

## *Perinatal Loss*

### CONSENSUS STATEMENT

#### EXECUTIVE SUMMARY

April 2008

<b>POSITION</b>	All Indiana families experiencing perinatal loss deserve compassionate, timely and individualized care. Together, professional and community caregivers can develop supportive environments, systems and resources for women and families during and after a perinatal loss.
<b>DEFINITION</b>	Perinatal loss is defined as any loss, regardless of reason, from conception through the first year of an infant's life.
<b>ROLE OF PROVIDERS</b>	Professional and lay caregivers can provide unique opportunities for perinatal loss support through encouragement, teaching, role modeling, counseling and problem-solving. Caregivers can also mentor significant others in providing supportive care as well.
<b>RECOMMENDATIONS</b>	<p><b>Recommendations: Inpatient and Outpatient Settings</b></p> <ul style="list-style-type: none"> <li>• Assure the same <b>standard of care</b> for all patients of perinatal loss regardless of gestation or cause of death.</li> <li>• Create <b>policies</b> specific to perinatal loss that serve as guidelines in providing comprehensive, compassionate and culturally respectful care.</li> <li>• Develop an <b>interdisciplinary team</b> to support families at time of perinatal loss.</li> <li>• Organize perinatal loss <b>education</b>, including new employee orientation, for all staff.</li> <li>• Create/adapt <b>education tools for families</b> to assist in making decisions and coping.</li> <li>• Assure all families have an opportunity to <b>create memories</b> as they choose.</li> <li>• Gather up-to-date <b>local resources</b> to help meet families' cultural requests.</li> <li>• Offer information and support for families in <b>after-death testing</b> and <b>disposition</b> of the body.</li> <li>• Organize a <b>hospital disposition program</b> for products of conception that is respectful and culturally sensitive.</li> <li>• Provide <b>aftercare support</b> for all families of perinatal loss that includes connections to grief caregivers and access to helpful resources in the community.</li> </ul> <p><b>Recommendations: Home Settings</b></p> <ul style="list-style-type: none"> <li>• <b>Assess home setting</b> in a sensitive and respectful manner consistent with Sudden Unexpected Infant Death guidelines (Centers for Disease Control and Prevention)</li> <li>• Designate a <b>liaison for the family</b> throughout the process.</li> <li>• Assure <b>connections to support systems</b>, such as local organizations, crisis intervention teams, funeral-planning, breast feeding cessation, and caring for grieving children.</li> </ul> <p><b>Recommendations: Aftercare</b></p> <ul style="list-style-type: none"> <li>• Provide <b>access to supportive people</b> in the facility and in the community.</li> <li>• <b>Follow-up</b> with families by phone, mail or in person throughout the first year after loss.</li> <li>• Provide support during <b>special times</b> such as due dates, holidays, anniversaries, etc.</li> <li>• Provide access to <b>support materials</b> such as books, internet and peer support groups.</li> <li>• Develop a plan for parents experiencing <b>complicated grief</b>.</li> <li>• Organize <b>remembrance events</b> such as memorial services or a Walk to Remember</li> </ul>

**Suggested Inpatient Practices**

- Express condolences to family and refer to the baby by name.
- Adapt unit environment to meet family's needs for comfort and privacy.
- Provide a comforting and supportive atmosphere for the delivery.
- Provide comfort measures for non-viable infant that is born alive such as wrapping in warm blankets, holding, and limiting exams/procedures until after death.
- Provide opportunities for family to say hello and goodbye. Families may need support in seeing their baby for the first time. If the family declines to see their baby after delivery, offer again at a later time, being sensitive to the family's wishes.
- If the baby has birth defects, facilitate family's first experience by focusing on the "perfect" features and encouraging them to view 'their entire baby' as they are ready.
- If baby dies in a facility different than mother's, assure coordination of care between facilities, including mother's transfer to baby's facility and/or discharge mother. If the mother is unable to be moved, bring the baby's body back to the delivering facility after death.
- Assist siblings, grandparents and extended family and friends with holding, dressing and bathing the baby, with parent's permission.
- Create memories. Culturally sensitive photos, foot/hand prints, clothing, blanket, hat, baby bracelet, lock of hair, crib card, etc. can be included in memory box. If the baby is one of multiples, offer mementos together if possible.
- Discuss options of after-death studies and genetic testing with the family.
- Notify Organ Procurement Organization per facility policy for deliveries greater than 20 weeks gestation.
- Offer transfer of mother to a non-OB unit per facility policy and if desired by family.
- Provide verbal and written post-partum education that includes bereavement aftercare, self-care at home and hospital contact numbers.
- Discuss options for hospital disposition, if applicable, and/or private disposition (i.e. burial or cremation) and offer guidance and resources in making disposition arrangements.

**Suggested Outpatient Practices**

- Mark chart to alert staff of perinatal loss.
- Assess patient/family's perception of loss to help guide the level of support.
- Offer a memory packet for ultrasound pictures, a positive pregnancy test, etc.
- Include information about perinatal grief and care in discharge instructions.
- Discuss disposition options and allow the family to choose what best meets their needs.
- Explore family's interest in genetic testing and/or genetic counseling post loss.
- Assure supportive bereavement care is added to post-surgical standards of care.
- Offer to access hospital and community resources for support after discharge.

**Home Settings**

- Complete a thorough, non-accusatory investigation per Sudden Unexpected Infant Death guidelines, avoiding assumptions about the possible cause of death.
- Call the baby by name in all discussions.
- Assist families in saying goodbye before the body is removed from the home, if possible.
- Inform family of any post-death testing mandated by the Coroner and the 'next steps', including access to investigators.
- Designate a person who can act as a liaison to provide immediate support, escort family to the hospital if needed and notify other family members and friends.
- Assure connections to support systems, such as crisis intervention teams, funeral-planning, breast feeding cessation, and caring for grieving children.