Dr Larissa Korostenski, Head of Newborn Services, NICU, JHCH
Michelle Jenkins, Senior Pharmacist, JHCH
Michelle Stubbs, Research Nurse, NICU, JHCH
Joanna Proctor, Clinical Nurse Educator, SCU, The Maitland Hospital
Mel Hanson, Staff Specialist, Paediatrics, Tamworth Hospital
Tamworth Special Care Unit, Tamworth Hospital

CONSULTATION: Tiered Neonatal Network/Newborn Services HNELHD
Women's Health and Maternity Services Network
Children, Young People and Families Services
District Quality Use of Medicines Committee
Indigenous End of Life Care Quality Improvement Project (2019) – including representatives from Awabakal LALC, Mindaribba LALC, Indigenous staff NICU

APPROVED BY:	Natalie Butchard, Manager Newborn Services, NICU JHCH Dr Larissa Korostenski, Head of Newborn Services, NICU JHCH CYPFS Strategic Leadership Group & Clinical Quality Committee Dr Paul Craven, Executive Director, CYPFS

APPENDICES

1. Glossary & Abbreviations
2. Last Days Of Life Initiation Management Plan - Page 1 & 2
3. COSA P&N Chart - Page 1-4
4. NSW Health Mortuary Tag (Front & Back View)
5. Paediatric Resuscitation Plan

REFERENCES

1. American Academy of Pediatrics. Pediatric palliative care and hospice care commitments, guidelines and recommendations. (2013)
2. *Australian Indigenous Health InfoNet* Culturally Appropriate Palliative Care and End of Life Care (2018)
3. Australian Centre for Grief and Bereavement (2018) Working with Aboriginal or Torres Strait Islander Grief and Bereavement: A Resource for Workers.
4. Indigenous Program of Experience in the Palliative Approach (PEPA). CULTURAL CONSIDERATIONS: Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples. (2020)
5. Larcher,V; Craig,F; Bhogal,K; Wilkinson,D & Brierly,J for Royal College of Paediatrics and Child Health (2015) Making Decisions to limit treatment in life-limiting and life threatening conditions in children: a framework for practice. *Archives of Disease in Childhood.*
6. Queensland Aboriginal & Torres Strait Islander Health Branch (2015) Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying.
7. Perinatalhospice.org Perinatal Hospice & Palliative Care

FEEDBACK

Any feedback on this document should be sent to the Contact Officer listed on the front page.

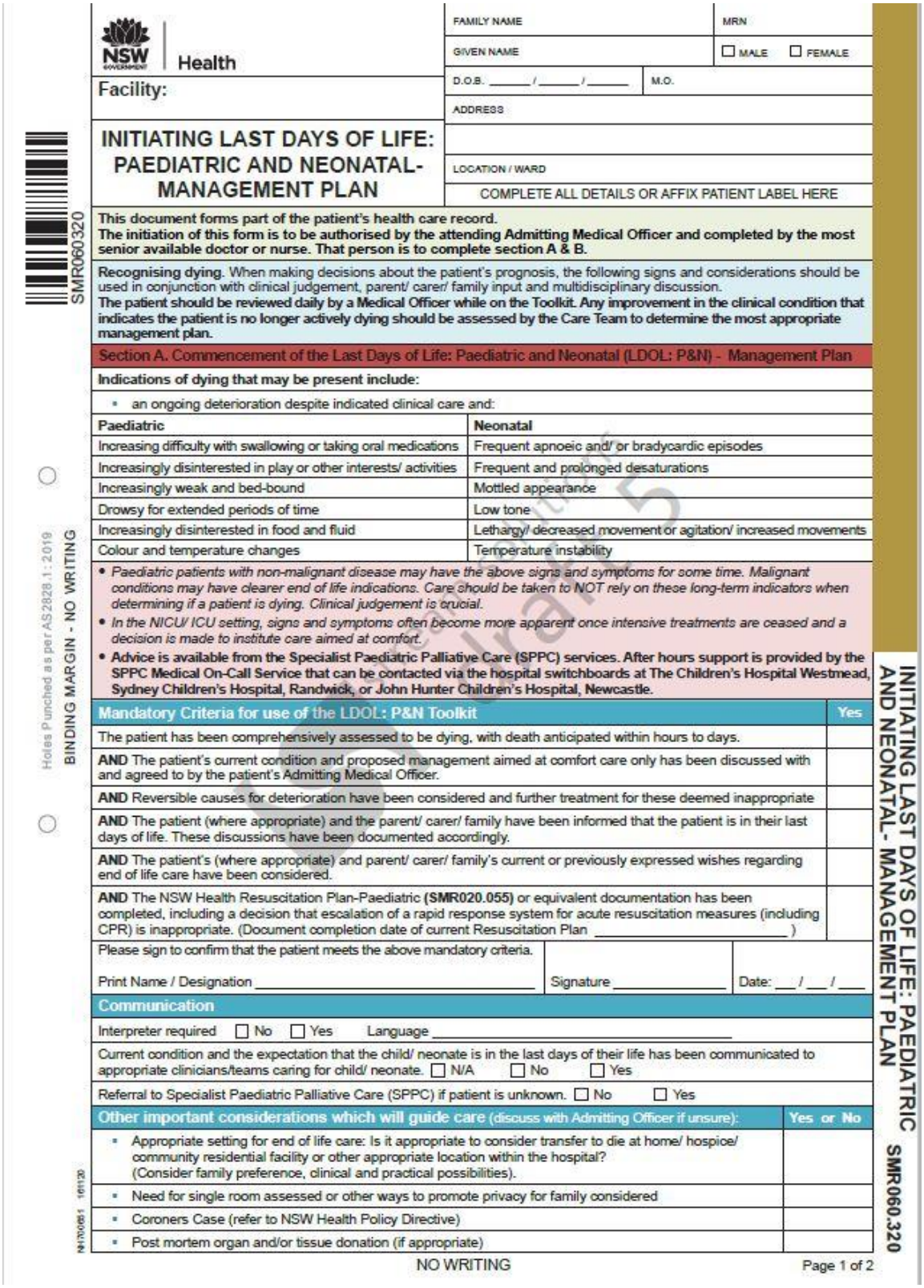
APPENDIX 1

GLOSSARY & ABBREVIATIONS

Acronym or Term	Definition
CID	Clinical Information Department
COSA	Comfort Observation and Symptom Assessment
COSA P&N	Comfort Observation and Symptom Assessment - Paediatric & Neonatal
CPR	Cardiopulmonary Resuscitation
DCJ	Department of Community and Justice
DMR	Digital Medical Records
DOB	Date of Birth
EAP	Employee Assistance Program
GP	General Practitioner
HNELHD	Hunter New England Local Health District
ID	Identification
LDOL	Last Days of Life
MCCD	Medical Certificate Cause of Death
MRN	Medical Record Number
NBS	Newborn Bloodspot Screen
NICU	Neonatal Intensive Care Unit
NNP	Neonatal Nurse Practitioner
PHR	Personal Health Record (also known as ‘blue book’)
P&N	Paediatric & Neonatal
SCU	Special Care Unit
TL	Team Leader
WHaM	Women’s Health and Maternity Network

APPENDIX 2

LAST DAYS OF LIFE INITIATION MANAGEMENT PLAN (PAGE 1)



NSW Health

Facility:

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. ____/____/____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

INITIATING LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL- MANAGEMENT PLAN

SMR060320

This document forms part of the patient's health care record.
The initiation of this form is to be authorised by the attending Admitting Medical Officer and completed by the most senior available doctor or nurse. That person is to complete section A & B.

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.
The patient should be reviewed daily by a Medical Officer 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.

Section A. Commencement of the Last Days of Life: Paediatric and Neonatal (LDOL: P&N) - 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/ decreased movement or agitation/ increased movements
Colour and temperature changes	Temperature instability

- *Paediatric patients with non-malignant disease may have the above signs and symptoms for some time. Malignant conditions may have clearer end of life indications. Care should be taken to NOT 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.*
- **Advice is available from the Specialist Paediatric Palliative Care (SPPC) services. After hours support is provided by the SPPC Medical On-Call Service that can be contacted via the hospital switchboards at The Children's Hospital Westmead, Sydney Children's Hospital, Randwick, or John Hunter Children's Hospital, Newcastle.**

Mandatory Criteria for use of the LDOL: P&N Toolkit	Yes
The patient has been comprehensively assessed to be dying, with death anticipated within hours to days.	
AND The patient's current condition and proposed management aimed at comfort care only has been discussed with and agreed to by the patient's Admitting Medical Officer.	
AND Reversible causes for deterioration have been considered and further treatment for these deemed inappropriate	
AND The patient (where appropriate) and the parent/ carer/ family have been informed that the patient is in their last days of life. These discussions have been documented accordingly.	
AND The patient's (where appropriate) and parent/ carer/ family's current or previously expressed wishes regarding end of life care have been considered.	
AND The NSW Health Resuscitation Plan-Paediatric **(SMR020.055)** or equivalent documentation has been completed, including a decision that escalation of a rapid response system for acute resuscitation measures (including CPR) is inappropriate. (Document completion date of current Resuscitation Plan _____)	

Please sign to confirm that the patient meets the above mandatory criteria.

Print Name / Designation _____ Signature _____ Date: ___/___/___

Communication

Interpreter required ☐ No ☐ Yes Language _____

Current condition and the expectation that the child/ neonate is in the last days of their life has been communicated to appropriate clinicians/teams caring for child/ neonate. ☐ N/A ☐ No ☐ Yes

Referral to Specialist Paediatric Palliative Care (SPPC) if patient is unknown. ☐ No ☐ Yes

Other important considerations which will guide care (discuss with Admitting Officer if unsure):	Yes or No
Appropriate setting for end of life care: Is it appropriate to consider transfer to die at home/ hospice/ community residential facility or other appropriate location within the hospital? (Consider family preference, clinical and practical possibilities).	
Need for single room assessed or other ways to promote privacy for family considered	
Coroners Case (refer to NSW Health Policy Directive)	
Post mortem organ and/or tissue donation (if appropriate)	

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INITIATING LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL- MANAGEMENT PLAN SMR060.320

NO WRITING

Page 1 of 2

APPENDIX 2

LAST DAYS OF LIFE INITIATION MANAGEMENT PLAN (PAGE 2)

NSW Health

Facility:

INITIATING LAST DAYS OF LIFE: PAEDIATRIC AND NEONATAL- MANAGEMENT PLAN

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. _____/_____/_____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

Section B. Management Planning to be completed by Medical Officer/ delegated senior nurse.

It may be necessary to complete this section in stages (review daily, date, and document the patient's medical record rationale). When completing this section refer to LDOL: P&N Toolkit e.g. Anticipatory Prescribing Recommendation, COSA: P&N and Symptom Management guides.

Area of Assessment	Record Date & Signature Document change in medical records			
Medication review				
N.B. Essential medication should be continued as tolerated. These may include medications that provide comfort and/ or prevent adverse symptoms. e.g. seizure medications. Medications reviewed and rationalised, discussed with parent/ carer and agreed non-essential medications ceased. Refer to LDOL: P&N PRESCRIBING RECOMMENDATIONS or contact a Specialist Paediatric Palliative Care Service for advice if unsure				
Consider the most appropriate route of medications i.e. enteral/ intravenous/ subcutaneous				
PRN parenteral medication ordered				
Food and fluids: Consider the comfort of the neonate/ child/ adolescent when determining a need for food/ fluids/ hydration. It is a normal dying response for a patient to have reduced or no food/ fluid intake. N.B • If the mother is breastfeeding or expressing breast milk, provide support if necessary to prevent pain and/ or mastitis (Refer to LDOL: P&N Managing Lactation & Breastfeeding Information Sheet). • Initiation or continuation of medical fluids and nutrition can contribute to excess secretions.				
Review oral food/ fluids/ breast/ bottle feeding and explain aspiration risks if continued.				
Review the need for assisted artificial nutrition/ hydration.				
Observations: The Comfort Observation & Symptom Assessment: Paediatric & Neonate (COSA: P&N) chart usually 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 parents/ carers to assess standard observations.				
Standard Paediatric Observation Chart (SPOC) or Neonatal Flow chart ceased.				
Comfort Observation & Symptom Assessment: Paediatric & Neonate (COSA: P&N) chart initiated				
N.B alarm noise may be distressing for the patient. De-escalation of monitoring (turning off monitors or lowering/ turning off alarms to be negotiated with patient/ parents/ carers).				
Investigations/ Interventions:				
Non-essential interventions rationalised (e.g. vascular access, imaging, pathology, IV fluids, BGL)				

Name of Medical Officer/ delegated senior nurse completing this page:

Print name: _____ Signature: _____

Designation: _____ Date: ___/___/_____

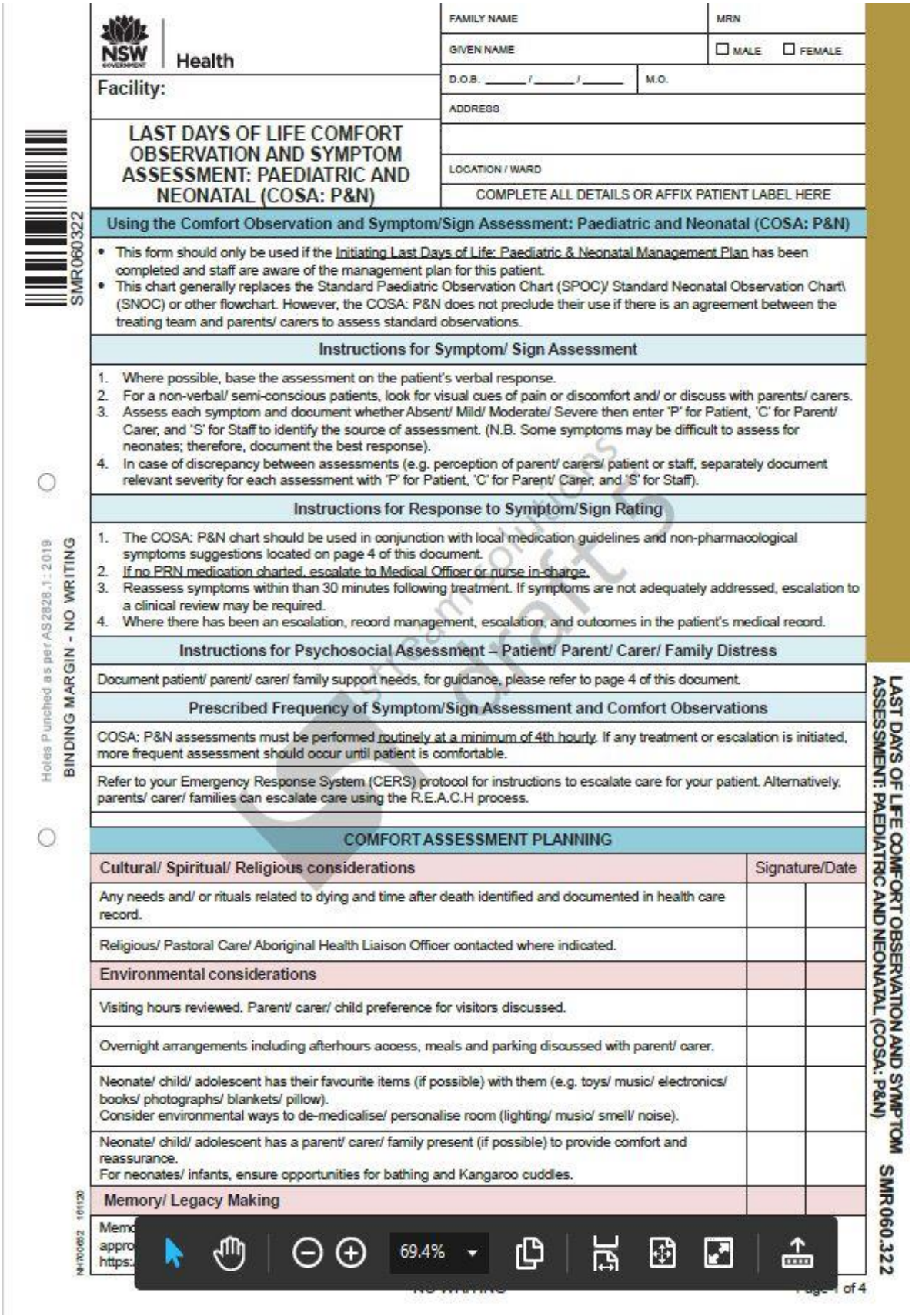
Last Days of Life Paediatric & Neonatal

Page 2 of 2

NO WRITING

APPENDIX 3

COSA P&N CHART (PAGE 1)



NSW Health

Facility:

LAST DAYS OF LIFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N)

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. ____/____/____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

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Using the Comfort Observation and Symptom/Sign Assessment: Paediatric and Neonatal (COSA: P&N)

- This form should only be used if the Initiating Last Days of Life: Paediatric & Neonatal 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 flowchart. However, the COSA: P&N does not preclude their use if there is an agreement between the treating team and parents/ carers to assess standard observations.

Instructions for Symptom/ Sign Assessment

1. Where possible, base the assessment on the patient's verbal response.
2. For a 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 enter '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 the best response).
4. In case of discrepancy between assessments (e.g. perception of parent/ carers/ patient or staff, separately document relevant severity for each assessment with 'P' for Patient, 'C' for Parent/ Carer, and 'S' for Staff).

Instructions for Response to Symptom/Sign Rating

1. The COSA: P&N chart should be used in conjunction with local medication guidelines and non-pharmacological symptoms suggestions located on page 4 of this document.
2. If no PRN medication charted, escalate to Medical Officer or nurse in-charge.
3. Reassess symptoms within than 30 minutes following treatment. If symptoms are not adequately addressed, escalation to a clinical review may be required.
4. Where there has been an escalation, record management, escalation, and outcomes in the patient's medical record.

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

Document patient/ parent/ carer/ family support needs, for guidance, please refer to page 4 of this document.

Prescribed Frequency of Symptom/Sign Assessment and Comfort Observations

COSA: P&N assessments must be performed routinely at a minimum of 4th hourly. If any treatment or escalation is initiated, more frequent assessment should occur until patient is comfortable.

Refer to your Emergency Response System (CERS) protocol for instructions to escalate care for your patient. Alternatively, parents/ carer/ families can escalate care using the R.E.A.C.H process.

COMFORT ASSESSMENT PLANNING

Cultural/ Spiritual/ Religious considerations	Signature/Date	
Any needs and/ or rituals related to dying and time after death identified and documented in health care record.		
Religious/ Pastoral Care/ Aboriginal Health Liaison Officer contacted where indicated.		
Environmental considerations		
Visiting hours reviewed. Parent/ carer/ child preference for visitors discussed.		
Overnight arrangements including afterhours access, meals and parking discussed with parent/ carer.		
Neonate/ child/ adolescent has their favourite items (if possible) with them (e.g. toys/ music/ electronics/ books/ photographs/ blankets/ pillow). Consider environmental ways to de-medicalise/ personalise room (lighting/ music/ smell/ noise).		
Neonate/ child/ adolescent has a parent/ carer/ family present (if possible) to provide comfort and reassurance. For neonates/ infants, ensure opportunities for bathing and Kangaroo cuddles.		
Memory/ Legacy Making		

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https:

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LAST DAYS OF LFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N) SMR060.322

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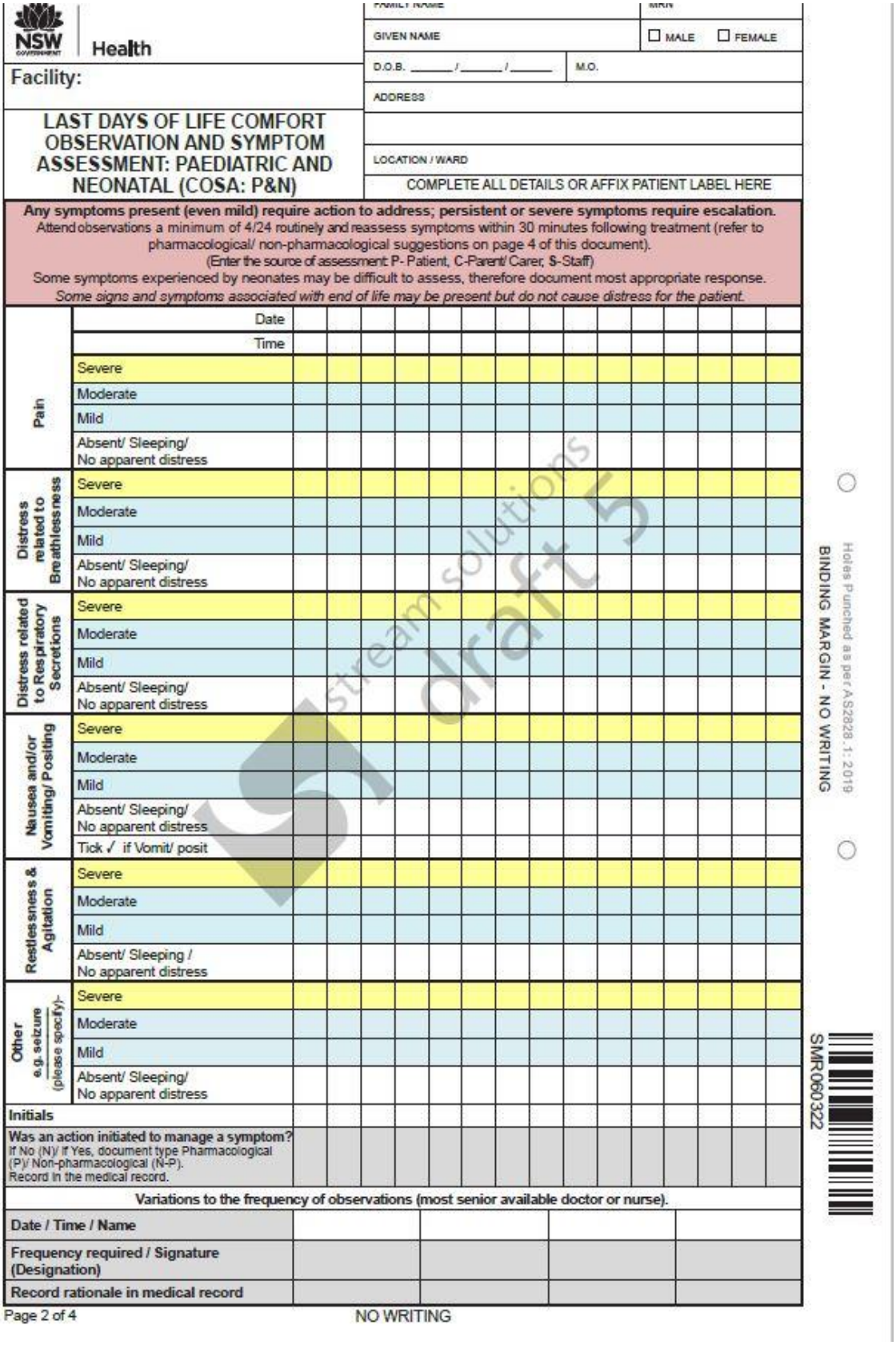
Page 1 of 4

APPENDIX 3

COSA P&N CHART (PAGE 2)



NSW Health

Facility:

LAST DAYS OF LIFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N)

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. ____/____/____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

Any symptoms present (even mild) require action to address; persistent or severe symptoms require escalation.
Attend observations a minimum of 4/24 routinely and reassess symptoms within 30 minutes following treatment (refer to pharmacological/ non-pharmacological suggestions on page 4 of this document).
(Enter the source of assessment: P- Patient, C-Parent/ Carer, S-Staff)
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 and/or Vomiting/ Positing	Severe														
	Moderate														
	Mild														
	Absent/ Sleeping/ No apparent distress														
	Tick ✓ if Vomit/ posit														
Restlessness & Agitation	Severe														
	Moderate														
	Mild														
	Absent/ Sleeping / No apparent distress														
Other e.g. seizure (please specify)-	Severe														
	Moderate														
	Mild														
	Absent/ Sleeping/ No apparent distress														
Initials															
Was an action initiated to manage a symptom? If No (N)/ If Yes, document type Pharmacological (P)/ Non-pharmacological (N-P). Record in the medical record.															

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

Date / Time / Name				
Frequency required / Signature (Designation)				
Record rationale in medical record				

Page 2 of 4

NO WRITING

APPENDIX 3

COSA P&N CHART (PAGE 3)

NSW GOVERNMENT Health

Facility:

LAST DAYS OF LIFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N)

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. ____/____/____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

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Instructions for Comfort Assessment and Management

- Review Comfort and Assessment Management Plan, attend assessments 4/24 routinely in consideration of child/ parent/ carer wishes. Document change in plan at least every shift.
- Assess each care and tick ✓ when action complete - Note N/A if after assessment no action required

If Further Action Required – document reasons and actions in patient medical record

			Date													
			Time													
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														
Mouth care	Assess	Mouth/ lips clean and moist														
	Action	Provide mouth care														
Eye care	Assess	Eyes are clean and moist														
	Action	Clean with Normal Saline. Escalate a review if redness/ irritation present														
Bladder care	Assess	Urinary: Patient clean/ comfortable (consider retention or incontinence)														
	Action	Urinary aids as required														
Bowel care	Assess	Bowels: Patient clean comfortable (consider constipation or diarrhoea)														
	Action	Bowel movements documented														
		Bowel/Stoma care managed														

- Families will require psychosocial support in the last days of life but needs vary depending on family. Some considerations are below. Psychosocial needs should be assessed once per shift and documented in medical records. These assessments do not necessarily require a discussion with patient/ parents/ carers/ family. Please refer to other clinical documentation and/ or discuss with nurse in-charge to ensure there is a support plan available.
- Assess and tick ✓ when action completed - Note N/A if after assessment no action required

			Date													
			Time													
Psychosocial support needs	Assess	Patient support needs														
	Assess	Parent/ carer/ family														
	Action	Consider non-pharmacological interventions- see page 4 of this document														
	Assess	Sibling needs														
	Action	LDOL Information brochures given to parent/ carer; procedures explained; new concerns identified; assess physical needs (nutrition), referral to social work or other allied health if required														
Spiritual/ Cultural needs	Assess	Spiritual/ religious/ cultural needs														
	Action	Appropriate support person/ pastoral care / Aboriginal Liaison Officer contacted and rituals facilitated as requested														
			Initials													

LDOL: P&N Information sheets may be used to support clinician discussion or be given to parent/ carer.
N.B. Careful consideration should be given to the relevance and timing of provision (Enter: P- Patient, C-Parent/ Carer)

- ☐ Asking questions can help
- ☐ What happens in the last days of life
- ☐ Medicines in the last days of life
- ☐ Taking your child home to die
- ☐ Supporting someone who is caring for a dying child
- ☐ Siblings and the last days of life
- ☐ Understanding your grief
- ☐ When a child dies in home
- ☐ When a child dies in hospital
- ☐ Arranging a funeral for a child or adolescent
- ☐ Arranging a funeral for a baby
- ☐ Managing lactation and breastfeeding

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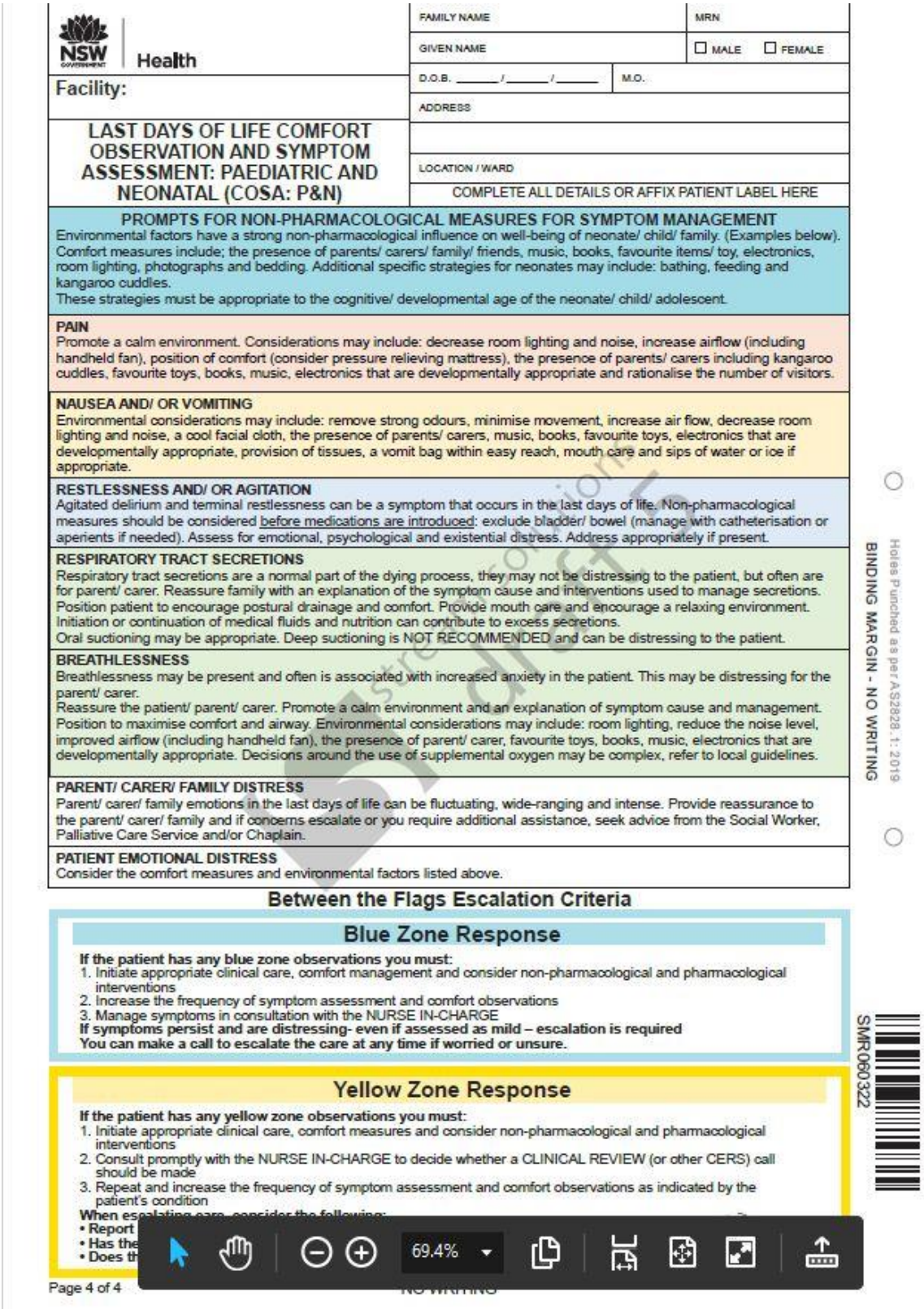
APPENDIX 3

COSA P&N CHART (PAGE 4)



NSW GOVERNMENT Health

Facility:

LAST DAYS OF LIFE COMFORT OBSERVATION AND SYMPTOM ASSESSMENT: PAEDIATRIC AND NEONATAL (COSA: P&N)

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. _____/_____/_____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

PROMPTS FOR NON-PHARMACOLOGICAL MEASURES FOR SYMPTOM MANAGEMENT

Environmental factors have a strong non-pharmacological influence on well-being of neonate/ child/ family. (Examples below). Comfort measures include; the presence of parents/ carers/ family/ friends, music, books, favourite items/ toy, electronics, room lighting, photographs and bedding. Additional specific strategies for neonates may include: bathing, feeding and kangaroo cuddles.
These strategies must be appropriate to the cognitive/ developmental age of the neonate/ child/ adolescent.

PAIN
Promote a calm environment. Considerations may include: decrease room lighting and noise, increase airflow (including handheld fan), position of comfort (consider pressure relieving mattress), the presence of parents/ carers including kangaroo cuddles, favourite toys, books, music, electronics that are developmentally appropriate and rationalise the number of visitors.

NAUSEA AND/ OR VOMITING
Environmental considerations may include: remove strong odours, minimise movement, increase air flow, decrease room lighting and noise, a cool facial cloth, the presence of parents/ carers, music, books, favourite toys, electronics that are developmentally appropriate, provision of tissues, a vomit bag within easy reach, mouth care and sips of water or ice if appropriate.

RESTLESSNESS AND/ OR AGITATION
Agitated delirium and terminal restlessness can be a symptom that occurs in the last days of life. Non-pharmacological measures should be considered before medications are introduced: exclude bladder/ bowel (manage with catheterisation or aperients if needed). Assess for emotional, psychological and existential distress. Address appropriately if present.

RESPIRATORY TRACT SECRETIONS
Respiratory tract secretions are a normal part of the dying process, they may not be distressing to the patient, but often are for parent/ carer. Reassure family with an explanation of the symptom cause and interventions used to manage secretions. Position patient to encourage postural drainage and comfort. Provide mouth care and encourage a relaxing environment. Initiation or continuation of medical fluids and nutrition can contribute to excess secretions.
Oral suctioning may be appropriate. Deep suctioning is NOT RECOMMENDED and can be distressing to the patient.

BREATHLESSNESS
Breathlessness may be present and often is associated with increased anxiety in the patient. This may be distressing for the parent/ carer.
Reassure the patient/ parent/ carer. Promote a calm environment and an explanation of symptom cause and management. Position to maximise comfort and airway. Environmental considerations may include: room lighting, reduce the noise level, improved airflow (including handheld fan), the presence of parent/ carer, favourite toys, books, music, electronics that are developmentally appropriate. Decisions around the use of supplemental oxygen may be complex, refer to local guidelines.

PARENT/ CARER/ FAMILY DISTRESS
Parent/ carer/ family emotions in the last days of life can be fluctuating, wide-ranging and intense. Provide reassurance to the parent/ carer/ family and if concerns escalate or you require additional assistance, seek advice from the Social Worker, Palliative Care Service and/or Chaplain.

PATIENT EMOTIONAL DISTRESS
Consider the comfort measures and environmental factors listed above.

Between the Flags Escalation Criteria

Blue Zone Response

If the patient has any blue zone observations you must:
1. Initiate appropriate clinical care, comfort management and consider non-pharmacological and pharmacological interventions
2. Increase the frequency of symptom assessment and comfort observations
3. Manage symptoms in consultation with the NURSE IN-CHARGE

If symptoms persist and are distressing- even if assessed as mild – escalation is required
You can make a call to escalate the care at any time if worried or unsure.

Yellow Zone Response

If the patient has any yellow zone observations you must:
1. Initiate appropriate clinical care, comfort measures and consider non-pharmacological and pharmacological interventions
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
• Has the
• Does th

Page 4 of 4

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SMR060322

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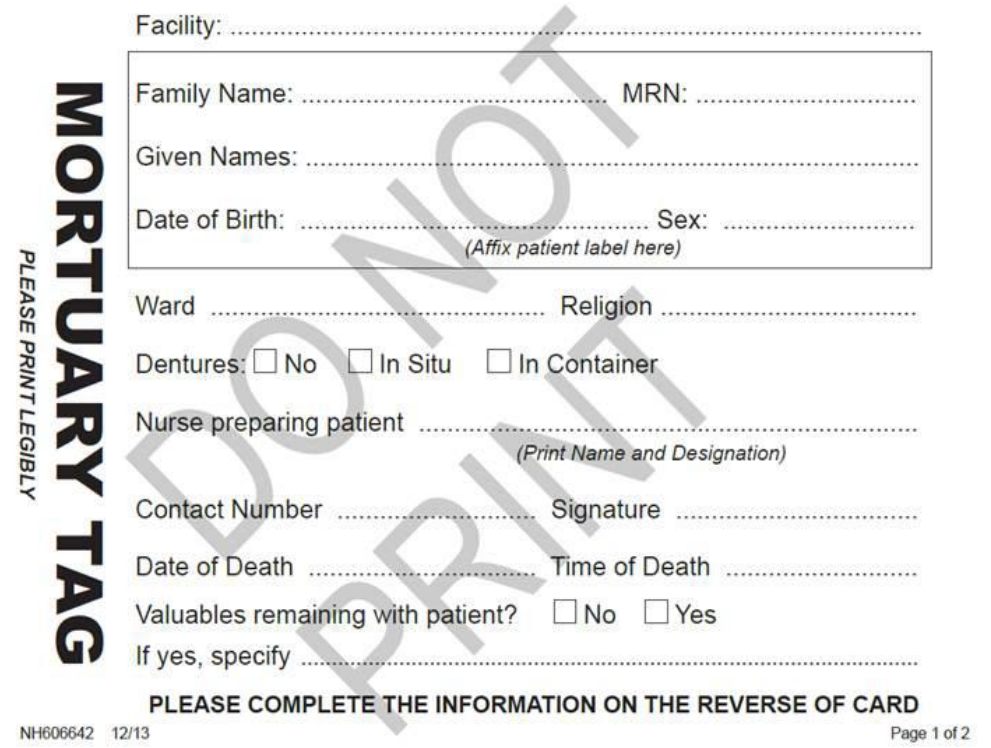
APPENDIX 4

NSW HEALTH MORTUARY TAG (FRONT & BACK VIEW)



MORTUARY TAG

PLEASE PRINT LEGIBLY

Facility: .....

Family Name: ..... MRN: .....

Given Names: .....

Date of Birth: ..... Sex: .....

(Affix patient label here)

Ward ..... Religion .....

Dentures: ☐ No ☐ In Situ ☐ In Container

Nurse preparing patient .....

(Print Name and Designation)

Contact Number ..... Signature .....

Date of Death ..... Time of Death .....

Valuables remaining with patient? ☐ No ☐ Yes

If yes, specify .....

PLEASE COMPLETE THE INFORMATION ON THE REVERSE OF CARD

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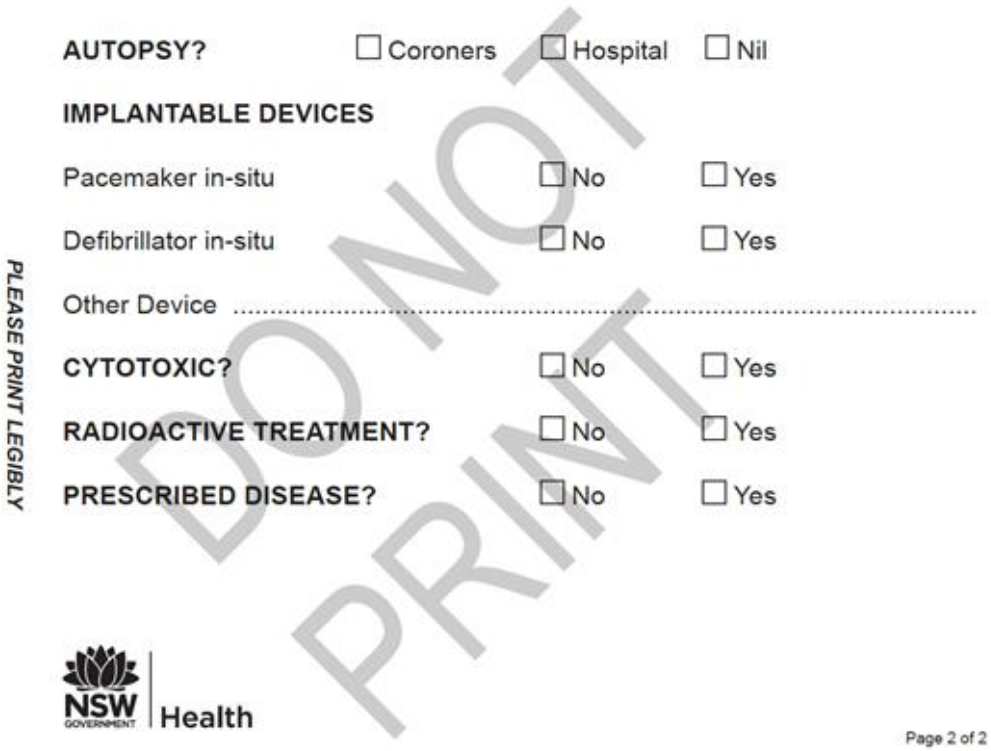
Page 1 of 2



PLEASE PRINT LEGIBLY

AUTOPSY? ☐ Coroners ☐ Hospital ☐ Nil

IMPLANTABLE DEVICES

Pacemaker in-situ ☐ No ☐ Yes

Defibrillator in-situ ☐ No ☐ Yes

Other Device .....

CYTOTOXIC? ☐ No ☐ Yes

RADIOACTIVE TREATMENT? ☐ No ☐ Yes

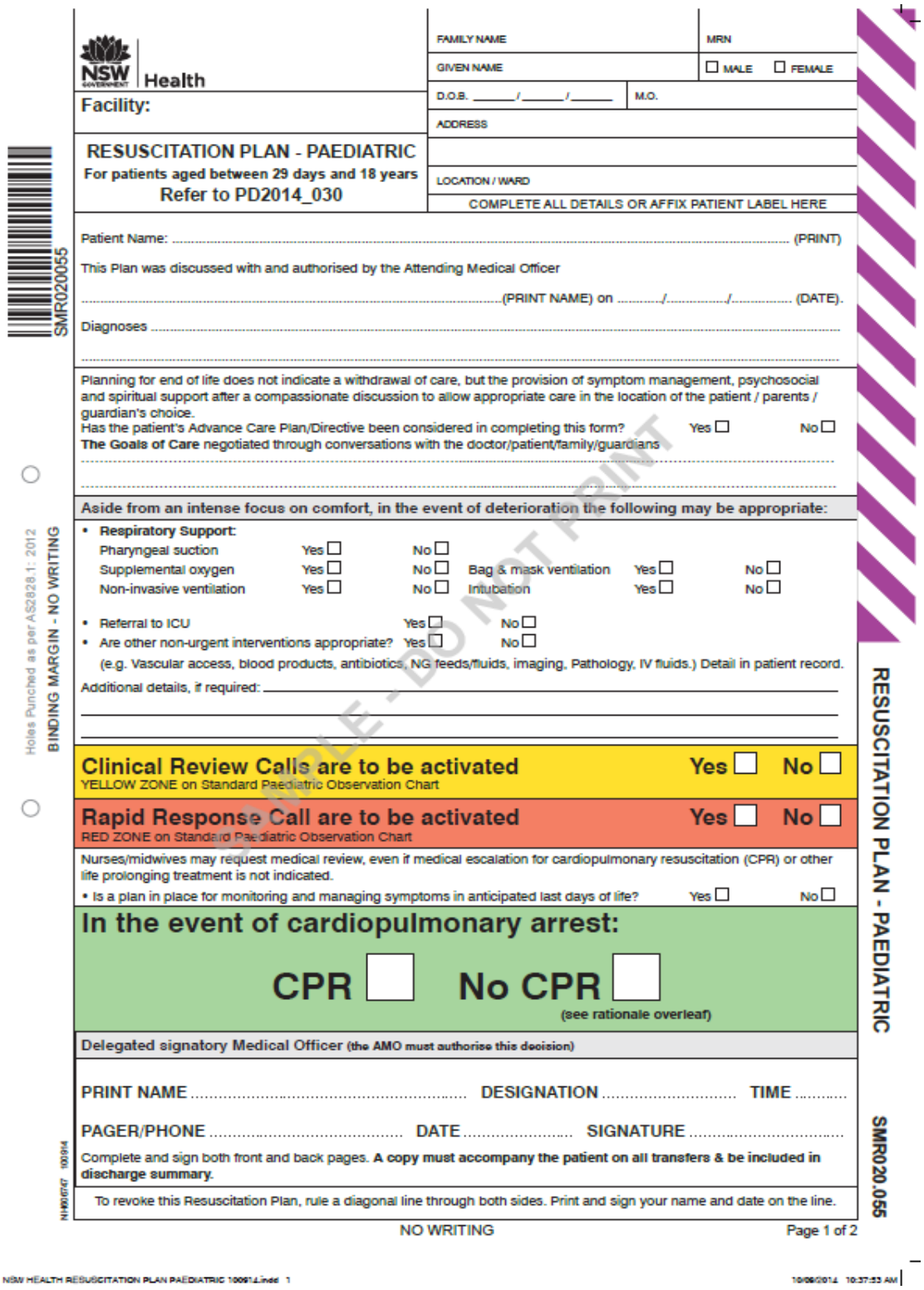
PRESCRIBED DISEASE? ☐ No ☐ Yes

NSW GOVERNMENT Health

Page 2 of 2

APPENDIX 5

PAEDIATRIC RESUSCITATION PLAN (front)



NSW Health

Facility:

RESUSCITATION PLAN - PAEDIATRIC
For patients aged between 29 days and 18 years
Refer to PD2014_030

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

SMR020055

Patient Name: ..... (PRINT)

This Plan was discussed with and authorised by the Attending Medical Officer

.....(PRINT NAME) on ...../...../..... (DATE).

Diagnoses .....

.....

Planning for end of life does not indicate a withdrawal of care, but the provision of symptom management, psychosocial and spiritual support after a compassionate discussion to allow appropriate care in the location of the patient / parents / guardian's choice.
Has the patient's Advance Care Plan/Directive been considered in completing this form? Yes ☐ No ☐
The Goals of Care negotiated through conversations with the doctor/patient/family/guardians

.....

.....

Aside from an intense focus on comfort, in the event of deterioration the following may be appropriate:

- **Respiratory Support:**

Pharyngeal suction	Yes ☐	No ☐			
Supplemental oxygen	Yes ☐	No ☐	Bag & mask ventilation	Yes ☐	No ☐
Non-invasive ventilation	Yes ☐	No ☐	Intubation	Yes ☐	No ☐

- Referral to ICU Yes ☐ No ☐
- Are other non-urgent interventions appropriate? Yes ☐ No ☐
  (e.g. Vascular access, blood products, antibiotics, NG feeds/fluids, imaging, Pathology, IV fluids.) Detail in patient record.

Additional details, if required: _____

Clinical Review Calls are to be activated Yes ☐ No ☐
YELLOW ZONE on Standard Paediatric Observation Chart

Rapid Response Call are to be activated Yes ☐ No ☐
RED ZONE on Standard Paediatric Observation Chart

Nurses/midwives may request medical review, even if medical escalation for cardiopulmonary resuscitation (CPR) or other life prolonging treatment is not indicated.

- Is a plan in place for monitoring and managing symptoms in anticipated last days of life? Yes ☐ No ☐

In the event of cardiopulmonary arrest:

CPR ☐ **No CPR** ☐
(see rationale overleaf)

Delegated signatory Medical Officer (the AMO must authorise this decision)

PRINT NAME ..... DESIGNATION ..... TIME .....

PAGER/PHONE ..... DATE ..... SIGNATURE .....

Complete and sign both front and back pages. **A copy must accompany the patient on all transfers & be included in discharge summary.**

To revoke this Resuscitation Plan, rule a diagonal line through both sides. Print and sign your name and date on the line.

NO WRITING

Page 1 of 2

Holes Punched as per AS2828.1: 2012
BINDING MARGIN - NO WRITING

RESUSCITATION PLAN - PAEDIATRIC
SMR020.055

NSW HEALTH RESUSCITATION PLAN PAEDIATRIC 10091.indd 1 10/09/2014 10:37:53 AM

APPENDIX 5

PAEDIATRIC RESUSCITATION PLAN (back)

NSW Health

Facility:

RESUSCITATION PLAN - PAEDIATRIC
For patients aged between 29 days and 18 years
Refer to PD2014_030

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

Capacity and Participation:

Use this Resuscitation Plan for minors aged from 29 days up to and including 17 years. For 18 years and above use the Adult Resuscitation Plan.
Good practice involves consulting with the family. The patient / parents / guardian have been advised they can revisit these decisions at any time.
This Plan was discussed with the patient / parents / guardians (circle which one/s apply)

on...../...../..... (date). Include the family in discussions where possible.

- **An interpreter (if required) was present.** Yes ☐ No ☐ N/A ☐

If no to any of the above, or the patient / parents / guardian have not been involved in discussions, record details in the patient's health care record.

Name of the parents / guardians / family members.....(PRINT)

Relationship to patient..... Phone number/s .....

When a child is under the parental responsibility of the Minister, only the Director General of FaCS has the delegated authority to authorise a Resuscitation Plan. Phone the Child Protection Line: 133 627 available 24/7.

Rationale for withholding CPR:

- Following consensus with the patient / parents / guardians, resuscitation is inappropriate. ☐
- The patient's condition is such that CPR is likely to result in negligible clinical benefit. ☐

Referral/Transfer/eMR Alert: (tick as appropriate)

- Referral to Palliative Care Specialist/Team/Facility ☐
- Transfer to other facility (specify) ..... ☐
- Transfer home (if patient/family choice) ☐
- Has the eMR clinical alert 'Check Resuscitation Plan' been activated ☐

This Resuscitation Plan remains valid:

- Until a change in prognosis warrants medical review. ☐
- Until the patient / parents / guardians request a change. ☐
- For this admission only (including inter-facility Ambulance transfers). ☐
- For up to 3 months for frequent and routine admissions (e.g. regular immunoglobulin infusions) ☐
- Until review date at ...../...../..... and/or time at..... ☐

Delegated signatory Medical Officer (the AMO must authorise this decision)

PRINT NAME..... DESIGNATION..... TIME.....

PAGER/PHONE..... DATE..... SIGNATURE.....

Complete and sign both front and back pages. **A copy must accompany the patient on all transfers & be included in discharge summary.**

To revoke this Resuscitation Plan, rule a diagonal line through both sides. Print and sign your name and date on the line.

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NO WRITING

Appendix 6

Perinatal Post-Mortem Service

NSW Perinatal Postmortem Service

Postmortem Indication Guide (February 2019)

Indications for postmortem examination

All families should have the value of a postmortem examination discussed with them, but not all families will benefit from a postmortem examination of their baby. The decision to progress to postmortem examination should include an open discussion with the family, the consulting obstetrician and the perinatal pathologist, if required. We acknowledge this is an incredibly difficult time for the family and a very personal decision.

When guiding the family, consider what is already known about baby and maternal factors contributing to either the death or termination reason, and what the postmortem examination might provide to inform future pregnancies.

When antenatal testing has already confirmed a major genetic abnormality, a postmortem examination might not provide any additional information. A discussion with the perinatal pathologist will highlight the types of tests that might be indicated with the aim to limit invasive examinations where possible.

All families that would benefit from a postmortem examination of their baby and the placenta should be offered the service. The examination should occur as close as possible to the baby's death, while still respecting the bereavement process and the family's need to bond with their baby.

This service now manages all non-coronial perinatal postmortems across NSW. All referrals must be in line with the NSW Perinatal Postmortem Service's referral objectives and have an appropriate testing pathway determined.

Potential referrals to the NSW Perinatal Postmortem Service include:

- Registered and unregistered babies from 14 weeks' gestation where there is an intact fetus
- Neonates up to 28 days (corrected) post-partum
- Placentas from registered and unregistered babies, neonatal deaths and high-risk neonates.

Appendix 7

Purple Butterfly Stickers

Parents from around the world have chosen the symbol of the purple butterfly to make others aware that one or more of their infants has not survived. As part of this program, purple butterfly stickers are placed near the cot cards of infants who have lost one or more siblings from the same pregnancy. This acknowledges their loss and supports the parents by recognising the mixed feelings they may be experiencing.

It is the responsibility of the nurse caring for the infant & family to be aware of the family history, discuss with the family and if consented, place a sticker by the surviving sibling's cot card.

To apply the purple butterfly to the cot surface remove the white backing and adhere the butterfly to the surface. The butterfly can be cleaned as part of the normal cleaning procedure of the cot using neutral detergent wipes.

This practice is well recognised and used in other parts of the world, particularly the UK and is being promoted in Australia by the Australian Multiple Birth Association.