Guideline: Perinatal Palliative Care for Families and their Newborns at ANMC

1. Background: Perinatal palliative care provides comfort and quality of life for newborns with confirmed life-limiting diagnoses, for which long-term survival after birth is not expected.

2. Purpose: To guide coordinated perinatal palliative care provided on the Alaska Native Health Campus.

3. Scope: Maternal child health care teams at on the Alaska Native Health Campus.

4. Prenatal Workflow:

    a. Initial MFM Consultation
        i. Referral reviewed by MFM and RN Case Manager
        ii. Plan for level II anatomy ultrasound and MFM consultation
        iii. Plan MFM follow up visit one week after diagnosis
            1. Office visit if local, phone visit if rural
            2. Review questions
            3. Evaluate emotional well being
            4. Discuss plan and desires
        iv. MFM to present at high-risk meeting to decide place of delivery and initiate discussion with other specialty teams
            1. Generally, the pediatrics service at ANMC will support infants with a life-limiting diagnosis
            2. If the infant's diagnosis is unclear or if the infant's family is not sure about allowing natural death/resuscitative efforts, neonatology care at a level 3 NICU is recommended

    b. From first MFM visit to second MFM visit (usually a four-week period)
        i. Schedule ultrasound and follow up MFM consultation
            1. Place referrals to other specialties for consultation as needed
            2. Place referrals to PAMC neonatology for consultation
            3. Place referral to BHC and coordinate with future MFM visits
        ii. MFM RN Case Manager meets with patient after MFM consultation
            1. RN to assess patient understanding, processing, emotional state, etc. to see where they are at
            2. Discuss what to expect with the next visit, plant seeds about the birth plan (what they may want to start thinking about, give handout if ready)
            3. Discuss how the plan will evolve, discuss moving at patient own pace, family's own pace, based on their needs
            4. Place referrals to BHC, child life specialist, pediatrics
            5. Notify and set expectations with PCP or Southcentral Foundation Pediatric Field Health Team

        6. If newborn might survive past discharge, think about whether the family's health care plan covers Hospice:
            a. Hospice covered by Medicaid and private insurance
            b. Hospice not covered by PRC

c. MFM follow up visits
    i. MFM team meeting to solidify plan of care, discuss if anything further is needed to support patient/family
    ii. Start the birth plan, triggers a warning with a pop-up box for all provider to know this patient has a current palliative care birth plan and where to find it in the chart
    iii. Let patient guide how far we get on the birth plan together
    iv. Include the following information in the birth plan (ideally prior to presentation for labor/delivery):
        1. Resuscitation plan (including if no resuscitation planned)
        2. Whether the family would like the pediatrician at the delivery
        3. If the family would like the pediatrician at the delivery, what specifically are their needs? (i.e. confirmation of diagnosis, when possible, comfort care initiation support)
    v. Notify L&D about palliative care patient
        1. Identify staff who want to be involved
        2. Meet with staff, discuss patient's plan of care
    vi. Ensure all documentation is in the chart from specialty services
    vii. Set up transfer prenatal appointment with OB/GYN for out-of-town patients

5. Labor and Delivery Workflow

    a. Notifications to Labor and Delivery unit of potential palliative care patients
        i. Notify staff at monthly high-risk rounds (first Monday of each month)
        ii. Notify staff at Team Steps that there is palliative care patient pending delivery
        iii. Confirm staff who wish to be involved with patient's labor and delivery
            1. Bedside RNs who are comfortable with the clinical scenario, ensuring staff have a good understanding of diagnosis and prognosis
            2. Include staff from L&D, postpartum, NICU, inpatient pediatric pharmacy
            3. Review with staff where to find the birth plan
            4. Discuss patient and family expectations, specific requests

    b. Day of delivery
        i. Identify L&D RN to be 1:1 with patient
        ii. Notify MFM
        iii. Notify pediatric hospitalist on for deliveries, expectation for pediatrician to touch base with family, unless the family does not want this
        iv. Notify child life specialist
        v. Notify pediatric pharmacist on duty
        vi. Ensure all support staff are aware of the situation in the room

vii. Review birth plan and diagnosis as a team, and ensure this is repeated at each Team Steps with the whole team

c. Postpartum
   i. Refer to the fetal demise checklist and birth plan prepared by the family
   ii. Place door marker on door – to notify all staff members that will interact with the family
   iii. Provide support for parents, siblings, extended family, and friends
   iv. Assure appropriate medical care for the birth parent
   v. Lactation consultation, anticipate milk coming in after discharge
   vi. Offer bereavement counseling through SCF behavioral health services
   vii. Follow up postpartum visit at 1 or 2 weeks, coordinate with BHC
   viii. Follow up postpartum visit at 6 weeks scheduled with OB/GYN

6. Newborn care

   a. In general, care should focus on comfort and closeness with family, any interventions that do not align with these goals should be reviewed and not offered. Monitors and routine vital signs are not required. The family may choose to decline any intervention.

   b. Continue support as above and consider whether any of the following apply to the infant and family:
      i. Notify the PCP (if local) or appropriate provider from the region of the delivery and the infant's expected course, advise this person on whether they will be expected to participate in care (i.e. if infant is discharged into Hospice care, the family may still want general care from the PCP)
      ii. Notify Hospice if the infant is expected to live beyond the newborn stay and the family qualifies:
         1. Hospice covered by Medicaid and private insurance
         2. Hospice not covered by PRC
      iii. The palliative care team at ANMC will not routinely consult in these cases, but they are an available resource to providers for guidance
      iv. Ask the family whether we can help with other support needs (religious, cultural, etc.)
      v. Offer memory making if it is available, child life specialist can help with this
      vi. Change the infant's resuscitation status to reflect DNR status and document this with a note in the chart
      vii. It is acceptable to forego the newborn metabolic screen, critical congenital heart disease screen, and the newborn hearing screen, per the state's newborn screening program, please email the program at newborn.screening@alaska.gov briefly explaining why there will be no results for the infant, so the program does not try to contact the family (this process was cleared by the newborn screening program)
      viii. Birth certificates are required by law for any fetus born with signs of life, regardless of gestational age

c. Language and communication considerations:
    i. Phrases that may be helpful:
        1. "We will continue to provide the best care for your infant"
        2. "Your infant will be assessed frequently"
    ii. Avoid phrases such as "withdrawal of care" or "nothing else can be done," as we can always strive to comfort and care for infants and their families
    iii. Be direct, such as when saying the infant is dying, avoid euphemism
    iv. When appropriate, guide the family on what to expect when the infant is nearing death, such as color change, agonal respirations, wheezing noises

d. Non-pharmacologic and pharmacologic therapies to consider:

Symptom	Non-pharmacologic and Pharmacologic Therapies
Pain/Discomfort	Skin to skin Hat, blankets, diapers all as desired by the family Breastfeeding or other feeding Sweet-ease as needed for pain Acetaminophen (PO, PR) Morphine (buccal, PO) Fentanyl (IN)
Dyspnea	Passive air, free flow oxygen (consider that oxygen may be perceived as resuscitation and therefore prolonging suffering Morphine (buccal, PO)
Secretions	Oral suctioning Glycopyrrolate (PO)
Agitation	Lorazepam (PO) Midazolam (IN)

e. Nutrition:
    i. It is appropriate to offer nutrition to the infant if the family feels it would be of comfort to the infant
    ii. Chest feeding, feeding expressed colostrum, and feeding formula are all acceptable
    iii. Pediatric SLP/feeding therapists are available to support the family as needed

7. Caring for colleagues

    a. Consider holding an immediate debrief with staff after an infant passes away or after an infant is discharged into Hospice care
        i. Suggest colleagues who have primarily cared for the birth parent and infant participate in the debrief while a less involved colleague leads the debrief
        ii. This allows colleagues who have had more extensive involvement more freedom to reflect on the case during the debrief

b. Consider holding a more formal debrief a few weeks after the infant passes or is discharged into Hospice care (this can be arranged with SCF Behavioral Health Services)

References:

1. Perinatal palliative care. ACOG Committee Opinion No. 786. American College of Obstetricians and Gynecologists. Obstet Gynecol 2019; 134:e84-9.
2. Perinatal palliative care. AWHONN Position Statement. Association of Women's Health, Obstetric and Neonatal Nurses, 2023.

Approved:

MCH CCBG 1/17/24