End of life care for neonate: care of infant having treatment redirected/dying infant in Newborn Intensive Care Unit (NICU)

Procedure Responsibilities and Authorisation

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Procedure Review History

Version	Updated by	Date Updated	Summary of Changes
3	Leanne Baker	2008	3-yearly update
4	Chantelle Hill	Nov 2012	3-yearly update
5	Amanda Gifford	Sep 2016	Includes nursing care of infant and whānau/family during pre-death, active dying and after death; brief overview of alternative religions / cultural needs
	Dale Marriott & approved by Te Puna Oranga	Sep 2016	Māori spiritual, cultural / emotional support for parents and whānau/family during the end of life journey
6	Hemi Curits, Pou Herenga, John Kopa, Team Leader Kaitiaki Frontline Service, Dale Marriott, Kaitiaki, and Richard Pagdanganan, Aira Javier, Miranda Bailey-Wild	April 2023	Māori spiritual, cultural and emotional support on decision making, priority on timing of karakia and cultural and religion needs, afterhours Kaitiaki service, exit points Medication guidelines for use in palliative care

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1 Overview

1.1 Introduction

Hutia te rito O te harakeke

Kei hea te komako e koo

Ki mai ,ki ahau he aha te mea nui

Te mea nui O teenei ao maku e ki atu kia koe

He taangata he taangata, he tāngata

Pull out the shoot

Pull out the root of the flax bush

Where will the bellbird sing

What is the greatest thing in this world

I say

The people, the people, the people

The care required for a dying child and their whānau/family is complex and challenging for the family, their community and for the health care providers involved. It requires a multidisciplinary approach with clear communication.

Irrespective of whether the death is sudden or expected, the care that is provided to an individual and their family can help minimise the immediate and long-term distress and grief commonly associated with dying and death. This healthcare should encompass the total care of the dying child's body, mind and spirit and that of their whānau/family, respecting any cultural considerations and family requests wherever feasible.

Notably, this care may be difficult to provide when the death is compounded by complex circumstances. This may include when complex medical treatment is being provided (i.e. active resuscitation), when there are time constraints surrounding the death (i.e. post mortem time frames, organ donation) or when there are legal requirements (i.e. deaths referred to the Coroner's Court). However, when whānau/families are involved in decision-making, kept informed and allowed opportunities for questions, holistic whānau/family-centred healthcare can still optimised.

1.2 Purpose

To outline the procedure during and following end of life care provided for babies in NICU so staff will be able to provide appropriate care and support that addresses the physical, emotional, social, cultural and spiritual needs of the pēpē/infant and their whānau/family.

1.3 Staff group

Te Whatu Ora staff working in Waikato NICU.

1.4 Patient / client group

Pēpē / infants and their parents, whānau/families.

1.5 Definitions

ACP	Advanced Care Plan
CNS	Clinical Nurse Specialist
CVAD	Central venous access devices
Kaitiakawaenga	Cultural support for Māori patients and whānau in mental health and addictions services.
Kaitiaki	
LMC	Lead Maternity Carer
NNP	Neonatal Nurse Practitioner
PFM	Patient Flow Management
Phases of end of life	End-of-life care should be divided into three phases: pre-death, active dying and after-death care.
SMO	Senior Medical Officer

2 Clinical Management

2.1 Advanced Care Planning

Advance Care planning is a process of discussions between whānau/families and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health. This should be documented in the pink clinical notes section for whānau/family discussions and actions summarised on the Advanced Care Plan (orange sheet) and filed in Clinical Notes.

People who may be involved in Advanced Care Planning are the following:

- Parents/caregivers/legal guardian
- nominated whanau spokesperson
- SMO
- Nurse caring for the infant
- ACNM/Coordinator

- True Colours/Kaitiaki/Chaplain or other services e.g. Rainbow Place as requested by parents. Contact can be facilitated by ACNM.
- NICU Social worker
- LMC (if <6 weeks postnatal age)
- Interpreter if required
- When such a meeting is arranged, if the birth parent remains an inpatient, the postnatal staff should also be informed to ensure sensitivity to the whānau/family.
- If antenatal diagnosis of palliation – obstetric team, Rainbow Place, True colours

2.2 Competency required

- Registered Nurses who have completed Level 3 orientation
- Kaitiaki, Kaitiakawaenga or chaplain to provide cultural support for whānau/family
- SMO, Fellow, Registrar, NNP and CNS

2.3 Equipment

- Ventilator or Neopuff
- Air and oxygen cylinders if required
- Camera
- The following items can be found in Store Room opposite Quiet Room, first cupboards on the right:
  - SANDS pack
  - Memory box
  - Keepsake cards, stamp pads, cot card, ID bracelets
  - Bathing equipment towel, face clothes, designated bath
  - Wee-Care gown
  - Measuring tape
- CuddleCot™ Cooling cot

2.4 Māori spiritual, cultural and emotional considerations

- Staff to be aware that some whānau/family may have a delegated person or spokesperson who will perform cultural practices. Obtain parental consent about involvement of spokesperson
- Seek Kaitiaki or Kaitakawaenga mental health support, or other appropriate support where needed and requested by the whānau/family. Contact the Kaitiaki, Kaitakawaenga by phone if urgent and then complete a referral via the PFM
- A karakia will be offered in consultation with whānau/family
  - Before withdrawal of care
  - Immediately after infant or mother has passed away (in situation when the baby is alive in NICU but the mother dies)
  - **Priority must be given to the cultural and religious needs of the whānau/family.** Therefore karakia should be performed before other activities, e.g. professional photography, Angel Casts and mementos. Avoid cutting pēpē/infant's hair unless in consultation with whānau/family
  - Offer the parents/whānau the option of having the Kaitiaki to accompany them to the Parent Room
  - If parents/whānau request, contact Kaitiaki/chaplain and karakia will be performed before going to mortuary/home
- Where possible, the pēpē/infant is not left alone and remains in the unit until whānau/family arrive.
- Discuss with whānau/family if they would wish to take their pēpē/infant home or transported to the mortuary.
- A Kaitiaki, if requested by parents/whānau, may support and/or accompany the whānau and pēpē/infant to the mortuary.
- Ensure any tissue from the pēpē/infant (e.g. cord) is returned to whānau/family. Check if placenta is to be retrieved from Delivery Suite or Laboratory.
- Contact the Kaitiaki or chaplains to bless the nursery and the room after the pēpē/infant has passed. All linen and equipment, e.g. tubing, fluid, and anything that has been used for the infant must remain in the nursery and the room until the nursery and the room have been whakareti or blessed. From a Māori cultural perspective the room is not spiritually cleansed until an appropriate karakia has been performed.
- If the infant dies during afterhours, contact the Kaitiaki (any time including out of hours via duty manager) or send an email to the Kaitiaki in the early morning hours, e.g. 07:00 AM, so Kaitiaki or chaplain can whakareti/bless the room or nursery ASAP.

2.5 Procedure

Refer to Care of the Deceased - Tupapaku (0133) - *Ensure the family /whanau are treated with dignity and respect while coordinating and completing the legislative and organisational requirements as soon as possible to minimise inconvenience and distress to the whānau/family.*

2.5.1 Pre-death Procedure

Any intervention should focus on supporting the whānau/family during their infant's end-of-life care.

Communication

- Communication is vital, and the words spoken should serve to validate the pēpē/infant's life and death.
- Refer to the infant by name
- Inform the parents of what to expect while their pēpē/infant is dying (what they might see, hear, smell and feel).
- Discuss how they would like to participate. Decide in advance who will be responsible for the actual removal of the endotracheal tube and turning the ventilator off.
- Inform parents of their options following the death: transfer to morgue, taking pēpē/infant's home, coroner's case; organ donation may be discussed if considered appropriate after discussion with Organ Donation New Zealand (0800 436 667) .
- Use language that does not confuse the whānau/family. Use definite words like "death or dying". Try not to use euphemisms such as "not doing well" or "passing away". Words such as: good, stable or better could cause misunderstanding for the parents that the infant could improve or survive.
- Rainbow Place can be an option for certain babies – especially if antenatal counselling indicated a possibility of pēpē/infant dying shortly after birth or there is uncertainty about length of survival.

Environment:

- Arrange for an appropriate environment for the whānau/family to be with their pēpē/infant.
- If possible, transfer pēpē/infant to this environment prior to extubation.
- Provide privacy and comfort. Do not restrict the number of visitors.
- Use the Quiet Room or Parent Room in NICU. Provide an extra fob to the whānau/family so they can access the room.
- Document extra fob has been provided and get it back before the whānau/family leave NICU.

- If none of the above available, liaise with Delivery Suite (DS) ACNM re: Manaia Room if the mother is still an in-patient in DS. Alternatively consider a side room on the post-natal ward (should be negotiated with ward staff).
- Provide low lights, decrease noise and activity.

Cultural: tupapaku / all cultures

New Zealand has its own significant cultural heritage plus a diverse cultural demographic and care should reflect the personal cultural wishes and beliefs of each whānau/family. This will ensure the individual's spiritual needs are met for all families.

- Ask parents about any religious preferences and refer to religious services (i.e. chaplain) as requested
- Offer karakia tuku I te wairua/baptism/blessing/anointing/prayer. Ensure any tissue from the pepe/infant, e.g. umbilical cord, is returned to the whānau/family. Check if the placenta is to be retrieved from Delivery Suite.
- Refer to "Appendix B - Alternative Religions / Spiritual/ Cultural Needs" – for quick reference.

2.5.2 Active dying

The time when the pēpē/infant is dying presents special challenges for both the nursing and medical teams caring for the infant and their family members.

If there was an antenatal decision for palliation – some parents would like 'normal baby' cares to happen, e.g. Vitamin K, baby being weighed, offering comfort feeds, getting dressed etc. Please discuss as appropriate with the whānau/family.

Nurse responsibilities:

- Perform hand hygiene.
- Discontinue any painful procedures and vital signs assessment. Switch off monitors in discussion with parents/whanau.
- Aspirate the nasogastric tube – consider not feeding the infant immediately prior to extubation.
- Gently suction the infant's upper airway to clear any secretions and perform oral care after extubation to promote comfort.
- Stop all infusions, except pain and/or sedation as prescribed.
- Document end-of-life interventions, changes in neonate's condition, pain assessment, and medication administration to provide comfort, the neonate's responses and the time of death.
- Check heart rate by auscultation as required or requested by parents/whānau.

Pain /comfort management:

One of the main aims of palliative care is to keep the pēpē/infant comfortable. This can often be achieved by simple nursing care measures like:

- Keeping the pēpē/infant swaddled and warm.
- Ensuring the nappy is clean and dry.
- Cuddling the pēpē/infant.
- Comfort Feeding if pēpē/infant appears hungry and able to suck.

Some pēpē/infants, who appear distressed, in pain or are having seizures, require analgesia or anticonvulsants. This should be assessed on an ongoing basis and medication given as required. Medications to relieve distressing symptoms should be provided without hesitation, in response to specific symptoms and in appropriate doses. Medications should be titrated to achieve optimum symptom control, with minimal side effect.

In considering treatment of symptoms, it is important to consider "Whose distress am I treating here?" as some conditions (such as short seizures) may not distress the pēpē/infant whereas others (such as air hunger) may be distressing.

- Maintain infusion line access, e.g. intravenous/CVAD/umbilical line,
- Ensure appropriate analgesia and sedation is prescribed and administered.
- Assess pain frequently after withdrawal of life support using N-PASS.

Recommended medications include

- Fentanyl for neonates (2916) or Morphine for neonates (2940) for pain relief
- Midazolam for neonates (2939) for sedation
- Phenobarbital Sodium for neonates (2952) for seizures

Most can be offered as continuous intravenous or subcutaneous infusions. Please refer to relevant guidelines.

Communication:

- Once again, inform the parents what to expect. Describe what the pēpē/infant will look like and what changes are expected as the pēpē/infant deteriorates e.g. colour changes, breathing changes, very quiet if on ventilator. Terminal gasping should be explained in order to reassure parents that this is not an indication of suffering.
- Inform the parents that their pēpē/infant may not die immediately after the removal of the endotracheal tube. Stress that it is difficult to predict how long the pēpē/infant will take to die.
- Encourage the parents to inform the nurse if they feel that their pēpē/infant is in any pain.

- Knowledge that they will not be abandoned, that they will have an allocated nurse looking after them who will guide them through the process.
- Be available for any question or concerns the parents may have.

Environment:

- Do not restrict the number of visitors.
- Provide privacy and comfort.
- Offer low lights, decrease noise and activity.

2.5.3 After death

Once the pēpē/infant has died, creating memories is integral to the healing of the whānau/family. It is therefore the nurse's responsibility to help ensure that as many memories as possible are created.

Nurse's responsibilities:

Notify medical staff so they can confirm and document the pēpē/infant death.

- Karakia should be offered and performed as required before other activities, e.g. before professional photography takes place and mementos can be obtained. Avoid cutting infant's hair unless in consultation with whānau/family
- If the infant is not going for a post-mortem/coroner's case, remove any lines.
- Collect mementos for parents, e.g. photos, prints, etc. Angel Casts and Heartfelt Photography contact numbers are in the L3 ACNM/Coordinator's phone and pinboard.
- Prepare the pēpē/infant for transport, as necessary, e.g. discuss preservation of the body using CuddleCot™ if not engaging with a funeral director.

Note: The casket that is available in NICU might not be big enough for some older babies, measure the length of baby for the family to be given to funeral director for length of casket to be made.

- Provide parents or whānau/family with the *Stillborn and Neonatal Death Society (SANDS) information package*. It contains information for families to guide them through care of the deceased / funeral director process.
- Offer the parents opportunities to be involved with all aspects of after-death care.
- If parents decline, respect their decision; however gently remind them that this may be the only time that they perform these tasks.
- If they still decline, encourage the parents to help the nurse with the pēpē/infant's care.
- Reassure them that the nurse is available at any moment if they require any assistance.

Environment:

- Encourage the whānau/family to spend time alone with their pēpē/infant. Provide extra chairs for whānau/family and friends.
- Show them the kitchen so they can make themselves beverages. Provide meals for the parents.
- Whānau/Family time with the infant is very important and should not be rushed or limited. This is the time when they can spend time with their infant cuddling, talking, reading stories and making ever-lasting memories.

Parental activities:

- If the infant is not going for a post-mortem/coroner's case, offer the parents the opportunity to bathe their pēpē/infant with tepid/warm water, not cold water.
- Encourage the parents to hold and dress their pēpē/infant and explain to parents the possibility of soiling from leakage of body fluids.
- Offer the parents mementos. They can include handprints, footprints, lock of hair, name bracelet, cot card and photographs. However, avoid cutting pēpē/infant's hair unless in consultation with the whānau/family.

2.5.4 Post-mortem:

In some cases a post-mortem is a legal requirement (coroner's inquest); this will be advised by the SMO. The SMO will discuss with the parents about their wishes and consent to a post-mortem. A (non-coronial) post-mortem examination may be offered to any whānau/family and may be limited to the organ(s) of interest at SMO and/or whānau/family discretion.

2.5.5 Coroner's Inquest

- If the death is unexpected, the cause of death is uncertain, or if there are concerns around the nature of the death, the case must be referred to the coroner. – Discuss this with the whānau/family
- Complete the Hospital Record of Death form - Notification of Death to the Coroner and email to address on the form. (If it is scanned to and sent from a staff member's personal hospital email address, a copy will be returned to that staff member indicating the coroner's decision to accept jurisdiction or not. This cannot be done if scanned directly from the copier)
  Please NOTE if the infant is >28 days this will be done via deathdocs, along with the electronic Medical Certificate of Death
- The duty SMO will then call the National Initial Investigation Office (NIIO) (0800 266 800) and ensure the form has been delivered. The coroner will likely phone the duty SMO back and discuss the case.

- If the coroner chooses to take jurisdiction:
  - Leave all lines/medical devices in situ (unless directed otherwise in discussion with the coroner)
  - Call Hamilton Police (07 858 6200) to inform the Duty Sergeant of the coroner's decision to take jurisdiction and that they must arrange transport of the body. Police will uplift the body from NICU to maintain a chain of evidence. They must also advise if there will be any delay to their attendance or any requirements they have whilst awaiting their arrival.
  - A death certificate is not required. This will be completed by the coroner after the inquest is complete.
  - Ensure pēpē/infant has a hospital ID bracelet on. An additional coroner's ID bracelet will be placed at time of uplift by the attending police officer. A pēpē/infant /paediatric body bag should be brought by the attendants, to be used once baby has reached the morgue.
- If the coroner declines to take jurisdiction:
  - Proceed as below
- Inform the family of the coroner's decision.
- Document the outcome in the pink section of the patient's notes.

2.5.6 Non-Coronial Post-mortem

- Please refer to Appendix D
- The SMO/Registrar/NNP is to gain permission for post-mortem and ask the parents to sign Consent for Post Mortem (Babies) (G1524HWF).
- Do not remove any lines or tubes until verified by the SMO on duty.
- Ensure infant has a hospital ID bracelet on.
- If post-mortem is required or requested out of hours:
  - When the baby is transported to the Mortuary nursing staff must send an email to mortuary@waikatodhb.health.nz to ensure they are aware of either the Post Mortem request or collection/ storage details,
- Copies of relevant medical notes must be sent to the Pathologist, therefore ensure copy of the medical notes go with the pēpē/infant during office hours. After hours, keep the medical notes in NICU office so the NICU Receptionist can forward the copies to the mortuary the following morning.
- If post-mortem is required immediately, follow the additional information in Women's Health Procedure: Post-Mortem and Mortuary Process (Ref 2989).
- Information for parents refer to

  https://www.hqsc.govt.nz/resources/resource-library/panuiinformation-for-whanaufamilies-about-post-mortem-examination-brochure/

- The mortuary staff will contact the office of the Pathologist so transport of the pēpē/infant can be arranged.
- If any belongings go with the pēpē/infant who require post-mortem, e.g. teddy, toy, clothes, these must be documented on the blue copy of Death Notice at the section "Family's/Funeral Director's receipt of valuables".
- Ensure the parents are informed about the time and date of the transport and are aware of the time of return of the pēpē/infant.
- The pēpē/infant can then be collected from the mortuary by the parents, whānau/family or the funeral directors.

2.5.7 Choices for parents after death:

1. Taking the infant to the mortuary:

- Not compulsory if it is not a Coroner's case.
- Ensure pēpē/infant has a hospital ID bracelet on.
- Blue copy of Death Notice (HP251) is sent with the pēpē/infant to the mortuary.
- If any belongings go with the pēpē/infant e.g. teddy, toy, clothes, these must be documented on the blue copy of Death Notice at the section "Family's/Funeral Director's receipt of valuables".
- Death Certificate and Cremation Certificate, if applicable, must remain in the NICU to be collected by the parents, the whānau/family or Funeral Director.
- Pēpē/infant (with ID bracelet on) can be taken carried by the parents/ whanau and escorted by an attendant to the mortuary.
- The nurse must not carry the pēpē/infant to the mortuary, use a cot and cover the pēpē/infant well to ensure privacy.
- The pēpē/infant can be collected from the mortuary by the funeral directors, whānau/family.
- Cultural practice requires that the deceased pēpē/infant should not return to NICU.

2. Arranging for a funeral director to collect the infant:

Note: It is not mandatory for the whānau/family to have a funeral director.

- Parents can ask for a funeral director to collect the pēpē/infant.
- The parents can choose a preferred funeral director, or use the local telephone directory/ google the Internet.
- Ensure pēpē/infant has ID bracelet on
- Pēpē/infant can be collected from the NICU, but if expected to be several hours or overnight without family presence, then the pēpē/infant is to be taken to the mortuary. This is due to the warm environment and temperature in NICU which will accelerate tissue deterioration. It is also not appropriate to leave the pēpē/infant alone/unattended.

- For pēpē/infants dying within 28 days of birth, the paper forms - *Medical Certificate of Causes of Fetal and Neonatal Death* (HP4721) is collected by the funeral director from the NICU Reception area.
- For pēpē/infant deaths occurring greater than 28 days old, the electronic form *Medical Certificate of Causes of death* (HP4720) will automatically be sent to the Ministry of Health and will be made available for funeral directors to retrieve digitally.
- Cremation Form, if applicable, is completed by the medical staff and collected at the same time.

3. **Taking the infant home:**
   - The family may want to contact a funeral director (they may ask you to do so).
   - Pēpē/infant can return home with parents. Ensure pēpē/infant has ID bracelet on.
   - Advice on how to transport of the baby's body by car: baby can be swaddled carried in arms by parents, carry cot, car seat or casket.
   - Parents or person uplifting pēpē/infant must sign a *Transfer of Charge of Body Form*. This process hands over the legal responsibility to the person for the handling and appropriate burial or cremation of the pēpē/infant. Give a copy to the parents and keep the form in the pēpē/infant's notes.
   - By law pēpē/infant must be buried in designated ground (a public/private urupa/cemetery). If parents wish to make alternative arrangements, they must do so through the District Court Judge.
   - The parents take Death Certificate, Cremation Form (if applicable) AND Transfer Charge of Body form with them, to give to a funeral director of their choice when they arrive home, and to register the death.
   - If the parents wish to have an open casket at the funeral, they will need to contact a funeral director within 24 hours of being home to preserve the integrity and appearance of the infant.

2.6 Documentation

All of these forms are available in a "Bereavement Pack" folder located in the NICU office in the drawer marked "Death Certificates". They should be completed as soon as the Doctor / NNP concerned is able to do so. Once used, please return the folder to the NICU admin team to restock.

N.B. A copy of any death certificate should be filed in the pēpē/infant's notes at the front so cause of death is easily located. (This will involve printing the electronic form from deathdocs if appropriate).

- Death Notice (HP251) - for hospital deaths (documents verification of death)
- Medical Certificate of Causes of death (HP4720) – now electronic through https://deathdocs.services.govt.nz/

- Medical Certificate of Causes of Fetal and Neonatal Death (HP4721)
- Certificate of Medical Practitioners (Cremation Form – Hamilton City Council form or equivalent).
- Transfer of Charge of Body (BDM39) - *If pēpē/infant is being transferred to a funeral director, a BDM39 is not required. This form is only required if the whanau/family are taking pēpē/infant home themselves.*
- Record of Death form - Notification of Death to the Coroner if required
- Requisition for post mortem form (HP561)
- Consent for Post Mortem (Babies) (G1524HWF)
- Other resources: if infants require post-mortem – *refer to flowchart in folder*
- Electronic Discharge summary within 24 hours completed by SMO and forwarded to GP and LMC

a) Nursing or Medical staff can complete

- Death notice (HP251): Pink form remains in pēpē/infant's chart and the blue form accompanies the pēpē/infant to the mortuary.

  NB: If family goes home with the pēpē/infant or funeral director collects the body from NICU, the blue copy is not required.

- Transfer of Charge of Body (BDM39), if parents take pēpē/infant home.

b) Clinical Records:

- If no post-mortem, clinical notes remain in NICU office.
- Post-mortem – clinical notes stay in NICU office. Receptionist will send copy the following morning.

NOTE:

- Copies of relevant medical notes must be sent to the Pathologist, therefore ensure copy of the medical notes go with the pēpē/infant during office hours. After hours, keep the medical notes in NICU office so the NICU Receptionist can forward the copies to the Mortuary for following morning.
- **If post-mortem is required immediately, follow the additional information in *Women's Health Procedure:* Post-Mortem and Mortuary Process *(Ref 2989).***
- Death Certificate is not required for a Coroner's case.

- Checklist before transfer (Refer to Appendix A) – Nurse must complete this checklist
- Add in that NICU administrator will arrange for appointment with caring SMO and family 6 weeks after death as optional appointment, and the process how to – e.g. proforma letter

2.6.1 Exit from the NICU - Provide options of exit

Note: Do not walk out of delivery suite entrance

Discuss options of exit with the whānau/family.

- The whānau/family can go out of NICU via the corridor past the Parent Rooms and then out of the building through the Exit next to CPASS.
- If the infant is transferred to the mortuary, inform the attendant to use the "tunnel" to go to the mortuary.

2.6.2 Follow up/ bereavement appointment

A follow up appointment will be arranged in consultation with the baby's named SMO by the NICU administrator.

Notify PMMRC coordinator

All cases will be reviewed in monthly NICU Mortality and Morbidity meeting .

Financial assistance on the death of a pēpē/infant

- Expenses associated with the death of a pēpē/infant can place great financial pressure on families. Social Welfare is able to assist families who are on a benefit meet some or all of these expenses.
- Special Needs Grant or Emergency Grant.

  An application for either of these grants can be lodged with the Social Welfare. Department to assist with general or indirect expenses associated with a funeral, e.g. travelling costs to return home, food expenses etc.
- Grant upon the Death of a Child

  This assistance is available to meet direct expenses with a funeral. The grant is income tested with each family receiving an amount appropriate to their circumstances.
- The family must present the Funeral Director's account to WINZ, who will then advise the amount of financial assistance that will be made available to the family. Some funeral directors will offer a family credit (give an account) while financial arrangements, such as Social Welfare Grant, are being arranged.

3 Staff support

An infant's death may be distressing – please refer to Critical Incident Debriefing – Neonatal Intensive Care Unit (NICU) (6349)

Further support and counselling are available through the Employee Assistance Ref 0286).

EAP contact is made via 0800327669 and is made by the person seeking EAP or by accessing the EAP website: www.eapservices.co.nz

Critical incident review as indicated

4 Patient information

- Stillborn and Neonatal Death Society (SANDS) information package
  See resources on https://www.healthpoint.co.nz/community-health-and-social-services/community-health/sands-nz/#:~:text=Sands%20New%20Zealand%20is%20a,matter%20the%20gestation%20or%20circumstances.
- Wheturangitia - https://wheturangitia.services.govt.nz/neonatal-death
- Te Hokinga ā Wairua End of Life Service - https://endoflife.services.govt.nz/welcome

5 Evidence base

5.1 References

- Garten& Bührer (2019). Pain and distress management in palliative neonatal care. *Seminars in Fetal and Neonatal Medicine, 24, (4)* https://doi.org/10.1016/j.siny.2019.04.008.
- https://www.clinicalkey.com.au/#!/content/playContent/1-s2.0-S1744165X19300381?returnurl=null&referrer=null
- Kumaran, V. & Bray, Y. (2010). Palliative Care for Newborn Infants. The Current Scene in New Zealand and the way forward. Sites: New Series. Vol 7 No 2.
- Neonatal Nurses College _ Comfort as Model of care 2015
- Safer care Victoria (2021). Palliative (end of life) neonatal care. Retrieved on April 14, 2022 from https://www.bettersafercare.vic.gov.au/clinical-guidance/neonatal/palliative-end-of-life-neonatal-care
- The Royal Children's Hospital Melbourne (2020). Death of a Child. Retrieved on April 14, 2022 from https://www.rch.org.au/rchcpg/hospital_clinical_guideline_index/Death_of_a_Child/
- Wiener, L et al. (2013). Cultural and religious considerations in paediatric palliative care. NIH Public Access Author Manuscript.

5.2 Associated Te Whatu Ora Waikato Documents

- Breaking Bad News (1696)
- Care of the Deceased - Tupapaku (0133)
- Post-Mortem and Mortuary Process (2989)

Appendix A – Checklist before transfer

1.	I.D. Bracelet on infant	
2.	Death Certificate	
3	Transfer of Charge of Body Form	
3.	Death Notices - Pink	
	Death Notices - Blue (if infant goes to Mortuary)	
4.	Cremation Forms - Pink Yes	
	- Yellow No	
5.	SANDS Information Package	
6.	**Ensure relevant contacts as per Appendix C are contacted**	

Appendix B – Alternative religions or cultural needs

New Zealand, a historically bi-cultural society, is transforming into a multicultural society which makes the delivery of palliative care more complex.

A reference file should be available listing procedural variances required for specific religious groups. This will ensure the individual spiritual needs are met for all families.

Jewish families:
Traditionally, the body is not to be touched for 10 minutes after breathing has stopped. After 10 minutes, a feather is then placed over the mouth and nose to ensure that breathing has stopped. Cleansing of the body is performed by specially trained members of the community of the same sex as the child.

Christian families:
Many Christians will want their child to be baptised if death is imminent. If this is not possible before death, a priest may conduct a naming and blessing ceremony after death.

Muslim families:
Muslims believe that all children are innocent and that after death their souls will ascend directly to paradise. This is also the case for stillbirths and miscarriages, in which case these babies are given names, bathed and shrouded. When someone dies within the Muslim culture, males always bathe males and females bathe females. The body must not be touched by a non-Muslim, but if it is unavoidable, a non-Muslim should wear disposable gloves. The body is then wrapped in plain white cotton, with the face facing towards Mecca. Hospitals' common practice of gathering memories, such as handprints or footprints as well as photographs of the infant, may cause distress to a Muslim family. This may be considered a desecration of the body.

Hindu families:
The death of a child within the Hindu faith is viewed as Gods' will. Hindus believe that things happen because they are predestined and that actions in the present life are the result of sins in a past life.

A Hindu family is likely to prefer that their child dies at home and may wish a priest to be present at the child's bedside to perform holy rites. A relative then bathes and anoints the body, males washing males and females washing females. A Holy thread is placed around the child's limbs or body, the skin may be marked with paste or a sacred leaf placed in the mouth. The body is dressed in white cloth and is faced north with the feet facing south in preparation for rebirth.

Sikh families:
It may be inappropriate to remove underclothing as this may have religious significance. The face may be cleansed if it is dirty. The body of a Sikh child is cared for by family members of the same sex as the child.

Any religious emblems (bracelets or necklets made from Holy thread) and jewellery on the body of a Hindu or Sikh child must be left in place on the body.

Chinese families:
There is no monolithic Chinese culture. Rituals will depend upon religion (Buddhism, Confucianism, Taoism, and Christianity). Illness and death is often viewed as a natural part of life. Health is the result of balancing competing energies: hot and cold, light and dark. May be reluctant to say “no” to a doctor or healthcare provider because it is considered disrespectful or cause disharmony.

Appendix C – Consider informing

Have you informed the following

This checklist serves as a reminder of who needs to be informed of an infant's passing.
Please file this in the patient clinical notes when complete.

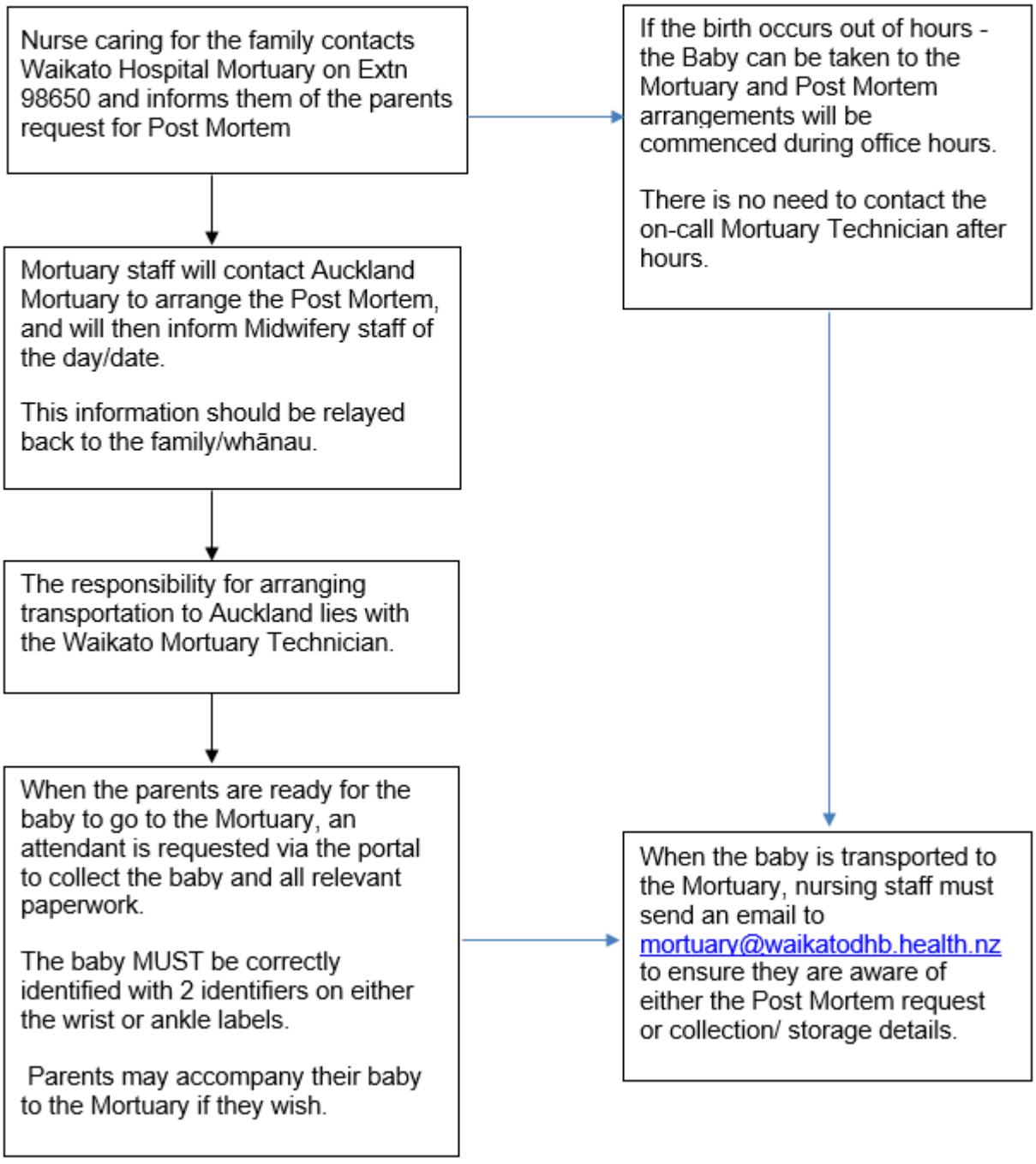
Designation	Name	Notified by	Date
Family			
GP	(need named GP, for DC letter only)		
LMC			
Duty NICU consultant			
Primary NICU consultant			
Obstetric team			
PMMRC liaison	Tracey Williams tracey.williams2@waikatodhb.health.nz		
NICU Admin	Rachel Posselt Rachel.posselt@waikatodhb.health.nz		
If Required			
Coroner	0800 266 800		
Regional centre Paeds team			

Appendix D – Post Mortem process

Port Mortem Process

(Non-coronial Office hours: Monday-Friday 08:00-16:00 hours)

Please complete all documentation as required



End of life care for neonate: care of infant having treatment redirected/dying infant in Newborn Intensive Care Unit (NICU)

Checklist for Post Mortem (to accompany pēpē/infant to Post Mortem, NOT to be filed in notes)

Place Baby sticker here

Gestation_____ Ethnicity:_____

Funeral Director used (*if known or write unknown*):_____

If family choose not to use a Funeral director please document a family contact name and number to be informed when baby is ready for collection:

_____

Include the following:

- A photocopy of the Baby notes.
- 10 printed labels for baby.
- Top white copy of medical certificate of cause of fetal and neonatal death (if Cause of Death known)
- Blue copy of Te Whatu Ora Waikato death notice (109523)
- Completed green cremation certificate (regardless of preference for cremation or burial) leave a photocopy in the notes.
- Completed return or disposal of body tissue form (*if required e.g. placenta or body tissue)*.

Ensure

- Baby has an ID bracelet on with his/her own NHI number.
- Post Mortem consent form is complete
- Parents provided with Information for parents about the Post Mortem examination of a baby (C1488HWF)

Post Mortem report to be sent to : (Consultant Neonatologist's name)

_____

Department of Neonatal Medicine, Waikato Hospital Private Bag 3200, Hamilton 3240 Please C.C report to

LMC (name & address)_____

G.P (name & address)_____

Please place baby sticker on outside of envelope and include infection status ie "Infection Free" or "known maternal carrier of……" Or "known …… infection"