Waikato District Health Board

Procedure

End of life care for neonate: care of baby having treatment withdrawn/dying baby

Procedure Responsibilities and Authorisation

Department Responsible for Procedure	NICU
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Procedure Review History

Version	Updated by	Date Updated	Description of Changes
5	Amanda Gifford	Sep 2016	Includes nursing care of infant and family/whanau during pre-death, active dying and after death; brief overview of alternative religions / cultural needs
	Dale Marriott & approved by Te Puna Oranga	Sep 2016	Maori spiritual, cultural / emotional support for parents and family/whanau during the end of life journey
4	Chantelle Hill	Nov 2012	3-yearly update
3	Leanne Baker	2008	3-yearly update

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1. Overview

1.1 Purpose

Providing end-of-life care to neonates is often a difficult experience for health care professionals. Staff must be able to provide appropriate care and support to the infant and their family/whanau that addresses the physical, emotional, social, cultural and spiritual needs of the neonate and their family. End-of-life care should be divided into three phases: pre-death, active dying and after-death care.

2. Clinical management

2.1 Competency required

Registered Nurses who have completed Level III orientation.

2.2 Criteria:

Any infant in the NICU with a medical condition incompatible with life.

2.3 Decision making:

- Discussion takes place with the parents and their support whanau/family if requested by parents regarding the seriousness of their baby's condition.
- Ask parents whether they have a nominated spokesperson.
- Staff to acknowledge some whanau/family may have a delegated spokesperson who will preform cultural practices and may also be involved in decision making. Communication is vital and should serve to validate the infant's life and death.
- In calling a family conference to discuss cessation of treatment, parents are given the opportunity to ask for support people to be with them.
  Persons to be included in this meeting:
  - i) Consultant on duty
  - ii) Parents and support person(s) nominated spokesperson
  - iii) Kaitiaki if appropriate
  - iv) Nurse caring for the baby – this is to enable explanation and reinforcement of information discussed during the meeting.
  - v) True Colours/Chaplain or other community resources as requested by parents.
  - vi) LMC
  - vii) Interpreter if required.

When this meeting is arranged:

- Inform post-natal ward staff if mother is still an inpatient. This ensures awareness of the sensitive needs of the family at this time.
- Inform social worker, with parents' consent.
- Inform Kaitiaki, if available, and requested by parents to attend the meeting. Kaitiaki will provide support for parents, family/whanau and offer karakia at the start and end of the meeting,

2.4 Equipment

- Ventilator on cot (cot in Store Room, ventilator tubing in NICU Technician Room)
- Camera

  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

2.5 Documentation:

All of these forms are available in the NICU office in the drawer marked "Death Certificates". They should be completed as soon as the Doctor concerned is able to do so.

- Death Notice (HP251)
- Medical Certificate of Causes of death (HP4720)
- 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 (BDM 39)
- Record of Death (and Notification of Death to the Coroner) form
- Requisition for Post Mortem Examination (R1026WHF)
- Consent for Post Mortem (Babies) G1524HWF)
- Other resources: if infants require post-mortem – *Delivery Suite guidance document for pregnancy and neonatal loss (A1139HWF): Appendix 2 – Perinatal post-mortems: Instructions for perinatal post-mortems in Wellington.*

Doctors are responsible for completing the following:

i) *Death Certificates* (2 books – depends on age of infant)

- Medical Certificate of Causes of Fetal and Neonatal Death (HP4721) for neonatal deaths are live-born infants, irrespective of gestational age, dying within 28 days of birth, or
- Medical Certificate of Causes of death (P4720) for infant deaths occurring greater than 28 days old.
- Certificate of Medical Practitioners (Cremation Form – Hamilton City Council form or equivalent), if requested, complete the pink form B/AB. It is collected by the funeral director from the NICU office.
- Requisition for Post Mortem Examination (R1026WHF)
- Record of Death (and Notification of Death to the Coroner) form.

ii) Nursing or Medical staff can complete

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

  NB: If family goes home with the infant or funeral director collects the body from NICU, the blue copy is not required.
- Transfer of Charge of Body (BDM 39), if parents take infant home or funeral director collects the infant.

Medical Notes:

a) If no post-mortem, notes remain in NICU office.

b) Post-mortem – notes stay in NICU office. Receptionist will send the following morning.

NB:

- Copies of relevant medical notes must be sent to the Pathologist, therefore ensure copy of the medical notes go with the baby 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 from Delivery Suite guidance document for pregnancy and neonatal loss (A1139HWF): Appendix 2 – Perinatal post-mortems: Instructions for perinatal post-mortems in Wellington (Pg17-18).

2.6 Maori spiritual, cultural/emotional considerations

- Obtain parental consent about involvement of spokesperson.
- Staff to be aware that some whanau/family may have a delegated person/spokesperson who will perform cultural practices.
- A discussion should be held with family/whanau and Kaitiaki to determine appropriate cultural response.

A karakia will be offered in consultation with whanau /family

- Before withdrawal of care
- Immediately after baby has passed away
- After karakia is performed, mementos can be obtained. Avoid cutting baby's hair unless in consultation with whanau

- If parents/whanau request, contact Kaitiaki/chaplain and karakia will be performed before going to morgue/home
- Where possible, the baby is not left alone, and remains in the unit until whanau/family arrive
- In discussion it should be determined the appropriate way the family/whanau would like the baby to be transported to the morgue.
- A Kaitiaki, as requested by parents/whanau, may support and/or accompany the whanau and baby to the morgue.
- Ensure any tissue from the baby, e.g. cord is returned to family/whanau. Check if placenta needs to be retrieved from Delivery Suite.
- Seek Kaitiaki or Kaitakawaenga mental health support (Waikato Hospital phone 021 806 171), or other appropriate support where needed and is available to the family/whanau.
- All linen and equipment, e.g. tubing, fluid, and anything that has been used for the baby must remain in the nursery and the room until the nursery and room has been whakareti or blessed by either Kaitiaki or chaplains. Contact the Kaitiaki or chaplains.

2.7 Procedure: Pre-death

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

2.7.1 Communication

Communication is vital, and the words spoken should serve to validate the infant's life and death.

- Refer to the infant by name
- Inform the parents of what to expect while their 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 baby home, coroner's case; and organ donation should be mentioned.
- Use language that does not confuse them. Use definite words like "death or dying". Try not to use euphemisms such as "not doing well or passing way". Words such as: good, stable or better" could cause misunderstanding for the parents that the infant could improve or survive.

2.7.2 Environment:

Arrange for an appropriate environment for the family to be with their infant.

- If possible, transfer baby prior to extubation.
- Provide privacy and comfort. Do not restrict the number of visitors.
- Use of Quiet Room or Parents Room in NICU.
- Side room on post-natal ward (needs to be negotiated with ward staff).
- Provide low lights, decrease noise and activity.

2.7.3 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 family. This will ensure the individual's spiritual needs are met for all families.

- Ask parents about any religious preferences
- Notify chaplain of the parents' choice
- Offer karakia tuku I te wairua/baptism/blessing/anointing/prayer. Ensure any tissue from the baby, e.g. umbilical cord, is returned to the family/whanau. Check if the placenta needs to be retrieved from Delivery Suite.
- Refer to "Appendix C: Alternative Religions / Cultural Needs" – for quick reference.

- (A reference folder is in the process of being developed and will be made available listing procedural variances required for specific religion groups.)

2.8 Procedure: Active dying

The time when the infant is dying presents special challenges for both medical staff caring for the infant and their family members.

2.8.1 Nurses responsibilities:

i) Perform hand hygiene.
ii) Discontinue any painful procedures and vital signs assessment.
iii) Aspirate the nasogastric tube – consider not feeding the infant just prior to extubation.
iv) Gently suction the baby's upper airway to clear any secretions and perform oral care after extubation to promote comfort.
v) Stop all infusion, except pain and/or sedation as prescribed.
vi) Document end-of-life interventions, changes in neonate's vital signs, pain assessment, medication administration to provide comfort, the neonate's responses and the time of death.
vii) Check heart rate PRN.

2.8.2 Pain management:

i) Maintain infusion line access, e.g. intravenous/central/umbilical line
ii) Sedate the infant appropriately, close attention being paid to their analgesia.
iii) Assess pain frequently after withdrawal of life support using the NICU Pain Scoring guideline.

2.8.3 Communication:

i) Once again, inform the parents what to expect. Describe what the baby will look like and what changes are expected as the baby deteriorates e.g. colour changes, breathing changes. Terminal gasping should be explained in order to reassure parents that this is not an indication of suffering.
ii) Inform the parents that their baby may not die immediately after the removal of the endotracheal tube. Stress that it is difficult to predict how long the infant will take to die.
iii) Encourage the parents to inform the nurse if they feel that their baby is in any pain.
iv) Knowledge that they will not be abandoned, that they will have an allocated nurse looking after them who will guide them through the process.
v) Be available for any question or concerns the parents may have.

2.8.4 Environment:

i) Do not restrict the number of visitors.
ii) Provide privacy and comfort.
iii) Offer low lights, decrease noise and activity.

2.8.5 Cultural:

If ceremonies or rituals have not yet already been performed, offer the family a chaplain of their choice, karakia, blessing, baptism, anointing or prayers.

2.9 Procedure: After death

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

2.9.1 Nurse's responsibilities:

i) Notify medical staff so they can confirm and document the infant's death.
ii) If the baby is not going for a post-mortem/coroner's case, remove any lines.
iii) Making memories, e.g. photos, prints, etc.
iv) Preparing the infant for transport, as necessary.

2.9.2 Communication:

i) Offer the parents opportunities to be involved with all aspects of after-death care.
ii) If parents decline, respect their decision, however gently remind them that this may be the only time that they perform these tasks.
iii) If they still decline, encourage the parents to help the nurse with the infant's care.
iv) Reassure them that the nurse is available at any moment if they require any assistance.

2.9.3 Environment:

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

2.9.4 Parental activities:

i) If the baby is not going for a post-mortem/coroner's case, offer the parents the opportunity to bathe their infant. Bear in mind that bathing the baby can accelerate the rate at which the skin structure alters and breaks down. Explain this to the parents and suggest bathing in tepid water.
ii) Encourage the parents to hold and dress their infant. Advise the parents not to dress baby in *SPECIAL* clothes at this time due to the possibility of soiling from leakage of body fluids.
iii) Offer the parents mementoes. They can include handprints, footprints, lock of hair, name bracelet, cot card and photographs. However, avoid cutting baby's hair unless in consultation with the family/whanau.

2.10 Post-mortem:

- In some cases post-mortem is a legal requirement; this will be advised by the Consultant. Consultant will discuss with the parents about their wish and consent to a post-mortem.
- The Consultant/Registrar is to gain permission for post-mortem and ask the parents to sign *Consent for Post Mortem (Babies) (G1524HWF).*
- Consultant will notify neonatal deaths with the Duty Coroner.
- Do not remove any lines or tubes until verified by the Consultant on duty.
- Ensure baby has a hospital ID bracelet on.
- If post-mortem is required or requested, Consultant has to contact the pathologist on call if outside office hours, so that post-mortem is not overlooked.
- Copies of relevant medical notes must be sent to the Pathologist, therefore ensure copy of the medical notes go with the baby 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 from *Delivery Suite guidance document for pregnancy and neonatal loss (A1139HWF): Appendix 2: Perinatal post-mortems: Instructions for perinatal post-mortems in Wellington* (pg. 17-18).
- The mortuary staff will contact the office of the Pathologist so transport of the baby can be arranged.
- If any belongings go with the infants 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 baby.
- The baby can then be collected from the mortuary by the parents, family/whanau or the funeral directors

2.11 Choices for parents after death:

2.11.1 Taking the baby to the mortuary:

- Not compulsory if it is not a Coroner's case.
- Ensure baby has a hospital ID bracelet on.
- Blue copy of Death Notice (HP251) is sent with the baby to the mortuary.
- If any belongings go with the baby 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 family/whanau or Funeral Director.

- Baby (with ID bracelet on) is taken to the mortuary escorted by an attendant and/or Kaitiaki. Where deemed appropriate, provided correct protocols are followed, the nurse can carry the baby, well wrapped, in arms or the baby can be placed in a cot.
- The baby can be collected from the mortuary by the funeral directors, family or whānau
- Cultural practice requires that deceased baby should not return to NICU.

2.11.2 Arranging for a funeral director to collect the baby:

- Parents can ask for a funeral director to collect the baby.
- A list of some of the local funeral directors is listed at Appendix B, or use the local telephone directory/ google the Internet.
- The parents can choose a preferred funeral director.
- Baby (with ID bracelet on) can be collected from the NICU, but if expected to be several hours or overnight without family presence, then the baby is to be taken to the mortuary. This is due to the warm environment and temperature in NICU which will accelerate tissue deterioration and also it is not appropriate to leave the baby alone/unattended.
- *Death Certificate* is collected by the funeral director from the NICU Reception area.
- *Cremation Form,* if applicable, is completed by the medical staff and collected at the same time.

2.11.3 Taking the baby home:

- The family may want to contact a funeral director (they may ask you to do so).
- Baby can return home with parents. Ensure baby has ID bracelet on.
- Baby can be swaddled carried in arms, carry cot or car seat.
- Parents or person uplifting baby 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 baby. Keep this *Transfer of Charge of Body Form* in the baby's notes.
- **By law** infants must be buried in designated ground (a public/private cemetery). If parents wish to make other arrangements, they must do so through the District Court Judge.
- The parents take *Death Certificate and Cremation Form* (if applicable) 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 baby.

2.12 Financial assistance on the death of a baby

Expenses associated with the death of an 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.

i) 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.

ii) 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. Evidence Base

3.1 Associated documents:

- Waikato DHB Service Specific NICU Medical Protocol (2010): Infant Death in NICU.
- Waikato DHB policy: Chaplaincy and pastoral care (0096)
- Waikato DHB policy: Care of deceased (0133)
- Waikato DHB guideline: Dying (care of) (4966)
- Waikato DHB guideline: Tikanga – recommended best practice (2118)

3.2 References

- Huband, S. & Trigg, T. (2000). *Practices in Children's Nursing. Guidelines for Hospital and Community.* London: Churchill Livingstone
- 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.
- Wiener, L et al. (2013). *Cultural and religious considerations in paediatric palliative care.* NIH Public Access Author Manuscript.
- De Lisle-Porter, M., Podruchny, A. M., (2009). The Dying Neonate: Family-Centered End-of-Life Care. *Neonatal Network*, 28, 2, p. 75-83.
- Wolters Kluwer (2016). End-of-life care, long-term care. *Lippincott Procedures*.

Appendix A: Checklist before transfer

1.	I.D. Bracelet on infant	
2.	Death Certificate	
3.	Death Notices - Pink	
	Death Notices - Blue (if infant goes to Mortuary)	
4.	Cremation Forms - Pink Yes	
	- Yellow No	
5.	SANDS Information Package	
6.	**Phone Calls**	
	- Duty Manager WWH	
	- Enquiries Office - 98666 (Switchboard afterhours)	
	- Kaitiaki – 021-806171	
	- Delivery Suite - 98800	
	- Mother's Ward	
	- General Practitioner (during office hours)	
	- LMC and/or Obstetrician	

Appendix B: Funeral Directors: Hamilton

Simplicity Funeral Directors Ltd
8F Railside Place
Frankton
Hamilton 3204
Phone: 07 847 6851
Fax: 07 847 6852
www.simplicityhamilton.co.nz
info@simplicityhamilton.co.nz

James R. Hill Funeral Directors
717 Grey Street
Hamilton 3214
Phone: 07 855 5541
Fax 07 854 7090
www.jamesrhill.co.nz

Pellows Funeral Service
138 Grey St
Hamilton 3216
Phone: 07 856 5129
Fax: 07 856 5132
www.pellows.co.nz
email: pellows@funerals.co.nz

Sadliers Funeral Services
358 Thames Street
Morrinsville
Phone: 07 889 4333 (Morrinsville) or 07 847 4336 (Hamilton) Fax: 07 889 4334

Seddon Park Funeral Home
49 Seddon Rd,
Hamilton.
Phone: 07 846 1561.
www.seddonpark.co.nz

Grinter's Funeral Home
3 Hallys Lane
Cambridge
Phone: 07 827 6037
office@grinters.co.nz
www.grinters.co.nz

Woolertons
127 Boundary Road
Claudelands
Hamilton 3214
Phone: 07 855 1878
Fax: 07 855 1879
phil@woolertons.co.nz
ana@woolertons.co.nz

All Funeral Directors listed offer a 24 hour, seven days a week service to the public.

Appendix C: Alternative Religions / Cultural needs

New Zealand, a historically bi-culture 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 baby, 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 card 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 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.