

PERINATAL PALLIATIVE CARE A POSITION STATEMENT

WHEN PARENTS CHOOSE TO CONTINUE A PREGNANCY AFTER THEIR
BABY IS DIAGNOSED WITH A LIFE-LIMITING CONDITION

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Endorsement

The Pregnancy Loss and Infant Death Alliance (PLIDA) endorses this position statement on perinatal palliative care (www.plida.org).

Resolve Through Sharing supports perinatal palliative care and education of healthcare professionals who provide it.

Introduction

She wasn't just alive for eleven days. She was alive for nine months and eleven days.

—A father of a baby with trisomy 18 and hypoplastic left heart who lived for 11 days after she was born

Perinatal Palliative Care, sometimes referred to as perinatal hospice, is a philosophy of family-centered care that addresses the expectations and intentions of families who choose to continue a pregnancy after their baby is diagnosed with a life-limiting condition. It includes the broad goals of palliative care: to anticipate, prevent, and relieve suffering (physical, psychological, and spiritual), to preserve dignity, and to promote quality of life for baby and family, while honoring parental preferences and wishes for their baby's care regardless of length of life.

Perinatal Palliative Care focuses on creating a relationship with parents and guiding them in decision making and caregiving. The relationship itself offers the potential for healing at a time of the baby's living and dying. After birth, the care also focuses on the comfort and well-being of the baby, with interventions to support quality of life for both baby and family. Parents must balance the dual experience of preserving hope with preparation for birth and the possibility of death—or death and then birth.

I think in our society people try to shelter themselves from uncomfortable things. And I don't believe in that. I think you have to face it all, the life, the death, and the ugly. I wish people would be more open. I should be, too, but I'm not sure how to do that. It makes people uneasy.

—A mother

A Continuum of Care

Providing perinatal palliative care services involves several disciplines working together to provide compassionate, non-judgmental care for the baby and family. This supportive healthcare should be provided in a seamless fashion, regardless of the site of care, and from the prenatal period through bereavement follow-up. The optimal model should create a continuum of care (including support, information, and guidance) for families among providers, across settings, and over time.

Depending on the setting and community, perinatal palliative care may involve nurses and nurse-midwives in clinics, home health, hospitals, perinatal hospice, and emergency departments; physicians in maternal fetal medicine, OB/GYN, neonatology, pediatrics, pediatric cardiology, family medicine, and genetics; genetic counselors; ultrasonographers; social workers; chaplains; community clergy; child life specialists; doulas; psychologists and other psychotherapists; funeral directors; language interpreters; and volunteers. Care may also include emergency care providers in the community (e.g., emergency medical technicians and paramedics).

Bereavement care is *integrated* throughout the perinatal palliative care continuum (see Figure 1). Bereavement support begins at the time of suspected or actual diagnosis and continues through follow-up care after the baby dies. This continuum of care and support among settings and over time is an essential feature of perinatal palliative care.

The Importance of Perinatal Palliative Care

Yes it was very hard, but just because it is hard doesn't mean it isn't worth doing and it was so worth doing. It was a wonderful experience, [but] not one that I want to repeat.

—A mother

- Many parents do not want to end a pregnancy prior to the onset of labor (or in some cases, death of the baby in utero). Their reasons vary but typically center on being consistent with their values, goals, beliefs, and feelings, and in the best interest of their baby.
- Providing care and support to families whose baby died or will die is our mission and is ethically and morally correct.
- Healthcare professionals and others can do more than is currently being done to create and preserve the dignity of the experience for parents and families in this difficult time.
- Recent national patient- and family-centered care initiatives recommend that healthcare providers and their patients and family members establish partnerships that reflect a central role for families in their own care.
- The Institute of Medicine's (IOM) report on Pediatric Palliative Care (released in 2002, see Field and Behrman, 2003) recommends that palliative care be coordinated and continuous among sites of care (e.g., hospital, outpatient service, home, community-based care facility) and among caregivers. The report also recommends that families and clinicians in outlying and rural areas be linked to services and support through regional information centers and clinical facilities. Support services include family resources, medical specialties, consultation, and

professional education. The report references perinatal hospice and supports the growth and development of this specialty area.

- As pediatric palliative care matures and becomes more widespread, perinatal palliative care is becoming more common as an extension of pediatric-focused care.
- The American Academy of Pediatrics (2000, reaffirmed in October, 2006) issued a statement that recommends that child-specific pediatric palliative care programs be widely available and accompanied by effective education for healthcare professionals.
- The National Hospice and Palliative Care Organization (NHPCO) support pediatric and perinatal palliative care through conference offerings and its Children’s Project on Hospice/Palliative Services (ChiPPS). The first Standards of Practice for Pediatric Hospice and Palliative Care Programs are currently in a national review process through NHPCO.
- Advance planning for care at the end-of-life reduces healthcare costs in other settings and is anticipated to reduce expenditures in perinatal palliative care.
- Respecting patients’ personal values, goals, beliefs, and feelings is mandated by The Joint Commission.
- Caregiver competency and confidence in caring for patients and families in a specialized area— such as bereavement and perinatal palliative care— are associated with continuing education in the specialty area.
- The Canadian Hospice Palliative Care Association has developed principles and norms of practice that support the right of parents to receive palliative care for their child that is planned, coordinated, and provided by providers who understand parents’ perspectives on their notion of quality of life for themselves and their child.

Elements of Successful Perinatal Palliative Care Services

- Healthcare providers are educated about the benefits of perinatal palliative care and bereavement support. The education includes *how* to offer perinatal palliative care in an objective way.

National anecdotal consensus is that an individual healthcare provider’s own bias is the most frequent reason for not offering perinatal palliative care as an option.

- Healthcare providers receive feedback on how families benefit from the continuum of support provided through perinatal palliative care.

- Through education, healthcare providers are aware of the potential for their own suffering and are aware of resources to care for themselves.
- One or two consistent support persons (i.e., RTS-trained) are identified as liaisons between the family and the healthcare providers.
- Parents are provided quick access to medical care when they are referred to a perinatal center for confirming diagnosis.
- Parents are provided unbiased information about what to do next after receiving their baby's life-limiting diagnosis and electing to continue the pregnancy.
- Early assessment of the family's expectations includes their religious/spiritual practice, financial concerns, relationship with and parenting concerns about other children, family reactions, and employment stability. Appropriate resources are offered.

Assessment also involves learning what the pregnancy, diagnosis, and ramifications of the current situation mean to the parents. Both parents may not perceive this experience in the same way and may need different types of support.

- Parents have prenatal education available, apart from classes intended for parents having healthy babies.
- Genetic counseling is available at the time of the diagnosis, as needed through the pregnancy, and may be recommended during follow-up care as well.
- Consultation with pediatric subspecialists, such as the neonatologist, geneticist, cardiologist, neurosurgeon, and others is provided as appropriate. Subspecialists are included in perinatal palliative care education.
- Advance care planning is provided, which includes discussions of treatment and potential delivery options (e.g., cesarean birth), but goes beyond decisions to administer or withhold medical treatment. Advance care planning also includes education about what to expect, what options are available (e.g., environment; site of care; plans for photos, DVDs, and other mementoes), and exploration of what parents consider most important for their baby.

Plan in advance for how parents wish to spend the last minutes, hours, or days of their child's life. For example, parents may want to leave the hospital quickly so their baby can die at home. These preferences and goals for care may be incorporated into a birth plan. Birth plans include psychosocial, physical, and spiritual needs if the baby is stillborn or if the baby is born alive.

It was a very fast delivery process. It was a water birth and the staff really put themselves out for us. The family birth room was reserved for us. It was wonderful. I felt really good about what they did for us.

–A mother

- Parents are given written materials appropriate to their concerns and interests.
- Parents may tour the birthing facilities and neonatal intensive care area, in advance, as desired.
- Regular prenatal care is standard. The care includes assessment of the baby and the baby's condition as well as signs of pre-term labor and how to respond.
- If the baby is born alive, comfort care includes warmth, being held, pain medication, and hydration as determined through the advance care planning process and assessment of the baby after birth. Address parents' goals and needs if their baby survives the initial 24-hour period.
- Family-centered care is promoted, encouraging parents to invite other children, family members, or friends to be present as they wish.
- If parents opt to take the baby home, home health care/hospice/palliative care is provided and planned for in advance.
- Bereavement follow-up is provided for at least a year, if the family desires, and a mechanism exists to link the family with community-based grief support.

Take Home Points for Healthcare Providers: Principles of Care

- Parents who choose perinatal palliative care wish to parent their baby for as long as the baby lives. These parenting moments will bring them great joy, as well as great sorrow. Engage with them in such a way that you can share these complex and varying emotions.
- Being obviously pregnant is seen in western culture as an invitation to ask personal and sometimes intimate questions. Help parents prepare for the inevitable, excited queries: “When are you due? Is it a boy or a girl? Is it your first?”
- If the baby is born alive, provide care in the hospital (nursery or NICU) or at home that focuses on how the parents want the experience to be for them, their family, friends, and their baby. This includes the opportunity to be with their baby after death. Be mindful of opportunities for ritual, changing hopes, and keepsake activities.
- Plan in advance for hospice or home care. If the baby goes home, make sure that the parents know how to reach a knowledgeable healthcare provider round the clock. Ensure that all of the appropriate documents (discharge summary, medication prescriptions, phone number list) accompany the baby and family.
- Include all those who need to know about the impending death (emergency medical providers, coroner, police, funeral director) in the plan.
- Ask, “What symptoms are most concerning to you right now?” and be prepared to treat each one. Or ask, “What are you hoping for?” Hope is dynamic and requires ongoing assessment.
- Provide written information using several different scenarios to describe what dying may be like. Think of all the senses.
- Provide guidance and resources on how to talk to other children about what is happening: the death, what to expect, the funeral; and how to create support at school.
- Develop avenues for communication between all members of the care team regarding changing hopes in order to ensure the seamless provision of care for the baby and parents from the prenatal period through bereavement (see Figure 1).
- Many situations over time call for parental decision making. Create processes to support parents in the hospital and at home.
- Establish relationships with community agents who may be involved in the baby’s care in the home environment.

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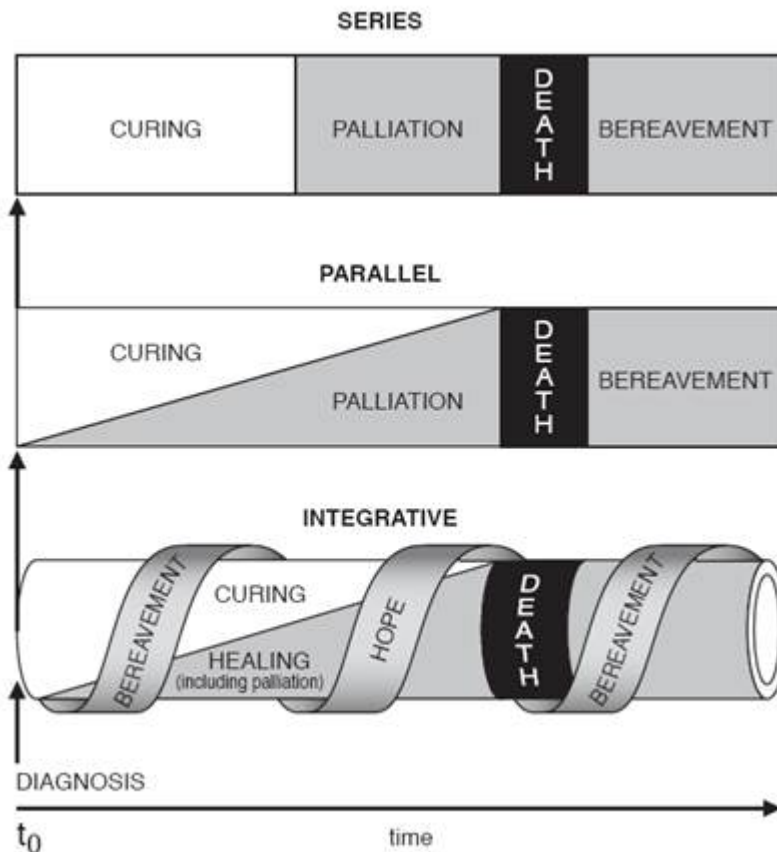
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Figure 1: Integrative Model of Curing and Healing



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