

A NEONATOLOGIST'S
PERSPECTIVE ON FAMILY
CENTERED PALLIATIVE
CARE PLANNING

Shabih Manzar, MD

Attending Neonatologist

A Neonatologist's perspective on family centered palliative care planning

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Dr. Manzar is a Board Certified Attending Neonatologist for Rockford Memorial Hospital, Level III, 48 bed NICU. He has been at Rockford Memorial Hospital since 2006. He currently is involved in the Newborn Palliative Care team and assists in teaching to the regional hospitals within the Perinatal Network. Dr. Manzar has published several articles in the areas of perinatal palliative care, which includes the reduction of pain strategies, identifying compassionate withdrawal, and survival patterns among extreme preterm infants.

David A. Munson, MD

Dr. Munson has a long held interest in ethics and end of life care, and the engagement of these issues in clinical care has shaped much of his career. Upon completion of his fellowship, Dr. Munson stayed at the Children's Hospital of Philadelphia as an attending in the Division of Neonatology, but also as a member of the Pediatric Advanced Care Team, which serves as the palliative care team for the hospital. Dr. Munson also directs the perinatal palliative care initiative at the Children's Hospital of Philadelphia, which is designed to provide support for mothers carrying a fetus with a life limiting diagnosis. Within the Division of Neonatology Dr. Munson helped lead a consensus conference aimed at improving the care when withdrawing technological support for infants. He has also published several articles and chapters in the areas of neonatal palliative care and the

Objectives for Conference

- Recognize the important role that communication/documentation plays in the development of the Newborn Palliative Care plan.
- Describe the Newborn Palliative Care process through examining a personal story of grief and loss.
- Identify goals and interventions that empower families to make care choices consistent with their values while maximizing the benefits of medical care.

**Newborn Palliative Care
"Strategies for
Transitioning from
Acute to Comfort Care"**

2008

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Cultural / Social Perspective:

31 wk male born vaginally to 32 y/o G4 P3 in (a developing country)*. Middle-class family, woman home maker, father office worker- no health insurance.

Issues : Cost of surfactant, ventilator, TPN, day to day care in level III NICU...can they afford it?

Regional / Religious Perspective:

Term baby with multiple anomalies and complex heart disease– born to G8 P5 in (an oil producing rich country)*. Mother's education middle school, father works at the airport.

Issues: Level 3 NICU-Government hospital but parents are willing to withdraw support (God's will)

**In compliance with HIPAA*

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National / Local

Mostly insured (Public aid or Private insurance)

Cases:

- 1) 24 wk on HFOV with severe pulmonary hemorrhage (twin 2, twin 1 died *in-utero*)
- 2) 26 wk with severe NEC, loss of 80% intestine (baby was fine at evening visit)
- 3) Term infant with Apgar 0, 1, 2 on hypothermia treatment with fixed dilated pupil possible brain dead (no response to therapy)
- 4) 25 wk with bilateral grade IV bleed (with esophageal duplication)
- 5) 24 wk with complex heart disease (no prenatal care)

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Points:

- Understanding grief and offering bereavement support are key components to providing beneficent neonatal palliative care.
- Clear understanding of disease progression/medical diagnosis
- Transition from acute to comfort care (parents feelings)
- Time adjustment to bad/sad news

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Points:

- Family conference meeting
- Communication
- NICU team (nurse, physician, family-extended)
- If family unable to accept –address the best interest of the baby
- Long term care (hospice care)
- Progress (infrastructure, lack of funding, financial aspect, emotional)

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