

## RESOURCES FOR PERINATAL LOSS

### 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®.

[Palliative care \(supportive and end-of-life care\): A framework for clinical practice in perinatal medicine](#) and its accompanying [report](#), from the British Association of Perinatal Medicine.

[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).

Collier R. [Providing hospice in the womb](#). Canadian Medical Association Journal, Feb. 17, 2011.

Engelder S, et al. A Model Program for Perinatal Palliative Services. Advances in Neonatal Care, February 2012; 12(1):28-36.

[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](#).)

Kobler K, Limbo R, Oakdale C. [Childbirth education for parents receiving perinatal palliative care](#). International Journal of Childbirth Education. April 2012;27(2):26-32.

Hoeldtke NJ, Calhoun BC. [Perinatal hospice](#). Am J Obstet Gynecol. 2001 Sep;185(3):525-9.

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.

Warland J, Davis DL, et al (2011) [Caring for families experiencing stillbirth: A unified position statement on contact with the baby. An international collaboration](#). Also available in [Spanish](#). See also [commentary](#) by Limbo R in *Illness, Crisis & Loss*, 2012.

Wool C. State of the Science on Perinatal Palliative Care. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 2013 May/June; 42(3):372–382.

## 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.

Resolve Through Sharing Bereavement Services/Gundersen Health System [webinars](#) including "Perinatal palliative care: Planning in advance and systems support," "Comfort care for babies with life-limiting conditions: Using the neonatal advance directive," and "Life-threatening diagnosis: What do I say next?"

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](#)

Allston S, Chichester M, Sturtz WJ. [Perinatal advance directives](#). CHiPPS E-journal, Children's Project on Palliative/Hospice Services, a project of the National Hospice and Palliative Care Organization, 2015 May (39):22-24.

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

Ambler J. [A closer look at perinatal palliative care](#), eHospice, March 11, 2014.

American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care statement, [Palliative Care for Children](#). Pediatrics 2000 Aug;106(2):351-357. Reaffirmed 2006 and 2012.

Balaguer A, Martín-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J. [The model of palliative care in the perinatal setting: A review of the literature](#). BMC Pediatrics 2012, 12:25.

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.

Bennett J, Dutcher J, Snyders M. Embrace: addressing anticipatory grief and bereavement in the perinatal population: a palliative care case study. J Perinat Neonatal Nurs. 2011 Jan-Mar;25(1):72-6.

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.

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

following diagnosis of fetal lethal condition: Rennes Teaching Hospital experience. *J Gynecol Obstet Biol Reprod (Paris)*. 2015 Sept. 29.

Black BP, Howard E, Bakewell-Sachs S. The evolving science of care in perinatal loss. *Journal of Perinatal & Neonatal Nursing*, January/March 2011, Vol. 25, Issue 1.

Bollenbach LM. [When end of life is near life's start](#). Vision, publication of the National Association of Catholic Chaplains, January/February 2014.

Boss R, Kavanaugh K., Kobler K. Prenatal and neonatal palliative care. Chapter 37 in Wolfe J, Hinds P, Sourkes B (Eds.), *Textbook of Interdisciplinary Pediatric Palliative Care*. Elsevier, 2011, pp. 387-401.

Breeze AC, Lees CC. Antenatal diagnosis and management of life-limiting conditions. *Seminars in Fetal and Neonatal Medicine* April 2013; 18(2):68-75.

Breeze AC, Lees CC, Kumar A, Missfelder-Lobos HH, Murdoch EM. Palliative care for prenatally diagnosed lethal fetal abnormality. *Archives of Disease in Childhood - Fetal and Neonatal Edition* 2007 Jan;92:F56-F58.

Brosig CL, Pierucci RL, Kupst MJ, Leuthner SR. Infant end-of-life care: the parents' perspective. *Journal of Perinatology* 2007; 27:510-516.

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

Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Perinatal hospice: Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med*. 2003 May;48(5):343-8.

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, Hoeldtke NJ. The Perinatal Hospice: Ploughing the Field of Natal Sorrow. *Frontiers in Fetal Health* 2000; 2(5).

Calhoun BC, Reitman JS, Hoeldtke NJ. Perinatal hospice: a response to partial birth abortion for infants with congenital defects. *Issues in Law and Medicine* 1997; 13(2):125-143.

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

Carey JC. Perspectives on the care and management of infants with trisomy 18 and trisomy 13: striving for balance. *Curr Opin Pediatr*. 2012 Oct 5.

Carroll K. The Miracle of Time. *Supportive Voice*. Winter 2004; Vol. 10, No. 1.

Carter BS, Levetown M. Eds. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. Baltimore, MD. Johns Hopkins University Press, 2004.

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

Carter BS. Comfort/palliative care guidelines for neonatal practice: Development and implementation in an academic medical center. *Journal of Perinatology*. 2001; 21:279-283.

Carter BS. Neonatal and Infant Death: What Bereaved Parents Can Teach Us. *Journal of Perinatology*. 2007; 27:467-468.

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. .

Catlin A, Carter BS. Creation of a Neonatal End-of-Life Palliative Care Protocol, *Journal of Perinatology*. 2002; 22(3):184-195.

Catlin A. Home Care for the High-Risk Neonate. *Home Healthcare Nurse*. 2007 Feb; 25(2):1-5.

Catlin A. [Perinatal Hospice Care during the Antepartum Period](#). *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2013 doi: 10.1111/1552-6909.12029

Catlin A. Thinking outside the box: Prenatal care and the call for a prenatal advance directive. *J Perin Neonat Nurs* 2005 Vol. 19, No. 2, pp. 169-176.

Chamberlain C, Spicer S, Curiel KD. [A primary care provider enhances family support in perinatal palliative care](#). *Paediatr Child Health*, 2015 April; 20(3):150-151.

Chichester M, Wool C. The meaning of food and multicultural implications for perinatal palliative care. *Nursing for Women's Health*. 2015 June;19(3):224-235.

Child Bereavement U.K. [Best Practice Guidance: Taking photographs following the death of a baby](#), 2011.

Chitty LS, Barnes CA, Berry C. For Debate: Continuing a pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendations for management. *British Medical Journal* 1996 Aug. 24;313:478-480.

Clark WD. [Pregnancy care: An apprenticeship for palliative care?](#) *J Am Board Fam Med*. 2008 Jan-Feb;21(1):63-5.

Cobb A. [Acknowledged dependence and the virtues of perinatal hospice](#). *Journal of Medicine & Philosophy*, Oxford University Press, published online Dec. 8, 2015.

Coffing J. [Let the little children come to me: A perinatal palliative care experience](#). *Chaplaincy Today* 2011 Vol. 27, No. 1, pp. 2-9. Published online Jan. 2, 2014.

Cole JCM, Jones T, Shaughnessy E, Chadwick S, Munson D and Moldenhauer J. [Multidisciplinary perinatal palliative care plan for a pregnant woman carrying a fetus with Trisomy 13 and her family](#). Journal of Obstetric, Gynecologic, & Neonatal Nursing, 2015 June (44): S79.

Cope, H., Garrett, M. E., Gregory, S., and Ashley-Koch, A. (2015) [Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome](#). Prenat Diagn, 35: 761–768.

Corr C, Torkildson C eds. Perinatal Loss. ChiPPS Pediatric Palliative Care Newsletter. From E-News, a program of the National Hospice and Palliative Care Organization. 2007 Feb;(6):1-22.

Cortezzo DE, Sanders MR, Brownell EA, Moss K. End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents. Amer J Perinatol 2015; 32(08): 713-724.

Côte-Arsenault D, Denney-Koelsch E. ['My baby is a person': Parents' experiences with life-threatening prenatal diagnosis](#). Journal of Palliative Medicine Vol 13, No. 12, 2011, 1-7.

D'Almeida MD, Hume RF, Lathrop A, Njoku A, Calhoun BC. [Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition](#). Journal of American Physicians and Surgeons Vol. 11, No. 2, Summer 2006. (includes sample birth plan)

Dangel T. [Lethal Defects in Foetuses and Neonates: Palliative Care as an Alternative to Eugenic Abortion, Eugenic Infanticide, and Therapeutic Obstnacy](#). The Warsaw Hospice for Children Foundation.

Davies V et al. Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study. Ultrasound Obstet Gynecol. 2005 Apr;25(4):389-92.

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.

Dean B, McDonald K. [Building an interprofessional perinatal palliative care team](#). NeoReviews, 2014 Oct 1;15(10):e422 -e425.

Denney-Koelsch E, Cote-Arsenault D. "My Baby Is A Person": Parents' experiences with life-threatening fetal diagnosis. Journal of Pain and Symptom Management, 2012 Feb;43(2):340–341.

Denney-Koelsch E, Cote-Arsenault D. "I Walk with Her Every Day": Parents' experiences of pregnancy with a lethal fetal diagnosis. Journal of Pain and Symptom Management, 2015 Feb;49(2):338.

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

February 2012; 12(1):28-36.

English NK and Hessler KL. Prenatal Birth Planning for Families of the Imperiled Newborn. Journal of Obstetric, Gynecologic, & Neonatal Nursing. (2013) doi: 10.1111/1552-6909.12031

Fenton LJ. [Trisomy 13 and 18 and quality of life: Treading "softly."](#) Am J Med Genet Part A, 2011.

Field MJ, Behrman RE. Eds. [When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families](#). Washington, D.C.: Institute of Medicine, The National Academies Press, 2003.

Gale G, Brooks A. A Parents' Guide to Palliative Care. Adv Neonatal Care, 2006 Feb;6(1):54-55.

Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. Adv Neonatal Care 2006 Feb;6(1):37-53.

Gale G, Brooks A. Obstacles to optimal palliative care in the labor and delivery unit. ChiPPS E-News, Children's Project on Palliative/Hospice Services Pediatric Palliative Care Newsletter, May 2007; Issue 7, p. 16.

Garten L, Glöckner S, Siedentopf JP, Bühner C. Primary palliative care in the delivery room: patients' and medical personnel's perspectives. J Perinatol. 2015 Dec;35(12):1000-5.

Goulette C. "[Guardians of Angels](#)." Advance Healthcare Network for Nurses, June 2008.

Guon J, Wilfond BS, Farlow B, Brazg T, Janvier A. [Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18](#). Am J Med Genet A, 2013 Dec 5.

Hochberg T. [Touching Souls: Healing with bereavement photography](#). The Forum, newsletter of the Association for Death Education and Counseling. Apr/May/June 2003;29(2):6.

Hoeldtke NJ, Calhoun BC. [Perinatal hospice](#). Am J Obstet Gynecol. 2001 Sep;185(3):525-9.

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



Hull D, Davies G, Armour CM. Survey of the definition of fetal viability and the availability, indications, and decision making processes for post-viability termination of pregnancy for fetal abnormalities and health conditions in Canada. *J Genet Couns*. 2015 Nov 5.

Iles S, Gath D. Psychiatric outcomes of termination of pregnancy for foetal abnormality. *Psychological Medicine* 1993 May;23(2):407-13.

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

Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Semin Perinatol*. 2014 Feb;38(1):38-46.

Janvier A, Farlow B, Wilfond BS. [The experience of families with children with trisomy 13 and 18 in social networks](#). *Pediatrics* 2012; 130:293-298.

Jaquier M, Klein A, Boltshauser E. [Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly](#). *BJOG* 2006;113:951–953.

Kavanaugh K, Roscigno C, Swanson K, Savage T, Kimura R, Kilpatrick S. Perinatal palliative care: Parent perceptions of caring in interactions surrounding counseling for risk of delivering an extremely premature infant. *Palliative and Supportive Care*, 2015 (13):145-155.

Kenner C, Press J, Ryan D. [Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach](#). *J Perinatol*. 2015 Dec;35 Suppl 1:S19-23.

Kenyon SL, Hackett GA, Campbell S. Termination of pregnancy following diagnosis of fetal malformation: the need for improved follow-up services. *Clin Obstet Gynecol*. 1988 Mar;31(1):97-100.

Kersting A. et al. Psychological impact on women after second and third trimester termination of pregnancy due to fetal anomalies versus women after preterm birth—a 14-month follow up study. *Arch Womens Ment Health*. 2009 Aug;12(4):193-201.

Kersting A et al. Grief after termination of pregnancy due to fetal malformation. *J Psychosom Obstet Gynaecol*. 2004 Jun;25(2):163-9.

Kersting A et al. Trauma and grief 2-7 years after termination of pregnancy because of fetal anomalies--a pilot study. *Psychosom Obstet Gynaecol*. 2005 Mar;26(1):9-14.

Kilby M, Pretlove S, Bedford Russel A. Multidisciplinary palliative care in unborn and newborn babies. *BMJ* 2011;342:d1808.

Kimman R, Doumic L. Perinatal palliative care: A developing specialty. *International Journal of Palliative Nursing*, 2014 Mar 28;20(3):143-8.

Kobler K, Limbo R, Oakdale C. [Childbirth education for parents receiving perinatal palliative care](#). *International Journal of Childbirth Education*. April 2012;27(2):26-32.

Kobler K, Limbo R. Making a Case: Creating a perinatal palliative care service using a perinatal bereavement program model. *Journal of Perinatal & Neonatal Nursing*, January/March 2011, Vol. 25, Issue 1.

Kramer R, Sehring S, Ratto T, Hopkins LM. Addressing perinatal palliative care program development. *Journal of Pain and Symptom Management*, 2010 Feb;39(2):371–372.

Kuebelbeck A., Davis DL. [A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief](#). Johns Hopkins University Press, 2011.

Kuebelbeck A. [Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life](#). Loyola Press, 2003.

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

Kuebelbeck A. Waiting with Gabriel. *Current Problems in Pediatric and Adolescent Health*. 2011 April;41(4):113-4.

Kuebelbeck A. [A Gift of Time: Continuing a pregnancy when a baby's life is expected to be brief](#). National Association of Perinatal Social Workers NAPSWS Forum, Spring 2013, Vol. 33, No. 2.

Kuebelbeck A. [Perinatal hospice: A holistic approach for when death comes at the beginning of life](#). The Forum, newsletter of the Association for Death Education and Counseling. 2005 Jan/Feb/Mar;31(1):6-7.

Lathrop A, VandeVusse L. Affirming Motherhood: Validation and invalidation in women's perinatal hospice narratives. *Birth*, 2011 September;38(3):256-265.

Lathrop A, VandeVusse L. Continuity and change in mothers' narratives of perinatal hospice. *Journal of Perinatal & Neonatal Nursing*, January/March 2011, Vol. 25, Issue 1.

Leuthner SR, Jones EL. Fetal Concerns Program: A model for perinatal palliative care. *MCN Am J Matern Child Nurs*. 2007 Sept/Oct;32(5):272-278.

Leuthner SR. Fetal palliative care. *Clin. Perin.* 2004; 31(3):649-665.

Leuthner SR. Palliative care of the infant with lethal anomalies. *Pediatr Clin N Am*. 2004; 51(3):747-759.

Limbo R, Lathrop A. Caregiving in mothers' narratives of perinatal hospice. *Illness, Crisis & Loss* January 2014, Vol. 22(1) 43-65.

Limbo R. [Caring for families experiencing stillbirth: A unified position statement on contact with the baby. Commentary.](#) *Illness, Crisis & Loss* 2012, 20(3):295-298.

Limbo R, Toce S, Peck T. [Resolve Through Sharing position paper on perinatal palliative care,](#) Gunderson Health System, August 2008.

Lin K. [Palliative care at the end and the beginning of life.](#) American Family Physician Community Blog, March 31, 2015.

Lindley LC, Fornehed ML, Mixer SJ. A comparison of the nurse work environment between perinatal and non-perinatal hospice providers. *International Journal of Palliative Nursing* 2013, Vol. 19, No. 11, pp. 535-540.

Locock L, Crawford J, Crawford J. The parents' journey: Continuing a pregnancy after a diagnosis of Patau's Syndrome. *British Medical Journal* 2005 Nov.19;331:1186-1189.

Macauley R, Elia G, Klein S, Lewandowski J. Perinatal palliative care. *Journal of Pain and Symptom Management* 2012, 43(2):369–370.

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

Marc-Aurele KL, Nelesen R. A five-year review of referrals for perinatal palliative care. *Journal of Perinatology*, online ahead of print Sept. 4, 2013, doi:10.1089/jpm.2013.0098.

Marc-Aurele K, Nelesen R et al. Perinatal palliative care: A retrospective study. *Journal of Pain and Symptom Management*, 2014 Feb; 47(2):391–392.

Mancini A et al. [Practical guidance for the management of palliative care on neonatal units.](#) Royal College of Paediatrics and Child Health/Chelsea and Westminster Hospital NHS Trust, February 2014.

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

Martel S, Ives-Baine L. "Most-prized possessions": Photography as living relationships within the end-of-life care of newborns. *Illness, Crisis & Loss* 2014, Vol. 22(4):311-332.

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.

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.

Miller LH, Lindley LC, Mixer SJ, Fornehed ML, Niederhauser VP. Developing a perinatal memory-making program at a children's hospital. MCN Am J Matern Child Nurs. 2014 Mar-Apr; 39(2):102-6.

Milstein JM. Detoxifying death in the neonate: in search of meaningfulness at the end of life. J Perinatol. 2003 Jun;23(4):333-6.

Moore DB, Catlin A. Lactation Suppression: Forgotten Aspect of Care for the Mother of a Dying Child. Pediatric Nursing, Sept/Oct 2003;29(5):363-364.

Munson D, Leuthner SR. Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis. Pediatr Clin N Am 54 (2007) 787-798.

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 Association of Neonatal Nurses [Palliative and End-of-Life Care for Newborns and Infants Position Statement](#), February 2015.

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.

Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. BJOG 2014; DOI: 10.1111/1471-0528.12695.

Palmer K. Peace and Pain. British Medical Journal 1994 July 23;309:279.

Parravicini E. [Is 'comfort' care a 'medical' care? Observations on a neonatal population](#). Journal of Medicine and the Person. Published first online Jan. 18, 2012.

Parravicini E, Lorenz JM. Neonatal outcomes of fetuses diagnosed with life-limiting conditions when individualized comfort measures are proposed. Journal of Perinatology, 2014 Jun;34(6):483-7.

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.)

Pierucci R, Kirby S, Leuthner S. End-of-Life Care for Neonates and Infants: The Experience and

Effects of a Palliative Care Consultation Service. *Pediatrics* Vol. 108 No. 3 September 2001, pp. 653-660.

Ramer-Chrastek J, Thygeson MV..A perinatal hospice for an unborn child with a life-limiting condition. *Int J Palliat Nurs*. 2005 Jun;11(6):274-6.

Riegel EL. [A great divide](#). Palliative and Supportive Care, Cambridge University Press. 2015 June.

Reitman JS, Calhoun BC, Hoeldtke NJ. Perinatal Hospice: A response to early termination for severe congenital anomalies. In TJ Demy, GP Stewart, Eds., *Genetics and Reproductive Technology: A Christian Response*. Grand Rapids, MI: Kregel Books, 1999:197-211.

Roush A, Sullivan P, Cooper R, McBride J. Perinatal Hospice. *Newborn and Infant Nursing Reviews*. 2007 Dec;7(4):216-221.

Roscigno C, Savage T, Kavanaugh K, Moro T, Kilpatrick S, Strassner H, Grobman W, Kumura R. Divergent Views of Hope Influencing Communications Between Parents and Hospital Providers. *Qualitative Health Research*, 2012, 22(9):1232–1246.

Ruiz T. [Practical considerations in preparing for a twin delivery with expected death of one twin: Isaac and Liam](#). *International Journal of Childbirth Education*. April 2012;27(2):80-82.

Rychik J. What Does Palliative Care Mean in Prenatal Diagnosis of Congenital Heart Disease? *World J Pediatr Congenit Heart Surg*. 2013 Jan;4(1):80-4.

Samsel S, Lechner BE. End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative. *J Perinatol*. 2015 Mar;35(3):223-8.

Stenekes SJ, Enx DCL, Harlos M, Chochinov HM, Mytopher K. [A descriptive study evaluating perinatal healthcare providers' perspectives of palliative programming in 3 Canadian institutions](#). *J Perinat Neonat Nurs* 2014 Oct/Dec; 28(4):280–289.

Stokowski LA. [Palliative Care and Neonatal Loss](#). From highlights of the National Association of Neonatal Nurses (NANN) 20th annual conference, Oct. 13-16, 2004, published by Medscape Today.

Storme L, De Mézerac I. L'accompagnement des parents face à une mort annoncée en périnatalité: pour l'introduction d'une démarche de soins palliatifs en maternité et en néo-natologie. (Dealing with parents facing imminent death of their neonate: introducing palliative care in maternity wards and neonatal intensive care units.) *Bull. Acad. Natle Méd.*, June 2010, 194(6):879-890.

Sudia-Robinson, T. Ethical implications of newborn screening, life-limiting conditions, and palliative care. *MCN, The American Journal of Maternal-Child Nursing*, May/June 2011.

Sumner LH. "Pediatric care: The hospice perspective." In: Ferrell BR, Coyle N, eds. *Textbook of Palliative Nursing*. New York: Oxford University Press, 2001, pp. 556–569.

Sumner LH. [Perinatal Hospice Services/Early Intervention Program purpose and procedures](#), 2006.

Sumner LH. [Perinatal palliative care: Lighting the way for families through a difficult but sacred journey of beginnings and endings](#). ChiPPS E-News, Children's Project on Palliative/Hospice Services Pediatric Palliative Care Newsletter, May 2007; Issue 7, p. 2.

Sumner LH. [Taking Palliative Care into Pregnancy and Perinatal Loss](#). National Perinatal Association Bulletin. 2004 Fall; 5(2).

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 Neonatal Nurs. 2006 Jan-Mar;20(1):113-6.

Terhaar M, ed. [Palliative Approach to Perinatal and Neonatal Care](#). eNeonatal Review (a joint publication of The Johns Hopkins University School of Medicine and The Institute for Johns Hopkins Nursing) July 2006, Vol. 2, No. 11.

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.

Toce S, Collins MA. The FOOTPRINTS model of pediatric palliative care. J Palliat Med. 2003 Dec;6(6):989-1000.

Tosello B et al. [Barriers in referring neonatal patients to perinatal palliative care: A French multicenter survey](#). PLoS One. 2015 May 15;10(5):e0126861.

Tosello B et al. Palliative care birth plan: a field of perinatal medicine to build. Gynecol Obstet Fertil. 2013 Apr;41(4):251-4.

Tosello B et al. Perceptions of lethal fetal abnormality among perinatal professionals and the challenges of neonatal palliative care. J Palliat Med. 2014 Aug;17(8):924-30.

Tyler M. "Perinatal Palliative Care: A Collaborative Approach," Greater Cleveland M.D. News, July/August 2008, p. 11.

"You Are Not Alone," a video for parents facing decisions about aggressive medical intervention in the NICU. Denver, Colo.; Colorado Trust, The Colorado Collective for Medical Decisions' Neonatal Subcommittee, Nickel's Worth Productions, 1998.

Walker LV, Miller VJ, Dalto VK. The health-care experiences of families given the prenatal diagnosis of trisomy 18. *Journal of Perinatology* (2008) 28, 12-19.

Warland J, Davis DL, et al (2011) [Caring for families experiencing stillbirth: A unified position statement on contact with the baby. An international collaboration.](#) Also available in [Spanish](#).

Watkins D. An alternative to termination of pregnancy. *Practitioner* 1989 Jul 8;233(1472):990,992.

Weinhold O. Development of the Perinatal Concerns Program: Care of mothers after diagnosis of fatal infant anomalies. *MCN Am J Matern Child Nurs.* 2007 Jan-Feb;32(1):30-35.

Wilkinson D et al. [Ethical language and decision-making for prenatally diagnosed lethal malformations.](#)

*Seminars in Fetal and Neonatal Medicine*, 2014 Oct;19(5):306-311.

Wilkinson, D., Thiele, P., Watkins, A. and De Crespigny, L. (2012), [Fatally flawed? A review and ethical analysis of lethal congenital malformations.](#) *BJOG: An International Journal of Obstetrics & Gynaecology*, 2012 Oct;119: 1302–1308.

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.](#)

Wool C. State of the Science on Perinatal Palliative Care. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 2013 May/June; 42(3):372–382.

Wool C., Dudek M. Exploring the Perceptions and the Role of Genetic Counselors in the Emerging Field of Perinatal Palliative Care. *J Genet Couns.* 2013 Apr 18. [Epub ahead of print]

Wool C. Clinician confidence and comfort in providing perinatal palliative care. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 2013 Jan;42(1):48-58.

Wool C. Clinician Perspectives of Barriers in Perinatal Palliative Care. *MCN: The American Journal of Maternal/Child Nursing*, January/February 2015;40(1):44-50.

Wool C. Instrument Psychometrics: Parental Satisfaction and Quality Indicators of Perinatal Palliative Care. *Journal of Palliative Medicine*, 2015 June. Epub ahead of print.



doi:10.1089/jpm.2015.0135.

Wool C, Côté-Arsenault D, Black BP, Denney-Koelsch E, Kim S, and Kavanaugh K. Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States. *Journal of Palliative Medicine*. December 2015, ahead of print. doi:10.1089/jpm.2015.0266.

Wool C. Systematic Review of the Literature: Parental Outcomes After Diagnosis of Lethal Fetal Anomaly. *Advances in Neonatal Care* 2011 June;11(3):182-192.

Wool C, Northam S. The Perinatal Palliative Care Perceptions and Barriers Scale Instrument©: Development and validation. *Advances in Neonatal Care* 2011 Dec;11(6):397-403.

Wood D. [Preparing expectant parents for perinatal death](#). NurseZone.com, Nov. 9, 2007.

Zeanah CH, Dailey JV, Rosenblatt MJ, Saller DN Jr. Do women grieve after terminating a pregnancy for fetal abnormalities? A controlled investigation. *Obstetrics and Gynecology* 1993

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## RESOURCES FOR CAREGIVERS



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## PERINATAL HOSPICE & PALLIATIVE CARE

Video for the [Neonatal Comfort Care program](#) at New York-Presbyterian Morgan Stanley Children's Hospital.



Video of Baby Amanda, diagnosed prenatally with Trisomy 18. Produced by the National Hospice and Palliative Care Organization [Moments of Life](#) campaign.

Video by Perinatal Palliative Care, a network of hospitals and clinics in Australia, with more videos and information on their [website](#).

Perinatal hospice [video](#) for caregivers by Tammy Ruiz RN, perinatal bereavement coordinator at Mary Washington Hospital, Fredericksburg, Virginia. Also translated into [Spanish](#), [Italian](#), [French](#), [Czech](#), [Japanese](#), and [Polish](#).

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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

### PERINATAL HOSPICE & PALLIATIVE CARE

*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](mailto: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

[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