POLICY

All newborns who require palliative care are referred to a Pediatrician/Neonatologist. The Pediatrician/Neonatologist involved directs newborn care with support from Canuck Place as needed.

Parents are involved in all aspects of decision making related to the care of their dying newborn.

Applicability: Interdisciplinary care for the palliative newborn and their family is offered throughout the Maternal Gyne Program given the parents have chosen to provide only comfort measures and do not require advanced treatment in the Neonatal Intensive Care Unit (NICU).

PROCEDURE

1.0 Advanced Care Planning - The Multidisciplinary Team

Appropriate services/departments are determined on a case by case basis. The multidisciplinary team includes the woman and family as well as:

- Pediatrician/Neonatologist
- Canuck Place Children’s Hospice team (physicians, nurses, counsellors)
- Primary Care Physician/Registered Midwife
- Perinatal Clinical Educator
- Charge Nurse
- Senior Practice Leader, Perinatal
- Program Coordinator
- Social Work
- Spiritual Care
- Aboriginal Liaison
- Ethicist

1.2 Care Plan and Support

- Provide a written care plan to assist staff in caring for the dying newborn and grieving family.
- Canuck Place Children’s Hospice can provide palliative care support; and it is helpful to, involve them as early as possible. For a perinatal or newborn palliative care consult, page the Canuck Place Physician-on-call through hospital paging, or contact an advanced practice nurse at Canuck Place (604-742-3475)
- Canuck Place Nursing staff is also able assist with questions regarding nursing care for the palliative newborn. Call the Canuck Place nursing station or Clinical Nurse Specialist if support is required (604-742-3475)

1.3 Nursing Care and Assessment

- There is no need for routine vital signs. Take baseline vital signs once and then only when a significant change from baseline is suspected, or at parental request
- Assess for signs and symptoms of respiratory distress. Relief strategies may include: repositioning, oxygen and oral morphine.
- Assess comfort, and consider morphine for pain management. Encourage other comfort measures such as skin to skin contact, lullabies, swaddling, pacifier use, and skin care. Respect and encourage cultural rituals.
1.4 Feeding
• Assess the parents’ wishes for feeding.
• Breastfeeding/ bottle-feeding may be offered if desired by the family.
• Ensure family understands that as newborns die, the gastrointestinal (GI) system slows down so feeding can become a source of discomfort. Feeding/ hydration may need to be reconsidered as the newborn's condition changes.
• For newborns who have on-going nutritional needs but are unable to feed on their own, tube feeding may be considered (See Enteral Feeding Guidelines, NN.08.01). Call the NICU Educator or CRN for support if required.

1.5 When to Call a Pediatrician
• If the newborn appears distressed: irritable, seizing, or appears uncomfortable (eg. grimacing, crying is more pronounced, breathing is laboured).
• If the team would like support with decision making.

1.6 Care of the Deceased Newborn
• Registered Nurse to note time of death and inform Attending Physician or delegate immediately.
• Physician to respond and assess within one hour of notification and complete necessary documentation (See Deceased Care of the Newborn: Any Gestational Age, WW.18.05) unless metabolic autopsy indicated.
  Note: When a metabolic autopsy is indicated, autopsy is conducted within one hour of death as it is time sensitive. Attending Physician to arrange via Pathologist-On Call beforehand (Call paging 2161).

1.7 Family Support
• Notify Social Work and complete a referral form
• Offer the family Spiritual Care - A multi-faith service providing spiritual (religious and/or non-religious) and emotional support. Spiritual care services are available 24 hours/ day, 7 days/ week.
• Offer Aboriginal Liaison services if the woman is of first nations heritage.
• Call translation services if the use of an interpreter is required.

1.8 Staff Support
• Staff who are not directly involved in the care of the palliative newborn/family are encouraged to provide acknowledgement and support to the staff who are providing palliative care.
• Staff are encouraged to access spiritual care, social work and the hospital ethicist as a means of support when emotional/ spiritual/ moral/ ethical issues arise.
• Staff may also access personal counselling services and emotional support through the Employee & Family Assistance Program (Contact: 1–800–505-4929).
1.9 Discharge

- If the parents wish to take their newborn out of the hospital during the dying process arrangements can be made to:

1. Take the newborn home with support from Canuck Place Children’s Hospice. Canuck Place can assist with ensuring appropriate resources and care plan in place and will provide support to any medical team caring for the family at home (e.g. Family Physician/Community Health RN)

2. Transfer the newborn to Canuck Place for ongoing care. The mother must be ready for discharge from hospital. The family may stay with the newborn at Canuck Place.

- When discharge or transfer is anticipated contact Canuck Place (604-742-3475) as soon as possible if.
- Non-urgent referrals can be made by any health care professional.
- Urgent consults can be made by paging the Canuck Place Physician-on-call through hospital paging, or contacting an advanced practice nurse at Canuck Place (604-742-3475)
- Canuck Place provides family support, symptom management and end-of-life care and will offer family follow-up for bereavement care.

2.0 If family is unable to care for a palliative newborn

- Newborn should not be left alone and comfort measures provided (as listed above) by available team member

DOCUMENTATION

- Nursing Care Plan
- Canuck Place Referral Form (Only required when MFM/Genetics Prenatal Consult)
- Interprofessional Progress Notes