



NCCU CLINICAL GUIDELINES

SECTION: 20

PALLIATIVE CARE, GRIEF AND LOSS

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Palliative care and death of an infant
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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 It is important to note that care is not being "withdrawn" but that the care plan is changed to **palliative care and the collaboration with the parents' and their wishes are paramount.** [See MR 235.01, Palliative Care Plan For Your Baby.](#)

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 NCCU 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. [See WNHS Publication: 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 ziplok 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. If the parents request an alternative ceremony, or their own religious representative to conduct a ceremony, the Chaplain will organise this. Use a small trolley and place the baptismal (e.g. bowl of water, cotton wool balls, cross and vase of flowers) on the lace cloth provided together with the

Baptismal Register and certificates. The Chaplain completes and signs the Baptismal Register and will give the parents the Baptism certificate.

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.*

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 100-200mcg/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](#) 20mg/kg IV load or 5mg/kg PO or IV maintenance
- Clonazepam drops 1 drop (100microgram) for agitation or seizure, repeat hrly if necessary

REDUCTION OF SECRETIONS

Glycopyrolate 20-40microgram/kg 8 hourly PO

EYE CARE

Artificial tears e.g. gental/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/After hours 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.

POST MORTEM EXAMINATION AND CORONIAL NOTIFICATION

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 2128, 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.

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