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Perinatal Loss

The overall subject of this issue of the newsletter – and of issue #7, which will follow in three to four months – is perinatal loss. This issue also includes “A Parent’s Guide to Palliative Care,” from Advances in Neonatal Care, Vol. 6(1), pp. 54-55, 2006, by Gay Gale and Alison Brooks, reprinted with permission from The National Association of Neonatal Nurses.

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A “Primer” on Perinatal Loss and Infant Death: Statistics/Definitions, Parents’ Needs, and Suggestions for Family Care

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Background

According to the *Institute of Medicine* report on *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, more children die in the first year of life than in all other childhood years combined (27,937 infants compared to 26,622 children aged 1-19 years in 1999). Importantly, two-thirds of these infant deaths are neonatal deaths. These staggering losses and their impact on the families require that more attention be given to the special needs of these families. As a result, PLIDA, the Pregnancy Loss and Infant Death Alliance, was formally established in 2002 to ensure that “all families experiencing the death of a baby during pregnancy, birth, or infancy will receive comprehensive and compassionate care from diagnosis through the reproductive years.”

This article presents key highlights from the 15th National Perinatal Bereavement Conference held in Chicago in October, 2006, by PLIDA. This is the first of a two-part series, providing an overview of key perinatal/neonatal mortality statistics, what support parents need before/during/after a perinatal loss, and suggestions for supportive care of families experiencing perinatal loss. The second part of this series will appear in the next ChiPPS Newsletter.

Definitions

Definitions of relevant terms:

- Premature infant: Infant born before 37 weeks of gestation
- Neonatal period: First 28 days of life
- Perinatal period: 28th week of gestation through first seven days after delivery
- Miscarriage or spontaneous abortion: Naturally occurring, spontaneous expulsion of a human fetus, especially between the twelfth and twenty-seventh weeks of gestation
- Fetal death: Death of fetus prior to complete expulsion or extraction from the mother of a product of human conception (irrespective of duration of pregnancy) that is not an induced termination of pregnancy. Some states use the term “stillbirth” for such fetal deaths
- Stillbirth: Fetal deaths \geq 20 weeks gestation (one of most common adverse pregnancy outcomes with 26,000 stillbirths every year-2002 data). No signs of life present at/after birth. (Williams Obstetrics 20th Ed.)



- Neonatal death: Death of a live-born infant before 29 days of life (Williams Obstetrics 20th Ed.)
- Perinatal death: Death between 22 completed weeks (~500g) and 28 completed days after birth (Williams Obstetrics 20th Ed.)

Statistics

Note: Different sources were referenced for this compilation, resulting in statistics that may differ slightly from one another depending on the source. Unfortunately, the end result is the same. A significant number of women and their families are impacted by the loss of a baby or infant each year in the U.S.

- Each year, nearly 900,000 families are effected by birth tragedies:
 - 800,000 miscarriages
 - 33,000 stillbirths
 - 18,000 neonatal deaths
- On a more micro level:
 - An estimated 15%-20% of all recognized pregnancies end prior to 20 weeks (Chen, 1986; Madden, 1994)
 - Approximately one-in-four women may experience miscarriage during her lifetime (Creinin, Mitchell, Schwartz, Guido & Pymar, 2001)
 - 20%-25% of all pregnancies end in perinatal loss (1,000,000 losses per year in the U.S.)
- Of an estimated 6.2 million pregnancies each year, about 6 in ten result in live birth, 20% in an induced abortion and 15% in fetal death.
- Other unspoken (and unaccountable) losses further add to these tragic statistics:
 - Before birth: abortion, unused embryos, multifetal reduction after infertility treatment
 - At birth: giving a child up for adoption, placing a child secretly in "safe haven", having an infant removed due to parental behavior
- The two key leading causes of neonatal deaths are disorders relating to short gestation and unspecified low birth weight (23%) and congenital anomalies (21%). Complications of pregnancy (7%), respiratory distress syndrome (6%) and complications of placenta, cord, membrane (5%) complete the top 5 causes of neonatal deaths.
- Perinatal deaths sharply cut along lines of race. There is a higher incidence of perinatal mortality in African Americans vs. other ethnic groups (e.g., more than twice as high vs. Caucasians)
 - Perinatal mortality rate (28 weeks-< 7 days of age): 5.9/1000 for Caucasians, 12.7/1000 for African Americans
 - Neonatal mortality rate: 3.8/1000 for Caucasians, 9.2/1000 for African Americans
- On the positive side, 50%-80% of women who've suffered a perinatal loss go on to a subsequent pregnancy (although it's very anxiety-laden, as might be expected)



What Parents Need from Their Healthcare Team in a Hospital, Palliative Care or Hospice Setting

The healthcare team and hospital/palliative care/hospice setting bring the following to families:

- Technical skills and knowledge
- Team of specialists
- Modern sophisticated care (e.g., high tech)
- New pharmacological and intervention strategies

Families also **need** other kinds of support from the healthcare team:

- Creation of a sacred space for them and their baby
- Recognition of their baby as special
- Preservation of normalcy
- To feel cared for and connected to their baby and his or her health care team
- To have some/any control whenever possible
- Honesty
- Compassion
- Good, clear gentle communication and an invitation to have a voice in decisions concerning their baby

How the healthcare team cares for and communicates with the families greatly influences how the families leave the healthcare setting and enter the long process of adapting to a new life without their child.

- A protocol for care at the time of death is only as good as the *humanness* with which it is carried out, the *compassion* it is delivered with.

Families need care for body, mind and spirit as they live in a dual reality:

- Balancing hope with realistic concerns and knowledge
- Living in the present, but desiring the future
- Making peace with a changed future
- Experiencing the blessings of the present

The families are not the “visitors” (and therefore, should not be treated as such); it’s *their* child that has died or is dying. The healthcare team is only visiting with them and their babies on this journey.

Do not forget about the fathers:

- Attention tends to be primarily focused on mothers, but fathers are also grieving
- It’s OK **not** to be strong

Caring for Families During and After a Perinatal Loss

Specific ways to provide compassionate and family-centered-care:

- Create birth and advanced care plans
 - Listen and anticipate family goals, needs, desires, and personal intentions



Children's Project on Palliative/Hospice Services

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- Discuss organ/tissue donation, autopsy, biopsy, genetic testing
- Establish specialized neonatal and perinatal hospice and palliative care services and programs
- Educate about diagnosis and what to expect
- Encourage parents to do what is best for them
- Honor families' decisions -- do not judge if their choices differ from yours
- Call baby by his/her name
- Be present with the parents—take the time to sit with them
- Staff expertise with symptom/pain management: provide physical comfort care for the baby
- Help families find ways of “being with” and “doing for” their babies...to be active in some aspect of care and to do for and be with their baby.
- Consider development of peer companionship programs—parents who have experienced similar perinatal/neonatal losses and who will respond to the needs of a bereaved parent before/at/after the loss of their baby
- Privacy and dignity:
 - Private room (quiet—turn off monitors/alarms, soft lighting)
 - Minimize the number of staff interruptions
 - Allow family to gather significant others (e.g., siblings, grandparents)
 - Bend the rules: visiting hours, etc.
- Provide opportunities for rituals and memory making
 - Create memory boxes/packets
 - ID bracelets
 - Lock of hair
 - Foot/hand prints—paper , molds
 - Photos/videos (including ultrasound)
 - Care for baby—hold , bathe, diaper/dress, feed/nurse
 - Take baby home or outdoors to peaceful/natural setting
 - Play music, read books
- Honor cultural beliefs and traditions
- Acknowledge the family's grief
- Facilitate spiritual support
- Connect family with social worker, chaplain, or grief counselor prior to discharge.
 - Provide information about grief process and bereavement support (group and individual counseling)
 - Follow-up during first year including Mother's/Father's Day, baby's due date, anniversary of death.
 - Possibly connect family with another family that had a perinatal loss
- Team/staff send cards and/or attend memorial service
- Offer support during subsequent pregnancy that may be emotionally difficult and/or require genetic counseling
- Strive to preserve their family “intact” for the future



References

Catlin, Anita, DNSc, FNP, FAAN. Creation of a Neonatal Palliative Care Protocol. PLIDA Conference, October 2006. (Note: Based on an article of same name in *Journal of Perinataology*, 2002;22:184-195).

Catlin, Anita, DNSc, FNP, FAAN and Rogoff, Marianne, MFA. Saying No: It's Right but it Still Hurts. Losses Due to Parental Decisions during Pregnancy or after Birth. PLIDA Conference, October 2006.

Cote-Arsenault, Denise, PhD, RNC. Pregnant Again after a Loss: Research-Based Insights for Parents & Professionals. PLIDA Conference, October 2006.

Davis, Deborah, PhD and Stain, Mara Tesler, Psy.D, When a Baby is Dying or After a Baby Dies: Putting Relationship-Based Care into Practice. PLIDA Conference, October 2006.

Godfrey, Teresa, RN, MSN, Jones, Emilie Lamburg,, RN, BS, and Nigh, Laura, RN, BSN. Fetal Concerns Program: Education, Counseling, and Perinatal Management Services for Childbearing Women with Prenatal Fetal Diagnosis or Concern. PLIDA Conference, October 2006.

Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. National Academies Press. 2002

Kavanaugh, Karen, PhD, RN, FAAN. The Experience of Pregnancy Loss and Infant Death in Low-Income African American Parents. PLIDA Conference, October 2006.

Kobler, Kathie, RN, BS. Walking Through Valleys Low: Perinatal Bereavement 101. PLIDA Conference, October 2006.

Kuebelbeck, Amy, MA and Klein, Annette, RN, ICCE. Birth Planning and Prenatal Decision-Marking for Parents Continuing a Pregnancy with a Terminal Prenatal Diagnosis. PLIDA Conference, October 2006.

National Center for Health Statistics report, Deaths: Final Data 1999.

Pregnancy Loss and Infant Death Alliance (PLIDA) website: www.PLIDA.org

Price, Sarah Key, MSW, PhD. Parenting after Pregnancy Loss: Risk and Resiliency in a National Sample of Parents. PLIDA Conference, October 2006.

Silver, Bob, MD. Stillbirth: Where Are We and Where Are We Going? PLIDA Conference, October 2006.

Sumner, Lizabeth, RN, BSN. Preserving Their Fragile Universe: The Vocation of "Being With" Families on this Sacred Journey. PLIDA Conference, October 2006.



Dealing with Perinatal Genetic Diagnoses

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The prenatal diagnosis or birth of a baby with a birth defect or genetic disease is a complicated, painful, and frustrating situation for parents. Bombarded by conflicting feelings and emotions, they struggle to answer questions they never expected to face—questions with no easy answers, and some which have no answers at all. At different times during this reckoning, uncertainty exists in all of the following areas.

What is happening to them? The shock of hearing there is a problem is all parents initially take in. Elaborate descriptions and medical jargon are often lost in the haze beyond that moment. If they receive a diagnostic name, they will have some ability to gather information. However, many times that is not the case, and the “diagnosis” is a collection of differences seen, either at ultrasound or in the nursery, with uncertain global implications.

Why and how can there be anything wrong? If the pregnancy has been planned and all the perceived “rules of care” have been followed, then the expectation is that everything will be all right. Furthermore, if there is no family history of any kind of genetic disease or defect, the typical perception is that there is no risk for problems. Questioning and doubt are natural consequences when something is said to be abnormal.

Is the assessment correct? What evidence exists that this is true? Hopes of diagnostic error or errant test results are more likely to occur during prenatal diagnosis than if there are visible defects at birth. Yet, even when there are observable physical differences, parents try to minimize their importance. Prenatally, they secretly hope that the diagnosis is wrong, that the condition will resolve by delivery, or that, at worst, the problem is reparable with no long-term consequences.

What is wrong with them or how did they cause this? In their search for understanding, parents scrutinize the pregnancy, themselves, and their actions to find a cause. Again, when coming from the perspective and belief that the outcome is within our control, when something is wrong the logical conclusion is that something must have happened, or someone must have done something to cause this to happen. And, in this day of high-tech medicine, surely such problems should be preventable or fixable. Despite the fact that we have no control of our genetic make-up, when genes are involved the table is set for a plate of guilt, shame, and apportionment of blame.

What options are available and what should they do next? Although rarely a prenatal option, sometimes corrective surgery after birth may be the only option in need of consideration. The course then becomes one of watchful waiting and self-preparation. That, too, may be the



course available when the prognosis is less predictable, or following late prenatal diagnosis. The ambiguity in this case, of course, makes watching and waiting much more difficult.

When the overall prognosis is poor, survival is in doubt or impossible, and there are no quick fixes, options vary depending on the condition, the couple, and the time of diagnosis. Although readily dismissed by some as not even being an option, thoughts about not carrying a pregnancy to term, or limiting heroic interventions at delivery almost always surface. Admitting to them is sometimes difficult, particularly for those who have always maintained a staunch pro-life position. But, if they remain unspoken and unexplored, these thoughts can produce anxiety and conflict. Long-held beliefs are challenged, and the course of action is less clear than it once seemed. Even when termination is not the ultimate choice made, discussing it and putting it to rest makes planning for the remainder of pregnancy and birth easier.

How will their choices now affect their lives? What will be the extent of this child's needs? Will he or she have cognitive limitations? Will the parents be able to keep the same work schedules? Will there be enough money from insurance or other resources to support the medical or other care needs for this child? Will family and friends be supportive of the choices parents make? How will the other children in the family cope? Will there be enough love, time, and energy to go around? Will the community view them differently? Will their own relationship survive the stress? All are relevant concerns without immediate answers.

What about their reproductive future? If a diagnosis has been made, then recurrence risks can be estimated. If a diagnosis is elusive, then so are future risks. Prenatal diagnosis or other reproductive technological alternatives in a subsequent pregnancy may or may not be options depending on the condition.

So how do we help couples down this path when uncertainty, and its potential to fuel anxiety, seems to lurk at every crossing? The collective experience of several of us who work in this area suggests that the following might be useful guidelines.

1. Start by presenting the problem in simple terms, and if possible provide some tangible evidence of its existence. Point out the abnormalities in the fetal ultrasound or on the newborn, or show them a chromosome report if it is available. It is hard to doubt something that is visibly obvious.
2. Give them appropriate space and time after the initial disclosure before delivering much more information. Be sure that all their initial questions and any pressing issues are addressed, and then, if feasible, schedule a follow-up appointment, or a time to call within the next day or two for further discussion. Be available during the interim for them to ask questions.
3. Limit the information provided to those things which we do know and which we are certain about. Avoid giving a laundry list of potential diagnoses since this just adds more uncertainty. If your experience with the condition is limited, defer from speculating or quoting statistics about potential outcomes. Instead, direct them to a genetic counselor or other specialist who is more familiar with the condition.



4. Avoid comparisons to other situations or cases, which might seem similar on the surface, but which may, actually, be very different. Despite an overall poor prognosis, two cases of Trisomy 18 may progress very differently throughout pregnancy, at delivery, and in the neonatal period. The course depends, to some extent, on the constellation of anomalies present. Help the parents to find appropriate resources for gathering objective, balanced information about a particular diagnosis.
5. Tactfully, facilitate communication about the “forbidden topics” of pregnancy termination, early delivery, or not instituting heroics if those are potential options. Remember that many people faced with the reality of their situation may respond differently than they thought they would when it was “someone else’s” story.
6. Encourage frequent communication between parents, providers, and other objective resources.
7. Try to limit the number of additional professional opinions they might solicit. A second opinion may be helpful. But third, fourth, or fifth ones usually just add to the confusion.
8. Encourage them to share their situation only with friends and family who will be objective and support whatever course of action they might choose. Dictatorial advice from well-meaning family and friends is not always helpful.
9. Reaffirm any strengths or positive aspects of their situation—their personal attributes, relationship, historical coping patterns, and so on.
10. Restore their sense of control by educating them about the normal conflicting and vacillating emotions of the grief process. Remind them of the uncontrollable aspects of reproduction and genetics. Help them to play an active part in the care planning.

These are only meant to be guidelines which will, hopefully, be of some use in working with families. As is typical of all situations involving human behavior and response, each circumstance seems to bring some unique twist to it as a simple reminder that there is no easy way to walk through this difficult life experience.

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Focus on Living: The Role of Antenatal Advance Care Planning

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*“There is no cure for
birth and death save to
enjoy the interval”*

George Santayana 1863-1952

When faced with a prenatal diagnosis of fetal anomalies associated with early death, one-fifth to one-third of families elect to continue the pregnancy. Antenatal advance care planning consistent with palliative care principles supports a family-centered approach to care of the fetus, family, and newborn. Advance care planning is the process by which the family is supported in making a contingency plan for the care of their fetus/newborn that is consistent with their goals and best interest of the fetus/newborn. Perinatal advance care planning can help these families focus on living and not dying, and allow them to parent their infant.

Case 1: After being counseled to terminate her pregnancy because of fetal diagnosis of Trisomy 18, Latasha ceased further prenatal care. She presented for delivery at the community hospital whose staff was unprepared for the care of her or her baby, David. The next day, the consulting neonatologist, after reviewing Latasha's level of understanding of Trisomy 18 and goals for David, transferred David to a NICU for an echocardiogram to help define life expectancy and to enroll him in a pediatric palliative care program. With the help of pediatric home health providers, Latasha was able to care for David at home until his peaceful death at 10 days of age. Clearly this was not optimal for the mother, the newborn, and the very stressed community hospital staff. The fact that health care dollars were very poorly distributed is a subject for another paper.

Case 2: Emma was diagnosed in utero with Trisomy 18 and a lethal cardiac anomaly. The parents were supported in decision making by the nurse midwife, perinatologist, neonatologist, genetic counselor, the social worker, their community priest, and nurses trained in bereavement support. Prior to delivery, there were a written birth plan, delivery room plan, and post discharge plan. To support nursery staff who might be uncomfortable with parents' choice to provide no artificial nutrition or hydration, in-services were provided. Plans for death at home in



a neighboring state were complicated but finalized prior to birth. With the help of the home pediatric hospice nurse, Emma died surrounded by her family at 7 days of age.

Antenatal advance care planning and perinatal palliative care are only possible because of three key components:

1. Increasingly accurate prenatal diagnosis
2. Understanding of modern palliative care and hospice principles
3. Understanding of perinatal grief

Advance care planning addresses the environment or site of care, physical needs, psychosocial and spiritual needs, and practical issues. The goals of antepartum advance care planning are to:

- Support accurate prenatal and postnatal (confirmatory) diagnoses
- Empower parents, engender hope, allay fear, and address feelings of guilt
- Provide anticipatory guidance
 - Anticipatory grief support
 - Support in goal identification and decision making
 - Unique birth plan
 - Plan for delivery room and postnatal care
 - After discharge plan if appropriate
- Identify family support resources
- Provide emotional and spiritual support
- Provide bereavement support before, during, after the death of the fetus or newborn
- Support the needs of involved health care providers
- Provide consistent care between care providers and across sites of care

The availability of antenatal ultrasound and other diagnostic techniques has enabled the prenatal identification of conditions where premature death during infancy is likely. Certainty of diagnosis and prognosis is helpful in identifying fetuses for whom advance care planning is beneficial. Certainty in diagnosis and prognosis is a necessity if withholding resuscitation in the delivery room is a treatment option. However, certainty is not an absolute requirement for antenatal advance care planning which is a process that evolves as additional information becomes available. Consider these fetal diagnoses potentially associated with death in infancy as types of triggers for antenatal advance care planning:

- Anomalies with diagnostic and prognostic certainty
 - Chromosomal anomalies such as Trisomies 13 and 18
 - Central nervous system anomalies such as anencephaly, large encephaloceles, and holoprosencephaly
 - Heart problems such as acardia
 - Renal problems associated with pulmonary hypoplasia such as renal agenesis/Potter's syndrome or dysplastic kidneys associated with oligohydramnios
- Anomalies with prognostic uncertainty:
 - Lethal cardiac defects such as hypoplastic left ventricle
 - Diaphragmatic hernia



- Anomalies in more than one organ system
- Neuromuscular problems such as severe spinal muscular atrophy
- Other syndromes associated with infant death such as thanatophoric dwarfism

To implement these strategies, an established perinatal palliative/hospice program is helpful but not necessary. The resources are likely available in any delivery service but need to be supported by education and coordination. An interdisciplinary team is necessary. The components may vary according to the organization and needs of the family. Consider as team members:

- The “family” (whoever is important to the mother and father)
- Obstetrical care provider, perinatologist, labor and delivery nurses
- Genetics team if indicated
- Social worker
- Bereavement counselor
- Pediatric care provider, neonatologist, newborn nurses
- Chaplains, community faith providers, psychosocial counselors
- Palliative care team if available
- Others as indicated, i.e., child life counselors for sibling support, teachers, home nursing and/or hospice providers

Policies or guidelines should include the process of identifying the fetus and family, providing advance care planning, identifying community resources, and coordinating care between providers and sites of care.

“Advance care planning models must reconfigure from what is to be avoided (CPR, feeding tubes) to what can be anticipated, planned for and embraced in a positive proactive way.”
-Zuckerman

Psychosocial, bereavement, and spiritual support should begin at the time the diagnosis is discussed with the parents. Soon after the diagnosis, interdisciplinary team members might:

- Provide information about the condition including certainty of diagnosis, potential course, complications/expected symptoms, etiology/potential contributing factors
- Review decision making guidelines and the advance care planning process
- Assess role of spirituality, religion, culture
- Determine family values and goals. Families tell me that they wish that their newborn not suffer and that they want to spend as much time with their baby as possible. Assess the parents’ hopes and fears. Parents frequently fear that they will not be competent to meet their baby’s needs.
- Review medically and ethically appropriate treatment options
- Assess family and community resources
- Discuss decisions which merit inclusion in the plan

Subsequent discussions focus on **living** with a newborn who will likely die during infancy. Parents are helped to feel in control, develop a sense of competency, and learn how to achieve a sense of normalcy for themselves, their other children and family members, and the new



baby. Health systems and care providers are supported in providing care suited to the unique needs of each family and newborn. Prior to the birth, plans should include:

- An overall advance care plan that is medically and ethically appropriate and consistent with the goals and values of the family.
- A birth plan
 - Timing of delivery
 - Mode of delivery: Vaginal or cesarean
 - Site of delivery: Community hospital or regional hospital, water birth, birthing room, high risk room
 - Fetal monitoring: Yes or no? Will cesarean section be an option? Does family want to know about absence of fetal heart rate or fetal distress?
 - Who will be in the room: family, medical/nursing providers
 - Who will be caring for siblings
 - Maternal medications
 - Who will receive the baby and cut the cord?
- Delivery room plan: Resuscitation of the newborn: modalities desired and not desired should be specified
- After delivery care:
 - Site of care for the baby: room-in with mom, newborn nursery, neonatal ICU
 - Visiting guidelines, desires for privacy, contact person to communicate with family/visitors
 - Identification of medical and nursing caregivers for the mother and baby
 - Plan for assessment and management of potential symptoms
 - Mode of feeding: Breast/bottle as able or artificial modes of feeding
 - Monitoring
 - Diagnostic and lab studies (note that some states mandate newborn screening; in others families can opt out)
 - Ceremonies or rituals desired
 - Support the meaningfulness of the baby's life: mementoes desired; making memories
 - Options for preventative care such as hearing screening, immunizations, car seat screening
- While some fetuses will be stillborn and some newborns will die in the delivery room or nursery, in many cases the baby will survive to discharge. If this is a possibility there should be plans for after discharge care:
 - Plan to prepare a **written** post discharge advance care plan and/or POLST (Physician Orders for Life Sustaining Treatment) which includes pain and symptom management
 - Determine availability of community resources such as 24-hour pharmacy, home nursing, or palliative care/hospice services that are necessary to support the advance care plan, and parent to parent bereavement support
 - Site of post discharge care
 - Assess desired site of death. Explain usual course of events, ranges of lifespan, typical symptoms, and signs that death is near
 - Discuss desires for and appropriateness of further diagnostic tests, autopsy, and organ or tissue donation



- Plan for death declaration, notification of medical examiner or coroner, completion of death certificate, plans for transferring the baby's body to the hearse, funeral plans, and communicating to involved providers
- Plan for availability of medical, nursing, and psychosocial/spiritual access and support
- Review psychosocial and spiritual support for parents, siblings, grandparents, and others affected
- Plan on regularly reviewing goals and the advance care plan. Ensure that the plan is communicated to all providers.
- Explore circumstances in which goals might change
- Team members should be accessible to the parents and staff members who will be caring for the mother and newborn.

Upon presentation of the mother to the labor and delivery suite, the copy of the birth plan should be retrieved and the appropriate staff notified. The contingency plan should be reviewed with the parents, and any changes made and communicated to the team. Unless parents change their minds and choose a different treatment option or there is new information that changes the diagnosis or prognosis of the newborn, all efforts should be made to comply with the advance care plan. The role of the neonatologist/pediatrician in the delivery room is to confirm the prenatal diagnosis, provide the resuscitation consistent with the care plan, and communicate with the family. After stabilization of the newborn:

- Assess the newborn focusing on factors that might be associated with pain or other symptoms. Review findings with the family, focusing on the normal beautiful aspects of their new baby
- Write orders delineating treatments desired and not desired including completing a DNR order if applicable
- Write prn orders for medications or other interventions anticipated.
- Discontinue interventions which do not provide comfort or address goals
- Support the family in their goals for themselves and their newborn. Save mementoes and make opportunities for memories. Comply with requests for rituals and ceremonies important to the family
- If baby is likely to die in the hospital, review plans for rituals, ceremonies, family support, diagnostic tests, autopsy, organ donation, care of the body, and communication with providers
- If discharge is a possibility
 - Finalize the written post discharge advance care plan and/or POLST (Physician Orders for Life Sustaining Treatment)
 - Communicate with the follow-up pediatric care provider. Complete the home nursing or palliative care/hospice referral. Notify the EMS district, coroner, funeral home, or others as indicated
 - For home emergencies, have a strategy that is consistent with the advance care plan. What if the family can't cope at home? What if symptoms can't be controlled at home? Who should they call? To which hospital should the baby be transported? In many communities, emergency medical services responding to a 911 call are obligated to resuscitate and transport to the nearest hospital.



- Engage community family support resources
- Review the post discharge plan with the parents and update as indicated
- Anticipate practical issues such as need for a car bed in infants with airway issues
- Provide ongoing support to the family and health care providers
- Be accessible to the parents and community health care providers

After the discharge, frequent home visits and/or phone contact are helpful to identify symptoms, assess the coping of the family, and identify practical issues that are barriers to excellent palliative care. At the time of death, presence of a physician licensed in the state of death or home/hospice nurse who can declare death and notify the medical examiner or coroner will significantly lessen the burden on the parents. Attendance by team members at the memorial or funeral is very meaningful to the family. Contact by the physician and other team members in person or by phone following the death is also important to the family. This is a good opportunity to review the baby's condition, any predisposing factors, preventable aspects if any, likelihood of recurrence, results from the autopsy (if done), and options for prenatal diagnosis with the next pregnancy. Bereavement support, including involvement in parent-to-parent support groups, continues as long as the parents and family are in need; frequently several years.

Families who are supported in this manner along their difficult journey have many things to tell us and teach us. One mother told me that she knew her baby was living on borrowed time and our team helped her make the most of it. A teenaged single mother living in poverty told me how the palliative care team became her surrogate family and supported her in her role as parent. Some families are surprised to know that they have choices before and after delivery. Many families tell us that they don't know how they could have gotten through the life and death of their newborn without support.

Antenatal advance care planning helps implement perinatal palliative care principles in the support of physical comfort, psychosocial and spiritual needs, family centered decision-making, and logistical planning. The process supports the parents' goals of focusing on the life of their baby, feeling competent to parent, and integrating the brief life of their newborn into the fabric of the extended family.

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Resources

1. Bijma HH, et. al. Parental decision making after ultrasound diagnosis of severe fetal anomaly. *Fetal Diagn Ther* 2005;20:321-327
2. Gale G, Brooks A. A parents' guide to palliative care. *Adv Neonatal Care* 2006;6:54
3. Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. *Adv Neonatal Care* 2006;6:37-53 *Very complete description of setting up NICU palliative care*
4. Hoeldtke JF, Calhoun BC. Perinatal hospice. *Am J Obstet Gynecol* 2001;185:525-529
5. Howard ED. Family-centered care in the context of fetal abnormality. *J Perinat Neonat Nurs* 2006;20:237-242
6. Leuthner SR. Fetal palliative care. *Clin Perinatol* 2004;31:649-665 *Excellent review; includes a draft advance care plan*



7. Leuthner SR. Palliative care of the infant with lethal anomalies. *Pediatr Clin North Am* 2004;51:747-759
8. Milstein JM. Detoxifying death in the neonate: In search of meaningfulness at the end of life. *J Perinatol* 2003;23:333-336
9. Moro T, Kavanaugh K, Okuno-Jones S, VanKleef JA. Neonatal End of Life Care: A review of the research literature. *J Perinat Neonat Nurs* 2006;20: 262-273
10. Pearson L. Family-centered care and the anticipated death of a newborn. *Pediatric Nursing* 1997;23: 178-182
11. Peller A, Westgate M, Holmes L. Trends in congenital malformations 1974-1999: Effect of prenatal diagnosis and elective termination. *Obstet Gynecol* 2004;34:244-252
12. Rempel GR, et. al. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *J Obstet Gynecol Neonatal Nurs* 2004;33:64-70
13. Sumner LH, Kavanaugh K, Moro T. Extending palliative care into pregnancy and the immediate newborn period: State of the practice of perinatal palliative care. *J Perinat Neonat Nurs* 2006;20:113-116

Web resources (accessed 9/18/06)

1. Center for Infant and Child Loss
http://www.infantandchildloss.org/index.php?module=pagemaster&PAGE_user_op=view_page&PAGE_id=44&MMN_position=39:7
2. Children's Hospital of Wisconsin Fetal Concerns program
<http://www.chw.org/display/PPF/DocID/32796/router.asp>
3. Children's Hospitals and Clinics. Deeya:
<http://xpedio02.childrenshc.org/stellent/groups/public/@xcp/@web/@hospice/documents/policyreferenceprocedure/web008384.asp>
4. Cincinnati Children's Starshine Hospice:
<http://www.cincinnatichildrens.org/svc/alpha/s/hospice/spiritual/perinatal.htm>
5. Parent/author website containing many resources:http://perinatalhospice.org/Home_Page.html
6. Perinatal loss support resources:
<http://www.cbsnews.com/stories/2004/01/07/earlyshow/main591952.shtml>
7. Share: Pregnancy and Infant Loss, Inc. <http://www.nationalshareoffice.com/>



A Family's Journey with Newborn Life and Death

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Legal and religious arguments aside, a baby becomes real to its parents the moment the pregnancy test is positive. Minds race imagining changes to the family dynamics, reconfiguring the living space, thinking about the gender of and possible names for the baby. More significantly, parents redefine themselves in terms of this new life and create hopes and dreams for who the child might become. Pregnancy loss, through miscarriage, stillbirth, or neonatal death robs the parent of connectivity, bonding, and memory making. Mourning the loss of an unborn baby or infant is very different than the loss of a child with whom one has shared years of memories.

Some have argued that the final stage of grief, popularly called “acceptance,” should be seen instead as finding a way to stay connected to the deceased in a meaningful and realistic way. The initial focus of bereavement support in these early loss cases should be on creating interactions between parent and baby, even if the baby dies before birth. Prenatal parents often express the hope that they have at least some moments to “get to know their child,” but even a dead child can be cuddled and kissed and examined, his or her features memorized. Physical evidence that the child exists, such as foot and hand prints, locks of hair, and hospital ID tags are treasured by families, especially when others do not validate their loss. A relatively new service offered by volunteer professional photographers who capture the moments with the most tender of poses (baby's hand laid in Dad's hand, or only the feet of the baby and the siblings lined across the photo) again provide physical memories during the small window of time that these parents have to lavish love on their child. Even a less than perfect looking baby can be photographed in the most appealing light by professionals.

Ideally bereavement support can begin when the news of a poor outcome is discovered. Hospice staff can join the family at the doctor or ultrasound appointments and walk through the journey with them. A nurse can help the family develop a detailed birth plan outlining how they would prefer that day to go, giving them the opportunity to make difficult decisions (such as those about life support, who they want present, tests they might want performed) when they have the quiet time to consider their options. The questions raised by this process help parents begin to face the reality of their child dying and, as one mom put it, “gave me some control in my out of control situation.” Parents begin to process their disappointment, guilt, and anger, as well as begin to grieve what might have been.

Moms sometimes feel the loss more intensely as they are the “incubator” of this unborn life. Some moms have expressed a wish to keep the baby inside for as long as possible where they can control the baby's viability. Dads struggle with their own feelings of loss but also feel the need to support the mom physically as well as emotionally. Sometimes dads may think prior to delivery that their own sad feelings are not as justified as those of moms. Encouraging open



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communication is essential because often moms feel that fathers distance themselves and “don’t care.”

Prior to delivery is a good time to think about funeral planning and burial sites. More often than with older children, parents may consider burying the child in a plot with another relative, or chose cremation so that they can postpone the burial until one parent is deceased and then both can be buried together. These options are foreign ideas initially and families need time to even begin to think about the horror of burying an infant. Some families cannot bear to contemplate this and prefer to wait.

Bereavement following the death often centers on the physical longing for a baby to hold, and the dramatic change from what parents expected their life to be with a newborn. Other issues include spiritual questions and, almost universally, disappointment in the lack of support from others who do not feel that a stillborn or infant baby is “real” enough to miss. Constant validation of this as a very real loss and providing opportunities to express their anger at others who are not supportive are common elements of bereavement visits. Future pregnancy and the option of genetic testing are often explored. Supporting the family’s efforts to create memorials to the child and to find meaning in the loss, or at least find something positive that can be created from the loss (such as supporting research into the fatal disease in the child’s name) is another way to help the family feel connected. Support groups dealing with perinatal and neonatal loss are invaluable for those who choose to use them.

One of the greatest challenges for prenatal programs is encouraging physicians to make referrals to hospice, particularly as early as the prognosis is known. Relationship building over several months of pregnancy can increase a family’s comfort level and the likelihood of a request for hospice staff to be present at the birth. This presence is often critical in facilitating additional support and interventions for the parents, siblings, and grandparents at an acutely emotional time.

* * *



Perinatal Hospice: Another Option

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"I am sorry ... the scans show your unborn child has a condition that is not compatible with life... When would you like to schedule the termination?"

One family facing this situation came to our pediatric hospice program for help. From this first situation, our perinatal hospice program began to grow and develop.

The Deeya¹ Perinatal Hospice is part of the Pain and Palliative Care services of Children's Hospitals and Clinics of Minnesota. The Pain and Palliative Care Programs serve children prenatally to 21 years of age. Services are available to children and their families, in hospital and at home. The program as a whole has an average daily census of 60-80 children.

Referrals for Deeya services come from physicians, midwives, genetic counselors, and families themselves. The volume of referrals is generally small, averaging 1-3 patient families at a time, often receiving care over several months. The Deeya Perinatal Hospice Program provides a menu of services for the family to choose from. Some families choose to use all the options while others simply find comfort in knowing helpers are available and access none of the services. Services include home visits with a nurse, social worker, child life specialist, and chaplain. A 24-hour telephone service is available for families if they feel the immediate need for assistance or support.

Case Example

The Johnsons were a professional couple who had a 12-year-old son from a previous marriage and now were delighted to be pregnant together. The couple had been trying to have a baby for some time. Their anticipation of the new baby was terrific. Their excitement and delight turned to dust when they were told their unborn child had severe congenital abnormalities and would not survive the pregnancy. They chose not to terminate the pregnancy, but were not sure how they could begin to plan for both the birth and death of their child.

While meeting with a genetic counselor they learned about the Deeya program. The Deeya nurse was contacted and called Mrs. Johnson at home to discuss the program. Mrs. Johnson was so relieved to know that there was support for them as they faced this difficult road. They requested the Deeya visit be at home in the evening so they could include their 12-year-old son.

The nurse and the social worker met with the family around a large dining room table in their house. Mrs. Johnson was 20 weeks pregnant. During the conversation the team offered the help of the whole team: nursing, chaplaincy, social work, and child life. They described concerns

¹ "Deeya" Sanskrit word meaning a small light, that is the aim of the program to be a small light in a time of darkness



about how to tell family and friends, how to cope with the reactions of others, and how to help their son cope with the events likely to occur. The family spoke of faith in God, but said they were not involved in a church, and wondered how to go about planning the funeral. In the following weeks they met with the chaplain and together worked together to plan a blessing ceremony before the birth, a baptism after, and a funeral once the baby died. For the Johnsons these discussions brought great comfort and relieved their fears of how to manage arrangements in the midst of deep grief.

The conversation turned to the actual birth. Individualized birth planning is often helpful in reducing anxiety and assisting the family in identifying what is most important to them. Birth classes offered to people with normal pregnancies are obviously not appropriate for families with these needs. Instead, individualized birth classes are offered and a birth plan specific to their likely needs is developed. This includes specifics about the labor and delivery, individuals to be present, and other comfort measures.

The couple worked on their birth plan at length, getting input from their doctor and close friends. One thing they were absolutely clear on was that they wanted to keep the baby comfortable and held until her death. She should not have any life prolonging interventions. This was documented on their birth plan, which they kept at home; a copy was put into the chart in the doctor's office, and provided to the hospital where Mrs. Johnson planned to deliver.

The Deeya team was available to the family on an ongoing basis. Representatives from different disciplines met with them over time to support, plan, and guide the family. The family started a journal for their thoughts and impressions. The pregnancy was going along without problem. When Mr. Johnson had to go on a short business trip there were no concerns about him leaving. While he was away, however, Mrs. Johnson had a seizure and was rushed to the hospital. While she was unconscious from the seizure's aftermath, the baby was born emergently and lived only a few hours. Because the birth plan was part of the hospital record, all of family's requests were honored. The baby did not suffer; she was baptized and held until her death. The family had private time with her after her death. This process brought the family much peace. The hospice chaplain performed the funeral a few days later. The service focused on the joy and closeness that had come out of anticipating this little one's life. Deeya's social worker and child life specialist assisted the chaplain in providing bereavement support services to the family after their baby's birth and death.

The way the Johnson family used the services of Deeya was not unique, yet the dramatic nature of their baby's birth and subsequent death underscores the importance setting goals and birth planning with families facing their baby's anticipated death. Perinatal hospice strives to support families in their choices at this difficult time.

Conclusion

Perinatal hospice is a "low frequency, high impact" program. While the program serves 5-10 families a year, the "high impact" emotional effect on the family and community is life changing. It can make the difference in moving from despair to hope.



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Hospice care is best delivered by a team which focuses on comfort and quality of life in a holistic way. Perinatal hospice does this and gives families the message that even when death cannot be avoided, there is always more we can do, and that families do not need to face this crisis alone.

* * *

References

1. Calhoun BC, Reitman JS, Hoeldtke NJ (1997, fall). Perinatal hospice: A response to partial birth abortion for infants with congenital defects. *Issues Law Med.* 13(2):125-43. Review.
2. Calhoun BC et al. (1997, Sept.). Perinatal hospice: Should all centers have this service? *Neonatal Network.* 16(6):101-2.
3. Catlin AJ, Calhoun BC, Carter BS. (2001, April). Care of the dying newborn: Perinatal hospice, research, and practice. *Obstetrics and Gynecology.* 97(4 suppl 1):S55.
4. Calhoun, BC, Napolitano, P. Terry, M., Bussey, C., Hoeldtke, N (2003, May) "Perinatal hospice: Comprehensive care for the family of the fetus with a lethal condition." *The Journal of Reproductive Medicine.* 48(5):343-348.
5. Hoeldtke, NJ & Calhoun, BC. (2001, Sept.). Perinatal hospice. *American Journal of Obstetrics and Gynecology.* 185(3):525-9.



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A Parents' Guide to Palliative Care

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Palliative care is focused on the relief of suffering when no cure is possible. Doctors and nurses will continue to care for your baby around the clock. Touching, holding, and talking to your baby will comfort both of you. You and your family are facing some serious decisions. You have likely had a series of discussions with the hospital care team. Like all parents, you want what is best for your baby. This resource will provide information about palliative care, which may be an appropriate option for your baby, either now or some time in the future.

What Is Palliative Care?

Palliative care is a dignified, family- and staff-supported care option for newborns who are not able to get better. The goal of palliative care is to provide the best quality of life for a baby and family while the baby is alive. In some cases palliative care can help you to plan for a natural and peaceful death.

What Kind of Babies Might Benefit From Palliative Care?

Palliative care is an option for infants who no longer benefit from intensive care. Babies who may benefit from a palliative care focus might include those with:

- A life-limiting illness
- Complex genetic disease
- Severe heart problem
- Extreme prematurity, or complications of prematurity
- Severe brain damage from lack of oxygen at or before birth

If I Choose Palliative Care, What Kind of Care Will My Baby Receive?

Once palliative care is chosen the focus of care will begin to shift away from intensive efforts aimed at curing and healing. Instead we will focus on intensive efforts to provide comfort and quality of life. Your healthcare team will work with you to decide what equipment and procedures are useful for your baby. Painful procedures will be limited. We will do everything possible to relieve pain and keep your



Palliative care is focused on the relief of suffering when no cure is possible.



Doctors and nurses will continue to care for your baby around the clock.



Touching, holding, and talking to your baby will comfort both of you.



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baby comfortable. You and your extended family and friends can spend as much time as possible with your baby. Your baby's doctors and nurses will be there to help you, to watch over your baby, and to answer questions and support you and your family.

Where Does Palliative Care Happen?

Some families choose to stay in the hospital for palliative care and use the support services in the intensive care unit. Others prefer to use hospice care at home or a local hospice facility. If you want to take your baby home, ask your baby's doctor, nurse, or social worker for information on palliative care outside the hospital.

How Long Do Babies Receiving Palliative Care Live?

Every baby is different. Infants who are on life support equipment, like a breathing machine, may die within minutes or hours once the equipment is removed. Other babies live longer, sometime for days or weeks. Ask your baby's doctor what is expected for your baby.

* * *

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