FEATURED RESOURCES FOR CAREGIVERS

Perinatal Palliative Care Toolkit and Position Paper on Perinatal Palliative Care, from RTS Bereavement Services/Gundersen Health System, and annual conference, Blueprint for a Perinatal Palliative Care Program®.


Children's Project on Palliative/Hospice Services (CHiPPS) Pediatric Palliative Care Newsletter, Perinatal Palliative and Hospice Care. A project of the National Hospice and Palliative Care Organization. Issue 30, February 2013.

Perinatal Palliative Care and End-of-Life Web-Based Toolkit from the Texas Pediatric Society Committee on Fetus and Newborn

Online perinatal palliative care training from The Royal College of Midwives, U.K.

The Journal of Perinatal & Neonatal Nursing, January/March 2011, Vol. 25, Issue 1: "Bereavement." Articles include "Making a Case: Creating a perinatal palliative care service using a perinatal bereavement program model" (Kobler K, Limbo R); "Continuity and change in mothers’ narratives of perinatal hospice" (Lathrop A, VandeVusse L), and "The evolving science of care in perinatal loss" (Black BP, Howard E, Bakewell-Sachs S).


Birth plan, in-house comfort care orders, and discharge comfort care orders from St. Joseph Health System's Perinatal Comfort Care Program, Orange, California. (Posted here with permission; see disclaimer.)


International Children's Palliative Care Network fact sheet on hospice and palliative care for children, including perinatal palliative care. July 2013

Kuebelbeck A. A Gift of Time: Continuing a pregnancy when a baby's life is expected to be brief. Children's Project on Palliative/Hospice Services pediatric palliative care newsletter, a project of the National Hospice and Palliative Care Organization. February 2013

McGovern K. Continuing the pregnancy when the unborn child has a life-limiting condition. Chisholm Health Ethics Bulletin, Caroline Chisholm Centre for Health Ethics, Melbourne, Australia, Autumn 2012.

National Perinatal Association Position Paper on Palliative Care, including perinatal hospice, December 2013.


CONFERENCES AND EDUCATION

Resolve Through Sharing Bereavement Services clinically based professional training for caregivers, including training in general perinatal loss and perinatal palliative care. Annual professional training workshops: "Blueprint for a Perinatal Palliative Care Program®: Caring for families who continue the pregnancy after their baby is diagnosed with a life-limiting condition" and "Blueprint for a Perinatal Palliative Care Program®: The Basics." Gundersen Health System, La Crosse, Wisconsin.

Pregnancy Loss and Infant Death Alliance (PLIDA): professional networking and biennial International Perinatal Bereavement Conference.

Presentations by Amy Kuebelbeck

Online education:

Hospice and Palliative Nurses Association Certification in Perinatal Loss Care

National Hospice and Palliative Care Organization: Evidence-based Neonatal and Perinatal Palliative Care with Brian Carter MD. CE/CME credit available for counselors, nurses, physicians, and social workers.

End-of-Life Nursing Education Consortium (ELNEC) perinatal and neonatal palliative care training module

Online perinatal palliative care training from The Royal College of Midwives, UK

PROFESSIONAL NETWORKING

Private e-mail listserv for caregivers interested in perinatal hospice and palliative care. List began in 2006 and currently has nearly 400 members. Moderated by Amy Kuebelbeck. Request to join here.

Pregnancy Loss and Infant Death Alliance (PLIDA); professional networking and biennial International Conference on Perinatal and Infant Death

Perinatal Society of Australia and New Zealand (PSANZ) perinatal palliative care special interest group

BIRTH PLAN RESOURCES FOR CAREGIVERS

Birth plan, in-house comfort care orders, and discharge comfort care orders from St. Joseph Health System's Perinatal Comfort Care Program, Orange, California. (Posted here with permission; see disclaimer.)

Texas Pediatric Society Committee on Fetus and Newborn perinatal palliative care birth plan, from their Perinatal Palliative Care and End-of-Life Web-Based Toolkit


May C. Perinatal advance care planning. CHiPPS E-journal, Children's Project on Palliative/Hospice Services, a project of the National Hospice and Palliative Care Organization, 2015 Feb. (38):9-10.
MATERIALS FOR PATIENTS

*A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* by Amy Kuebelbeck and Deborah L. Davis, Ph.D. (Johns Hopkins University Press, 2011), along with their other books, including:

- *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life* (Kuebelbeck)
- *Empty Cradle, Broken Heart: Surviving the Death of Your Baby* (Davis)

*Waiting for Birth and Death: Knowing your baby will not survive* brochure from RTS Bereavement Services/Gundersen Health System, available in English and Spanish.

*Gift of a Lifetime* brochure by Tammy Tate RN LCPC, available in English and Spanish [here](#).

REFERENCES RELEVANT TO PERINATAL HOSPICE AND PALLIATIVE CARE


Barrington K. *Guidelines to use when speaking with parents who have received a potentially life-limiting diagnosis for their fetus or child*. Adapted and reprinted in Berg SF, Paulsen OG, Carter BS. Why were they in such a hurry to see her die? American Journal of Hospice & Palliative Care, June 2013; 30(4):406-408.


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Bétrémieux P. TOP or palliative care for lethal foetal condition? Prenatal Diagnosis, 2010; (30): 1112.

Bétrémieux P, Druyer J, Bertorello I, Huillery ML, Brunet C, Le Bouar G. Antenatal palliative plan


Buller L. Perinatal palliative care: Beginning the journey. Poster presentation at Center to Advance Palliative Care national seminar, Nov. 7-9, 2013.


Calhoun BC, Hoeldtke NJ, Hinson RM, Judge KM. Perinatal hospice: should all centers have this service? Neonatal Netw. 1997 Sep;16(6):101-2.


Calhoun BC. Perinatal hospice: Compassionate and comprehensive care for families with lethal prenatal diagnosis. The Linacre Quarterly 77(2) (May 2010): 147–156.


Carter B. Comfort care principles for the high-risk newborn. NeoReviews, Vol. 5 No. 11 2004 e484.


Catlin A. Bringing Perinatal Palliative Care to the Forefront: One Nurse’s View. Journal of Hospice & Palliative Nursing. 2004 Jul/Aug/Sep; 6(3):142-143.


Dangel T. Lethal Defects in Foetuses and Neonates: Palliative Care as an Alternative to Eugenic Abortion, Eugenic Infanticide, and Therapeutic Obstinacy. The Warsaw Hospice for Children Foundation.


Davis DL. Providing emotionally supportive care to parents as they face decisions after prenatal diagnosis of a baby’s life-limiting condition. ChiPPS E-News, Children’s Project on Palliative/Hospice Services Pediatric Palliative Care Newsletter, May 2007; Issue 7, p. 22.


Engelder S, et al. A Model Program for Perinatal Palliative Services. Advances in Neonatal Care,


Horning ML, Braun CA. The lived experience of families who are told their child will die at or shortly after birth. Journal of Undergraduate Nursing Scholarship. Fall 2006, Vol. 8, No. 1.

"Perinatal hospice programs provide support for families facing a newborn's death," Hospice Letter, June 2008, pp. 4-5.

Hospice and Palliative Nurses Association online chat featuring Rana Limbo PhD RN PMHCNS-BC CPLC FAAN of Bereavement Services/Resolve Through Sharing and the Pregnancy Loss and Infant Death Alliance (PLIDA) answering questions about perinatal bereavement and perinatal palliative care.

HSE (Ireland Health Services) Proposed Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death, June 2015


International Children's Palliative Care Network fact sheet on hospice and palliative care for children, including perinatal palliative care. July 2013


Kuebelbeck A. A Gift of Time: Continuing a pregnancy when a baby's life is expected to be brief. Children's Project on Palliative/Hospice Services pediatric palliative care newsletter, a project of the National Hospice and Palliative Care Organization). February 2013


MCN: The American Journal of Maternal/Child Nursing. special issue devoted to the topic of perinatal and pediatric bereavement. May/June 2014


Marron-Corwin MJ, Corwin D. When tenderness should replace technology: The role of perinatal hospice. NeoReviews, Vol. 9 No. 8 2008 e348.


May C. Perinatal advance care planning. CHiPPS E-journal, Children's Project on Palliative/Hospice Services, a project of the National Hospice and Palliative Care Organizaton, 2015 Feb. (38):9-10.

McGovern K. Continuing the pregnancy when the unborn child has a life-limiting condition. Chisholm Health Ethics Bulletin, Caroline Chisholm Centre for Health Ethics, Melbourne, Australia, Autumn 2012.
Mendes J. Important research from the USA replicated in Portugal. eHospice, Aug. 19, 2013.


Murdoch E, Carragher P, McNamara K. Perinatal Palliative Care Framework: Goals and Standards for Perinatal Palliative Care, and NHS Scotland Regional Managed Clinical Network for Neonatal Services, December 2013


National Hospice and Palliative Care Organization Definition and Principles of Pediatric Palliative Care, Children's International Project on Palliative/Hospice Services, 2003.

National Perinatal Association Position Paper on Palliative Care, including perinatal hospice, December 2013

Nordin TA, Clark EC. A family's experience with perinatal palliative care. American Family Physician. 2015 Apr 1;91(7):442.


Pearce EWJ. Perinatal Hospice/Supportive Care for the Dying Unborn Infant. Supportive Voice, newsletter of the Supportive Care Coalition: Pursuing Excellence in Palliative Care, Summer 1999.

Perinatal Palliative Care Framework MCN (South East Scotland), Together for Short Lives (U.K.)

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Sumner LH. Perinatal Hospice Services/Early Intervention Program purpose and procedures, 2006.


Texas Pediatric Society Committee on Fetus and Newborn, Perinatal Palliative Care and End-of-Life Web-Based Toolkit.

Thiele P. He was my son, not a dying baby. J Med Ethics 2010 36:646-647.

Thiele P, Blair S. Destined to die: At 18 weeks’ gestation Pauline Thiele’s baby was diagnosed with trisomy 18, a usually lethal syndrome. Her problems began when she chose not to terminate the pregnancy. BMJ 2011;343:d3625. Response: Please, can we have the perinatal hospice approach now.

Thienprayoon R, Schreck B. A Symphony of Life: One Team’s Approach to Perinatal Palliative Care. Presentation about using music therapy in perinatal palliative care, American Academy of Pediatrics, October 2015.


Williams M. Neonatal Hospice Nursing, Part One: Interview with Jayne Taylor RN, explaining the outpatient perspective and Part Two: Interview with Debra Bolton RNC CLE, the inpatient experience.


RESOURCES FOR CAREGIVERS

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- Resources for parents
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PERINATAL HOSPICE & PALLIATIVE CARE

Video for the Neonatal Comfort Care program at New York-Presbyterian Morgan Stanley Children's Hospital.
As prenatal testing becomes increasingly routine, more parents are learning devastating news before their babies are born. In too many places, the ability to diagnose has raced ahead of the ability to care for these families and their babies. But in a beautiful and practical response, more than 250 pioneering hospitals, hospices, and clinics in the U.S. and around the world are now providing perinatal hospice & palliative care support for families who wish to continue their pregnancies with babies who likely will die before or shortly after birth.

A perinatal hospice approach walks with these families on their journey through pregnancy, birth, and death, honoring the baby as well as the baby's family. Perinatal hospice is not a place; it is a way of caring for the pregnant mother, the baby, the father, and all involved with dignity and compassion and love. It can easily be incorporated into standard pregnancy and birth care just about anywhere. Even in areas without a formal program, parents can create a loving experience for themselves and their baby, and health professionals and family and friends can offer support in the spirit of hospice (see A Gift of Time and the resources for parents and caregivers on this site).

PERINATAL HOSPICE & PALLIATIVE CARE PROGRAMS AND SUPPORT

Programs and groups listed below may vary in their scope of support and services. Most of the programs listed below are based in hospitals and are integrated into pregnancy and birth care; some are hospice-based; and a few are faith-based or independent. If your organization provides formal or informal perinatal hospice/palliative care support and you would like to be added to this list, contact info@perinatalhospice.org.

CALIFORNIA

Angel Babies/Bebitos Angelitos of Hinds Hospice, Fresno and Merced, California

Pediatric and perinatal hospice care at The Elizabeth Hospice and the affiliated Center for
Compassionate Care, which provides grief counseling and support. Contact: Center for Compassionate Care Director Lizabeth Sumner RN BSN, (760) 737-2050. Escondido, California

UCSF Benioff Children's Hospital Compass Care Pediatric and Perinatal Palliative Care Program. Contact: Tina Ratto RN MSN, (415) 353-7558. San Francisco, California

Paloma Comfort Care at UC Irvine Health, Orange, California

UCSF Benioff Children's Hospital Compass Care Pediatric and Perinatal Palliative Care Program. Contact: Tina Ratto RN MSN, (415) 353-7558. San Francisco, California

Perinatal Hospice Services, Life Choices Pregnancy Clinic of the Ojai Valley. Ojai, California

Perinatal and pediatric hospice at University of California San Diego/Rady Children's Hospital. Contact: Krishelle Marc-Aurele MD, board-certified in neonatology and hospice & palliative medicine, (619) 543-3759. San Diego, California

St. Joseph Health System Home Health Perinatal Comfort Care. Contact: Suzanne Engelder MSW, (714) 712-9559 x3311. Orange, California

St. Joseph Health System Mission Hospital Maternity Center Perinatal Hospice Care. Mission Viejo and Laguna Beach, California

Scripps Health Perinatal Hospice Care, with hospital locations in La Jolla, Chula Vista, Encinitas, and San Diego, California

TrinityCare Hospice TrinityKids Care. Contact Jamie Andrews, (310) 543-3400. Los Angeles, California

Journey to Remember, a Forever Footprints perinatal comfort care program. Contact: Amanda Balderrama RN BSN, (800) 714-9320. (See their video.) Riverside/San Bernardino/Ontario, California