## CLINICAL GUIDELINE

### End of Life Care

<table>
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<tr>
<th>Scope (Staff):</th>
<th>Nursing and Medical Staff</th>
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<tr>
<td>Scope (Area):</td>
<td>NICU KEMH, NICU PCH, NETS WA</td>
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This document should be read in conjunction with the [DISCLAIMER](#).

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Baptism
Parents can request the baptism of their infant to take place at any time. The ceremony can be conducted in private, depending on the condition of the infant.

To arrange a baptism or naming ceremony contact switchboard to page the on-call Chaplain.

The Chaplain will complete and sign the Register and will give a Baptism certificate to the parents.

Equipment
- Small trolley with lace cloth
- Baptismal bowl with water
- Cross
- Vase of flowers
- Baptismal Register and baptism certificates

Emergency Baptism
In an emergency and only if the Chaplain cannot arrive in time, a member of the nursing or medical staff may be the Minister of Baptism. The parents are responsible for requesting emergency baptism for their infant. If there is uncertainty as to the name of the infant, the baptism can be properly administered without the use of the name, so long as the identity of the infant is duly recorded in the Baptismal Register.

The Chaplain should be informed of any baptism administered in the form shown above so that she/he can offer ongoing pastoral care or referral.

In urgent circumstances at the parents’ request, a staff member present can baptise their infant.

To do this, sprinkle water on the infant’s forehead, and make the sign of the cross saying the infant’s name or not if unnamed - “I baptise you in the name of the Father, and of the Son, and of the Holy Spirit, Amen”. The Chaplain should be informed of any urgently administered baptism so that ongoing pastoral care or referral can be offered.

Note: there is a quiet room attached to the Chapel which is available at all times.

Palliative Care, Grief and Loss
Palliative care is offered to infants after extensive discussion with parents in conditions where intensive therapy is not in the infant’s best interest. Situations may include extreme prematurity, severe HIE, and extensive congenital anomalies.

It is important to note that care is not being “withdrawn” but that the care plan is changed to palliative care and the collaboration with the parents’ and their wishes are paramount.

- Palliative Care Plan For Your Baby MR235.01 is to be used to document the agreed plan with the parents.

Varying degrees of active treatment may coexist with palliative care. Although the discussion and care is led by the primary Consultant, the decision to initiate the process to offer palliative care is made in conjunction with Chaplain/spiritual person, Social Worker, Clinical Nurse Consultant and other Neonatal Consultants/other Specialist Consultants. Visiting by extended family, close friends and spiritual persons should be discussed with the parents and encouraged. A referral to Clinical Psychological Medicine may be offered and the multidisciplinary team should be aware that other family members may also need...
support. It is the parent’s choice if they would like to have any of these people present at their care plan meetings.

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

1. The child has been diagnosed as brain dead according to standard criteria.
2. 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’.
3. ‘No chance situation’: life-sustaining treatment simply delays death without providing other benefits in terms of relief of suffering.
4. ‘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.
5. The ‘unbearable’ situation. In the face of progressive, irreversible illness, the burden of further treatment is more than can be borne.

Decisions made about the nature and extent of palliative care should be carried out with an open and honest approach and documented the care plan in the medical record progress notes. Care plans need reviewing at least weekly, or at the parents’ request, or immediately if the infant’s condition changes unexpectedly. Changes to a plan must be communicated to all members of the multidisciplinary team by the person(s) amending it. If the plan is revoked this must be clearly indicated in the progress notes.

**When Meeting with the Parents Consider the Following:**

**Privacy**
Ensure both the parents (if applicable) are present for a face to face discussion. The presence of a support person, another staff member and Social Worker is encouraged. Use a quiet private room with minimal chance of disturbance. Use simple words and avoid medical terminology. Offer to come back and discuss again. Give contact details and written material where applicable and appropriate.

**Communication**
Good communication and allowing adequate time for questions and explanations is essential to a positive perspective of palliative care; always address the infant by his/her given name and arrange for an interpreter to be present if necessary. There are different methods on how to approach end of life decision making, ‘physicians should do more than offer a ‘menu’ of choices - they should recommend what they believe is the best option for the patient under the circumstances and give any reasons, based on medical, experiential, or moral factors, for such judgements’ (AAP statement).

**Palliative Care Plan**
Issues needing to be discussed include: Respiratory support, pain relief, comfort, fluids, feeding, sedation and ways of reducing noxious stimuli to the infant such as minimising uncomfortable procedures. The Palliative Care Plan will assist the parents to be involved in the plan of care for their baby.

**Anticipatory Guidance**
Prepare the parents for what the infant may look like and what to expect, for example colour changes to expect, changes in breathing patterns, how long the process may take (an honest estimate), and how time of death is defined. Discuss any fears they may have and how they might feel. It is also best to discuss post-mortem examination with the
parents at this point to allow them time to make an informed decision. Refer to the Path West Non-Coronial Post Mortem Examinations - Information for Parents.

Creating Memories
Both parents should be given every opportunity to hold, bath their infant, have photos taken, and have time together as a family (without the intrusion of health professionals) to create memories. Provide special soap or lotion to help remember scent. Keep all items that have been with the baby, for example, used measuring tape, BP cuff, ECG leads and all clothes/’cuddlies’ that have been in contact with their infant in a zip lock bag for parents to keep. Maintaining a caring and supportive environment allows the family to begin the grieving process. There are a variety of areas that the family can be together within the hospital and the parents should be supported to include the infant’s siblings during this valuable time of creating memories.

Note: where possible, infants from multiple births should have the opportunity to have a family photo taken.

Other Support/Resources
The Social Worker can assist with legal obligations such as the Registration of Birth and Death, Centrelink assistance and funeral arrangements.

Spiritual Needs and Opportunities
Religious and cultural beliefs may affect palliative care choices and need to be taken into account. Pastoral Care should be routinely offered to provide support and religious contact. Always offer the opportunity for the infant to be baptised or blessed according to the parent’s beliefs. If a Baptism or last rites need to be performed please contact switchboard to contact the on-call Chaplain.

Symptom Management
The management of symptoms is based on assessment of the infant in order to prevent or provide early relief and managing pain, discomfort, distress and hunger. Feeding can be for comfort rather than the need for IV fluids or gastric tube feeds. Care plans are always made in conjunction with the parents to incorporate choices and preferences. Maintain comfort measures using a gel mattress or sheepskin with regular repositioning of the infant using positioning aides to support the head and the limbs into the midline or on the side to enable self-regulatory measures. Encourage cuddles and skin-to-skin care. Maintain warmth for comfort. See care plan in progress notes.

Pain and/or Distress
When advising on the prescription of pain relief it should be remembered that preterm infants have an adequate development to experience painful sensations and the infant’s pain receptors are fully developed by 30-37 weeks gestational age.

- Oral sucrose with a pacifier for procedural pain.
- Morphine 100-200 mcg/kg PO as required (4-6 hourly). Sublingual morphine is available, consult pharmacy if required.
- Morphine IV infusion.

Agitation or Seizures
- Midazolam IV infusion for sedation (only to be used in conjunction with adequate analgesia).
- Phenobarbitone 20 mg/kg IV load or 5 mg/kg PO or IV maintenance.
- Clonazepam drops 1 drop (100 mcg) for agitation or seizure, repeat hourly if necessary.
Reduction of Secretions
Glycopyrrolate 20-40 mcg/kg 8 hourly PO.

Eye Care
Artificial tears e.g. genteal/lacrilube.

Lip and Mouth Care
Petroleum jelly/moist swabs.

Discharging an Infant Home for Palliative Care
A referral can be made to a general paediatrician at PMH or local hospital if the infant is likely to live for some time; or if the baby or family need on-going care. The Paediatric Palliative Care Clinical Nurse Consultant at PMH (page 7153) is available to provide extra information and help discharge the baby into the community. Silver Chain Hospice routinely provides continuing care for infants receiving palliation. Lactation suppression advice for the mother should be sought as necessary through the lactation consultant or the ward midwife.

Place of Death
Where possible the parents should be offered the opportunity to nominate where their infant dies. The following alternatives are available to the parents:

- The opportunity is provided to take their infant home if possible. A letter (Permission to transport a dying/deceased infant - MR 295.95 on letter headed paper) is given to the parents in case they are stopped by police.
- If this is not possible or not requested then the dying baby may be nursed in the parent room where there is time for the family to visit and spend time with their baby away from the rest of the unit.
- If parents prefer to return to the hospital prior to death then an appropriate place of stay must be arranged, this might be the parent room or ward area. It would be best for a case manager to be notified prior to this to limit confusion.

*Note: If death occurs at home the infant must be either brought back to the hospital within 24 hours of death or if Silver Chain/local GP are present, they can arrange collection from home by the Funeral Directors.

If returning to the unit inform the CNC/Afterhours Hospital Manager who will arrange where the parents are to bring their baby - staff will then need to arrange transfer to the mortuary.
After Death of the Infant

- Refer to “NCCU Perinatal Loss Handover and Checklist” MR 235.
- The Neonatal Paediatrician, Obstetrician, family GP and other practitioners involved in the infant’s care should be informed of the death. Post-mortem examination should always be offered to families and may be necessary in Coroners cases.
- Referral to Lactation Consultant for supportive and/or medical lactation management if necessary.
- Determination of death and notification of death via the Medical Certificate of Cause of Stillbirth or Neonatal Death (BDM 201 < 28 days age) or Medical Certificate of Cause of Infant Death (BDM 202 > 28 days age) may be completed by Silver Chain Hospice Doctor, or the General Practitioner, or Hospital Doctor if the infant is returned to hospital.
- Use of cooling Cuddle Cot allows babies who have passed away to remain with parents and families for an extended time.

Post Mortem

When an infant dies, it is the medical officer’s responsibility to discuss post mortem with the parents.

Non-Coronial or hospital Post Mortem Examinations can only be conducted with parental consent.

It is important to give detailed answers to any questions the parents may have. Although this is a very difficult time for parents, a full post mortem can provide significant information which can help them come to terms with their loss.

Parents may wish to discuss the option of a full versus limited post mortem examination.

The Post Mortem Coordinator is available to discuss with and advise the parents on all aspects of Non-Coronial post mortem examination and can be contacted on KEMH x82730 or PCH via the mortuary x60281.

Required documentation

- Non-Coronial Post Mortem Examinations: Information for Parents
- Consent for Post Mortem Examination MR236(KEMH) / MR102(PCH)
  - Copy is filed in patients notes. Original to Perinatal Pathology at KEMH and Mortuary with the body at PCH.
- Death in Hospital Form MR001
- Form 7 Cremation Act. Certificate of Medical

Coronial Matters

For planned withdrawal of care when the coroner is to be involved

Contacting the Coroner

- The Coronial Investigation Squad (CIS) hours are 07:00 – 24:00, 7 days a week. Contact via phone on 08 92675700
  - If death occurs after these hours, provide ongoing care for the family and deceased infant as per Last Office guideline. Then contact Coroner after 07:00 hours.
In certain cases the Consultant may ring the Coroners delegate prior to death to obtain a preliminary decision as to whether the death needs to be reported or a neonatal certificate can be issued.

The CIS will discuss with the family the process that will occur with the coroner’s office and provide them with contact numbers.

Infant and Parents
- The parents are allowed to hold and spend time with their infant – this time should not be rushed.
- Mementos such as lock of hair, hand and foot prints can be taken prior to CIS attending.

Medical Records
- Medical records are important to the investigation, so it is important to have a good colour copy available for the police when they arrive.
  - It is not usual for the original copy to be taken.

For unexpected or suspicious deaths
- The coroner’s delegate can be contacted at any time of the day to report a death. Contact via phone on 08 92675700.
  - Between the hours of 07:00 – 24:00 the CIS will attend.
  - Between 24:00 – 07:00 hours if the coroner is contacted police officers not attached to the CIS will attend. If staff are concerned the Consultant will determine if the police are required.

Coronial Investigation Squad
- While it is important police to gather as much information as possible it is also important ensure that the privacy and dignity of the infant and family is maintained at all times.
  - If a statement is taken it is appropriate to have a nurse/counsellor/other family member or support person present.
  - If photos are to be taken, they should be done so discreetly and with the assistance of a nurse who can maintain the dignity and privacy of the infant and parents.
  - The attending police from the CIS will attach a Coronial Office identification band to the infant.
  - The CIS will leave contact details with the family.

Infant and Parents
- The parents are allowed to hold and spend time with their infant – this time should not be rushed.
- Mementos such as lock of hair, hand and foot prints can be taken prior to CIS attending.
- Endotracheal tubes, lines, drains in these cases should not be removed.

Medical Records
- Medical records are important to the investigation, so it is important to have a good colour copy available for the police when they arrive.
Post mortem examination involving the coroner is required when:

- An infant has died within 48 hours of a surgical operation, death occurred under anaesthesia or within 48 hours of anaesthesia.
- A doctor cannot certify as to the cause of death.
- Death is due to violent or unnatural causes.
- There are suspicious circumstances.

Refer to CAHS Policy: Coronial Matters for further clarification.

Last Offices

The term ‘last offices’ is used to describe the process of preparing a deceased infant's body for transfer to the mortuary.

Parents should be offered and strongly encouraged to participate and to make mementos/memories of their infant.

Key Points

- Just prior to or immediately after death, a Newborn Screening Test (NBST) should be taken either from umbilical or arterial line. If the infant has no catheter one attempt should be performed to obtain sample and if unsuccessful document this in infant’s notes.
- Preparation of the infant’s body should be done in a private, quiet room, such as a parent room or the mother's room if she is still an inpatient. Religious and cultural considerations should be discussed with the parents. Notify Pastoral care for support and guidance.
- Once permission has been granted from the coroner all peripheral and central catheters, intercostal catheters, endotracheal tubes etc. can be removed. If permission is not granted, these catheters should where possible be coiled and taped to the infant’s body.
  - Refer to CAHS Policy: Coronial Matters for further information.
- If not a coroner’s case and the parents’ consent to a post mortem examination to be performed, it is a good idea to leave all lines in for the Pathologist to examine.
- The parents should be informed of their right to take their infant home with them for a time if they wish.
  - Complete MR295.95: Permission to Transport Deceased Baby, for the parents to carry with them.
- Parents should be referred to the Perinatal Loss Service, irrespective of the infant's age or gestation at the time of death.
  - Complete MR235 NCCU Perinatal Loss Referral and Neonatal Death Checklist.
Contents of Perinatal Loss Pack / Bereavement Pack
- Brochures: Pastoral Care Services, Non-Coronial Post Mortem Examinations, After the Death of Your Baby.
- Neonatal Perinatal Loss Service Handover and Checklist.
- BDM201 Medical Certificate of Cause of Stillbirth or Neonatal Death.
- BDM202 Medical Certificate of Cause of Death.
- Executive Director Public Health notification form.
- Special Referral to Child Health Services.
- Death in Hospital MR001.
- Death Notification form (PMH only).

Equipment

<table>
<thead>
<tr>
<th>Infant bath or washbowl</th>
<th>Mortuary box containing:</th>
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<tbody>
<tr>
<td>Towels and washcloths</td>
<td>2 x name bands</td>
</tr>
<tr>
<td>Cuddly</td>
<td>Nametags x 2 for addressograph labels</td>
</tr>
<tr>
<td>Scales and tape measure</td>
<td>Safety pins x 4</td>
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<tr>
<td>Clothes or Baptism gown chosen by parents</td>
<td>Scissors</td>
</tr>
<tr>
<td>Disposable nappy, Sheet.</td>
<td>Clear ziplok bag for lock of hair</td>
</tr>
<tr>
<td>Creating Memories booklet and Memory Box</td>
<td>Inkless wipe and card (hand and foot prints)</td>
</tr>
<tr>
<td>Perinatal Loss Pack/Bereavement Pack</td>
<td>Blueys</td>
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Procedure

<table>
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<tr>
<th>Steps</th>
<th>Additional Information</th>
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<tbody>
<tr>
<td>1. The infant is weighed and a head and length measurement is taken and recorded.</td>
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<tr>
<td>2. Take footprints and handprints using the inkless wipe.</td>
<td>A lock of hair can be placed in the booklet with the consent of the parents</td>
</tr>
<tr>
<td>3. The infant is bathed, dried and dressed in clothes of choice by the parents</td>
<td>Baptism dresses, bonnets and woollens are available, or the parents may provide their own clothing</td>
</tr>
<tr>
<td>4. Name bands x2 are replaced</td>
<td>Original name bands are given to the parents as mementos</td>
</tr>
<tr>
<td>5. Photographs are to be taken</td>
<td>If the infant is from a multiple birth, encourage taking photos with his/her sibling(s) as the parents may not have any photographs of their children together</td>
</tr>
<tr>
<td>6. Parents may place a special toy or</td>
<td>Give the parents and family as much time as</td>
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<tr>
<td>Steps</td>
<td>Additional Information</td>
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<tr>
<td>blanket with their infant</td>
<td>they need. When they are prepared for their infant to go to Perinatal Pathology, reassure them that their infant’s body will be kept safe and treated with respect</td>
</tr>
<tr>
<td>7. Once the family has completed their goodbyes, a label with an addressograph attached is pinned to the infant's outer clothing.</td>
<td></td>
</tr>
<tr>
<td>8. <strong>At KEMH</strong>, the infant is then wrapped in a bluey and then in a sheet which is secured closed with nappy safety pins. A second label with an addressograph attached is pinned to the outside of the sheet. An orderly is paged to bring the Moses basket to the nursery to take the infant to the mortuary. <strong>At PCH 3B</strong>, the infant is then wrapped in a blanket and then in a sheet which is secured closed with nappy safety pins. A second label with an addressograph attached is pinned to the outside of the sheet. The infant is then taken in arms by nursing staff to the mortuary.</td>
<td>A nurse may escort the infant to the mortuary. Complete the Orderly Mortuary Book. If staffing permits, two nursing staff members should attend for support. Complete the Mortuary Register.</td>
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<tr>
<td>9. Notify the ward clerk or Admissions to update TOPAS</td>
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**Memories Booklet:**
Cot card and all photos, baptism certificate, infant details, HC, length.

**Memory Box:**
All mementos (name bands, BP cuff, tape measure, spare disposable ECG leads, strappit etc.). These items 'belonged' to the infant and help form an identity.

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_Also refer to WA Health Statutory Medical notifications in Western Australia_

**Viewing the Infant**

**At KEMH**
Inpatients may view the infant in their room between 0830-2000 hours. Nursing staff need to phone Perinatal Pathology on extension 82730 to inform them of the infant to be viewed.
- The on-call orderly is paged to collect the infant from Perinatal Pathology.
- Ward staff will dress or wrap the infant appropriately and labels are removed before meeting with the parents.
End of Life Care

- At the end of the viewing, ward staff are to ensure the infant is labelled and wrapped correctly and then page the orderly to return the infant to Perinatal Pathology.

Following discharge the parents are able to spend time with their infant. From Monday to Friday 0800-1600 hours, this can be done in Perinatal Pathology in the Viewing/Quiet room. Parents are asked to ring Perinatal Pathology to arrange a time.

Out of hours the Hospital Clinical Manager can be contacted to arrange a viewing in a suitable location.

At PCH

The parents are asked to ring the ward or the Social Worker to arrange a visit. The infant may be viewed at any time by family and friends - with a parent present or with parental consent.

- During office hours and out of hours, Nursing staff on 3B have swipe card access to the mortuary. Nursing staff collect the infant from the mortuary and ensure the infant is wrapped appropriately. If staffing permits, 2 nursing staff should attend.
- The parents can spend time in private with their infant in either a parent’s room, if available, or the viewing room in the mortuary.
- At the end of the viewing, nursing staff are to ensure the outer wrapping around the infant is in place and has the addressograph securely fastened before returning the infant to the mortuary.

Funeral Arrangements

Hospital Cremation for Stillborn Infants and Infants < 28 Weeks

Hospital cremation can occur if the infant is stillborn and < 28 weeks gestation. A referral is routinely made to Pastoral Care Services who will provide parents with all necessary information. They complete and process the MR297 Consent for Cremation of Baby Less Than 28 Weeks Gestation. Written parental consent for cremation is required using this form. The MR297 form must be received by Perinatal Pathology before any cremation can take place. Perinatal pathology will not cremate an infant until at least three days after the MR297 form is received.

Hospital cremations are without cost to the parents, however, parents cannot attend the actual cremation.

Private Funerals Involving a Funeral Director

In the case of a stillbirth over 28 weeks of gestation or a neonatal death of any gestational age, it is necessary for parents to choose and make contact with a funeral director. Discussion with Pastoral Care Services staff and Social Worker will be valuable as these persons can offer parents support, resources, options and information that will assist with cultural, religious, spiritual requests.

Memorial Garden

The Memorial Garden is located within the grounds of King Edward Memorial Hospital. A service for the Interment of Ashes is held monthly. Details of this service are managed by Pastoral Care Services in conjunction with parents and Perinatal Pathology staff.

As an alternative to interring ashes in the Memorial Garden parents can choose to collect their infant’s ashes. This is information is given by Pastoral Care Services staff and included in the MR297 form.

In circumstances where a private cremation involving a funeral director has taken place, arrangements can be made to have the ashes interred within the Memorial Garden if requested. Arrangements will be made with Pastoral Care Services. Plaques and other
memorials are not permitted in the Memorial Garden but a register is kept of all whose ashes are interred.

**Follow Up**

Following the death of an infant, parents and family are always offered a clinical review and bereavement counselling session with the Perinatal Loss Service (extension 82128, page 3430 or mob 0416 019 020 - referral is by email, telephone or by the in-house hospital referral form). This multidisciplinary team includes a Neonatal Paediatrician, Obstetrician, Chaplain and a Pathologist and provides information, results (e.g. Post-mortem) and counselling for future pregnancy risk. The hospital provides a range of information including the KEMH Grief Package and the creation of further memories via Perinatal Pathology.

Parents of infant’s who have died are invited to attend an annual memorial service with their family and friends. The Chaplaincy service will make contact with the parents.

### Related CAHS internal policies, procedures and guidelines

<table>
<thead>
<tr>
<th>CAHS</th>
<th>PCH</th>
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<tr>
<td>- Coronal Matters</td>
<td>- Cuddle Cot</td>
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### References and related external legislation, policies, and guidelines

7. Partridge J. Wall S. Analgesia for dying infants whose life support is withdrawn or withheld. Pediatrics. 1997;99:76-9
This document can be made available in alternative formats on request for a person with a disability.

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<td>Neonatal Coordinating Group</td>
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<td>Neonatal Coordinating Group</td>
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