10 CARE OF THE NEONATE

10.1.2 IMMEDIATE PALLIATIVE CARE OF THE NEONATE AND FOLLOW UP OF THE POSTNATAL WOMAN

Key Words: neonatal palliative care, Perinatal loss

GUIDING PRINCIPLES

The Perinatal period is considered to commence at 20 completed weeks of gestation and ends 28 days after birth. Palliative care at King Edward Memorial Hospital is offered to new-born infants after extensive discussion with parents in conditions where intensive therapy is not in the infant’s best interest.

Generally three circumstances exist where Perinatal palliative care may be duly considered:

• Prenatally diagnosed fetal anomalies suitable for palliative care
• Pre-viable preterm fetus where birth is imminent
• Newborns with postnatally diagnosed condition/anomalies suitable for palliative care

It is important to note that care is not being withheld but that the care plan is for palliative management in collaboration with the parents as their wishes are paramount.

Perinatal palliative care is a holistic approach to supportive and end of life care. This holistic approach “...embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the neonate/infant and support for the family. It includes the management of distressing symptoms…and care through death and bereavement.”

• Decisions made about the nature of palliative care should be carried out with an open and honest approach.
• Often the decision is made in the second and third trimester of a pregnancy.
• Once a decision has been made this must be clearly documented in the patient’s notes.
• A care plan should then be developed and placed in the woman’s medical record.
• A copy of this plan should also be distributed by Perinatal Loss Midwifery Coordinator to the Paediatric Consultant in charge of the case, the Obstetric Consultant, and a copy placed in the Complex Care file on Labour & Birth Suite.

Care plans may need reviewing 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.
CONSIDER THE FOLLOWING WHEN MEETING WITH THE PARENTS

PRIVACY
- Ensure both the parents (if applicable) are present for a face to face discussion with a Paediatric Consultant and Perinatal Loss Midwifery Coordinator.
- 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:
  - Antenatal care and management
  - Labour and birth process and management.
  - Resuscitation methods (if any), including respiratory support, pain relief, comfort, fluids, feeding and sedation.
- 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 their baby’s scent.
- Keep all items that have been with the baby, for example, used measuring tape and all clothes, cuddlies’ blankets/quilts that have been in contact with their baby 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 Paper Centrelink assistance, and assist in linking with other social support agencies.
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.
- Refer to 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).
- Phenoobarbitone 20mg/kg IV load or 5mg/kg PO or IV maintenance
- Clonazepam drops 1 drop (100microgram) for agitation or seizure, repeat hourly if necessary

Reduction of secretions

- Glycopyrolate 20-40microgram/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

- Upon commencing discharge planning from the Labour and Birth Suite or postnatal ward, a routine referral will be made to the Paediatric Palliative Care Clinical Nurse Consultant at PMH 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.

See also WNHS NCCU Clinical Guidelines Section 20: Palliative Care, Grief and Loss

FOLLOW UP

- Following the death of an infant, parents and family are always offered a clinic appointment with the Perinatal Loss Service - extension 2128, page 3430 or mob 0416 019 020 – referral is to be made by telephone or by the in-house hospital referral form.

- The multidisciplinary team includes a Neonatal Paediatrician, Obstetrician, Chaplain and a Pathologist and provides information, results (e.g. Post-mortem) and counselling for future pregnancy

REFERENCES (STANDARDS)


Do not keep printed versions of guidelines as currency of information cannot be guaranteed.
Access the current version from the WNHS website.