



# Pregnancy Loss and Infant Death Alliance

Support :: Advocacy :: Awareness :: Education

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## RESOURCES LIST

*Updated: September, 2008*

### INTRODUCTION

This annotated list of materials, organizations, and websites is not exhaustive, but meant to provide a good starting place for tapping into the vast array of available resources that can offer support, information, insights, and guidance. Resources added or updated for this edition are marked by this flag: **■**

Some of these resources were specifically created for parents, and some cater to the needs of practitioners who work with bereaved families. If you are a practitioner, educator, researcher, or parent advocate, we encourage you to delve into the books and websites by and for grieving parents. Doing so can sensitize you to the issues parents struggle with, illuminate what they find supportive, and guide you in becoming more effective in your work with or on behalf of bereaved families. You'll also familiarize yourself with the resources available, and be able to point parents in a meaningful direction. Likewise, if you are a bereaved parent who is considering or already doing advocacy work, the professional resources can further inform your endeavors.

### PLIDA's RESOURCES LIST includes

- Books
- Professional Journal Articles and **■**Mortality Statistics
- Videos & DVDs
- Parent Support Organizations
- Resource Centers

This list is updated annually, and we are interested in hearing from you. If you have a resource you'd like the Resources Committee to consider for next year's list, please email [info@plida.org](mailto:info@plida.org).

### **DISCLAIMER**

*This **Resources List** was compiled by **PLIDA** to promote awareness, advocacy, support, and education. Views and opinions contained in these resources do not necessarily reflect those of **PLIDA**, its Board of Directors, members, or employees. In the interest of inclusiveness and sensitivity to diversity, resources that propound any particular religion are not included.*

*Being listed as a resource herein does not constitute or imply endorsement, recommendation, or favoring by **PLIDA**, and shall not be used for advertising or product endorsement purposes.*

## ~ BOOKS ~

Whether you are a practitioner or a parent (or both,) you will find some books supportive, guiding, or illuminating, and others not so much. When reading any book, embrace what you find helpful, and pass by whatever isn't. For more information on any of these books, look for online reviews by typing the title inside quotation marks (as in, "\_\_\_") into your Internet search engine. To find more books, look at the reference lists and bibliographies in the back of books you like, and if you like a particular author, look into other books s/he may have written, or other titles by the publisher. Online booksellers, like Amazon.com, show other books that were bought by customers on the same topic, as well as reader reviews so you can decide which ones suit your needs. For additional guidance or written materials, see the online catalogs of the book distributors and specialty publishers listed under "Resource Centers" as they distribute many of these books and carry even more, as well as their own specialty written materials. In addition, the Parent Support organizations (listed just prior to "Resource Centers") can make recommendations, and some offer their own written materials.

Books are divided into the following categories:

- Grief and Bereavement
- For Children
- Memoirs and Narratives
- Dying and Death
- Medical Ethics, Decision-Making, Palliative Care, Hospice Care
- Relationship-Based Care
- Subsequent Pregnancy and Parenting

### Grief and Bereavement

*Most of these books were written to offer information and support to grieving parents. Some are specific to understanding and coping with the death of a baby— some are even more specific, focused on a particular type of perinatal bereavement— while others are more general books that address grieving and coping. These supportive books also offer valuable insight to practitioners, and can guide their work with bereaved families. The academic books all pertain to perinatal bereavement, and are meant to educate and guide the practitioner, and inform the parent advocate.*

Allen, M. & Marks, S. *Miscarriage: Women Sharing from the Heart*. New York: Wiley, 1993. Focuses on the emotional experience of having a baby die early in pregnancy. Along with mothers' quotes in each chapter, a mother's whole story accompanies each section of the book.

\*Beattie, M. *The Grief Club: The Secret to Getting Through All Kinds of Change*. Hazelden, 2006. Written by the acclaimed author of books about codependence and recovery— after her son died. While this book tackles loss and grief in general, she has clearly "been there" and writes from the perspective of a bereaved parent with honesty and candor. Enlightening and comforting, it supports the reader in moving through the many losses and grief experienced throughout life's transitions.

Chethik, N. *FatherLoss: How Sons of All Ages Come to Terms with the Deaths of Their Dads*. New York: Hyperion, 2001. Exploration and accounts of men's experiences with grief. Written for men, about men, by a man. Affirming for any kind of bereavement.

Davis, D.L. *Empty Cradle, Broken Heart: Surviving the Death of Your Baby*. Rev. ed. Golden, Colo.: Fulcrum, 1996. A gentle, comprehensive book that focuses on the emotional aspects of grieving, coping, and healing after the death of a baby.

Davis, D.L. *Stillbirth, Yet Still Born*. Wayzata, MN: PILC, 2000. A small book that focuses on the heartache of coping and adjustment when a baby dies before birth. Available at [www.centering.org](http://www.centering.org).

Harmon RJ, Plummer, NS, Frankel KA. Perinatal Loss: Parental Grieving, Family Impact, and Intervention Services. In: Osofsky JD & Fitzgerald HE eds. *WAIMH Handbook of Infant Mental Health, Vol. 4: Infant Mental Health in Groups at High Risk*. New York: Wiley & Sons, 2000.

Ilse, S. *Empty Arms: Coping after Miscarriage, Stillbirth and Infant Death*. (Rev. ed.) Long Lake, MN: Wintergreen Press, 2008. A classic, one of the first books written for grieving parents. A small book that's most affordable for hospitals to give to parents.

Kluger-Bell, K. *Unspeakable Losses: Understanding the Experience of Pregnancy Loss, Miscarriage, and Abortion*. New York: W.W. Norton, 1998. Advocates for bereaved parents and their emotional experiences. Includes therapeutic abortion.

Kohn, I., Moffitt, P., & Wilkins, A. *A Silent Sorrow: Pregnancy Loss - Guidance and Support for You and Your Family*. (Rev. ed.) New York: Brunner-Routledge, 2000. Covers the medical, social, and psychological aspects of perinatal bereavement.

Leon I.G. *When A Baby Dies: Psychotherapy For Pregnancy and Newborn Loss*. New Haven, CT: Yale University Press, 1992. A classic, combining theory, practice and research, written by a respected clinician who understands the depth of the parents' grief.

Levang, E. *When Men Grieve: Why Men Grieve Differently and How You Can Help*. Minneapolis, MN: Fairview Press, 1997. Essays by men who've experienced varying types of loss, and commentary for men's partners about giving a man space and understanding for his unique perspective and needs, while requiring respect for one's own.

Limbo, R.K., Wheeler, S.R., & Hessel, S.T. *When a Baby Dies: A Handbook for Helping and Healing*. Lacrosse, WI: Lutheran Hospital, 1989. Written by RTS Bereavement Services directors, this book offers information and support for families, as well as guidance for health care practitioners.

Mander R. *Loss and Bereavement in Childbearing*. Oxford: Blackwell Scientific, 1994. This book considers ways in which midwives can assist grieving families. A variety of situations, including miscarriage, termination for fetal abnormality, prenatal and neonatal death are comprehensively discussed.

✦ Manning, D. *Don't Take My Grief Away From Me*. Oklahoma City, Okla: In-Sight Books, 2005. Written by a former minister and inspirational speaker, this comforting book walks through where to start, the funeral, and about understanding death, grief, and how to live again.

Martin, T.L. and K.J. Doka. *Men Don't Cry, Women Do: Transcending Gender Stereotypes of Grief*. New York: Brunner-Routledge, 1999. Looks at the ways that men and women differ in expression of grief, and proposes the framework of instrumental and intuitive grieving styles.

✦ McCracken, A and Semel, M. *A Broken Heart Still Beats: After Your Child Dies*. Hazelden, 2000 A compilation of articles and book excerpts, some fiction, some nonfiction, that feature the death of a child. Full of highest quality writing from many well-known authors, this book offers solace, that you are not alone and there are others who understand exactly what you're going through.

Mehren, E. *After the Darkest Hour the Sun Will Shine Again: A Parent's Guide to Coping with the Loss of a Child*. New York: Simon and Schuster, 1997. Comfortingly written by a bereaved parent, author of *Born Too Soon*, which is listed in "Personal Stories."

Miller, S. *Finding Hope When a Child Dies: What Other Cultures Can Teach Us*. New York: Fireside Books, 2002. Acknowledges our limited Western customs and language when it comes to death and grief; examines other cultures and offers other rituals and ways of expressing grief and finding meaning.

Peppers, L.G. & Knapp, R.J. *Motherhood and Mourning: Perinatal Death*. Westport, CT: Praeger Publishers, 1980. One of the first books to recognize and respect the significance of perinatal bereavement.

Rando, T.A. *Grieving: How to Go On Living When Someone You Love Dies*. Lexington, MA: D.C. Heath/Lexington Books, 1988; 1995. Comprehensive, practical, and encouraging, explores grieving, coping, adjusting, and healing.

Rosof, B.D. *The Worst Loss: How Families Heal from the Death of a Child*. Owl Books, 1995. Explains why grieving is necessary, and how to move toward healing. Focuses on parents as well as on surviving siblings.

Schiff, H.S. *The Bereaved Parent*. New York: Penguin, 1978. The classic, a book that lets parents know that they are not alone in their overwhelming grief, with affirmation for what parents find supportive.

Seftel, L. *Grief Unseen: Healing Pregnancy Loss through the Arts*. London: Jessica Kingsley Publishers, 2006. Explores women's emotional experiences, artistic expression, and the art therapy movement with perinatal bereavement. Includes a chapter on how to create your own healing practice through the arts.

Woods, J.R. & Esposito Woods, J.L. (Eds.) *Loss During Pregnancy or in the Newborn Period: Principles of Care with Clinical Cases and Analyses*. Pitman, NJ: Jannetti, 1997. Written for all practitioners and counselors, this book recognizes that training is often inadequate, and working with bereaved families is challenging. Provides a framework

for those who want to develop or improve their skills and effectiveness. Includes chapter on subsequent pregnancy.

Zimmerman, S. *Writing to Heal the Soul: Transforming Grief and Loss Through Writing*. New York: Three Rivers Press, 2002. For parents who find journaling therapeutic. Using anecdotes and observations from her own life, the author introduces helpful exercises, including writing love and hate letters, examining one's blessings-in-disguise, and comparing how much one does for others versus how much one does for oneself.

## For Children

*These books offer opportunities to talk about death with children born before or after the baby(s) who died. Many parents report finding these books soothing for themselves as well. You can find more children's books offered by the organizations listed under "Resource Centers."*

■ Arenella, BB. *Isabelle's Dream: A Story and Activity Journal for a Child's Grief Journey*. Naples, Fla: QOL Publishing, 2007. For young children, this interactive book uses a story and art therapy format, inviting readers to fill in the black and white drawings that tell the tale of a young girl's dreamlike visit to "Heaven" with her recently deceased baby sister. Angel imagery but not overtly Christian. Helpful tips for parents. All proceeds are donated to the CJ Foundation for SIDS.

■ Blanford, C. *Something Happened: A Book for Children and Parents who have Experienced Pregnancy Loss*. Perfect Paperback, 2008. Wonderful illustrations; simple and to the point. Below the one or two sentences for children is information to the parents on how to help, placed in such a way that it does not distract from the child's story. [www.SomethingHappenedBook.com](http://www.SomethingHappenedBook.com)

Brown, L.C. & Brown, M. *When Dinosaurs Die: A Guide to Understanding Death*. New York: Little, Brown Young Readers, 1998. Answers kid's questions and curiosity about death, emotions, and customs.

Hansen, W. *The Next Place*. Golden Valley, MN: Waldman House Press, 1997. An inspirational, all-inclusive, spiritual pondering about death and what happens after we die. Appropriate for any age.

Johnson, M. *Where's Jess? For Children Who Have a Brother or Sister Die*. Omaha, NE: Centering, 1982. A classic for the very young child with simple answers to typical questions about the death of a sibling.

Mellonie, B. *Lifetimes: The Beautiful Way to Explain Death to Children*. New York: Bantam, 1983. A classic, this soothing book looks at the life cycle and universality of death.

Mills, J.C. *Gentle Willow: A Story for Children About Dying*. Washington, D.C.: Magination Press, 2003. Explains the dying process, how the living can comfort the dying, and how we cherish memories of them after death. Can prepare a sibling for the

impending death of a baby. Spiritual without being religious, it describes death as change of form rather than an ending.

■ Sabin, E. *The Healing Book: Facing the Death, and Celebrating the Life, of Someone You Love*. Watering Can, 2006 Supportive, interactive resource, scrapbook, and journal for children, ideal for ages 6 to young teen. Invites kids to ask questions, to process their experience and feelings, to figure out how to cope and adjust, and to record their memories.

■ Schaefer, D. & Lyons, C. *How do we tell the children? A step by step guide for helping children two to teen cope when someone dies* (3rd ed.) New York: New Market Press, 2002. Straightforwardly explains how to inform children about the realities of death; what most children can easily understand, what they might need help understanding, and the importance of being open and honest. Helpful for parents who are uncomfortable talking about death.

■ Schwiebert, P. *We Were Gonna Have a Baby, But We Had an Angel Instead*. Portland, OR: Grief Watch, 2003. Explains death with a focus on the spiritual aspects and angelic presence without preaching a particular religious faith. For young siblings and their parents. [www.griefwatch.com](http://www.griefwatch.com)

■ Trozzi, M. with Massimini, K. *Talking with Children about Loss*. New York: Berkley Publishing, 1999. Explains how to talk with children and adolescents about loss, including death, disability, and divorce; helping children face funerals; how to address fears, and when to seek professional help.  
<http://www.bmc.org/pediatrics/special/goodgrief/overview.html>

## Memoirs and Narratives

*All of these books are beautifully written, filled with honesty and insights into the journey of parental grief. While the reader may be brought to tears, these books offer reassurance and inspiration to bereaved parents, and enlightenment to the practitioners who work with them. Although the details of these stories vary widely, and some of these books deal with the death of a child older than infancy, they all carry childbearing and parenting themes that resonate with parents who've experienced the death of a baby. The themes of grieving, coping, adjustment, and personal growth are universal. You are not alone.*

Alecson, D. *Lost Lullaby*. Berkeley: University of California Press, 1995. A personal account: medical ethics and parental rights to decline medical intervention for a baby whose prognosis is grim.

Ash, L. *Life Touches Life: A Mother's Story of Stillbirth and Healing*. Troutdale, OR: New Sage Press, 2004. This mother describes her journey from pain to acceptance, looks at the lasting inner changes she experienced, delves into spiritual questions, and examines the connection between mother and child that transcends death. Heartfelt and supportive.

Barney, A. *Stolen Joy: Healing after Infertility and Infant Loss*. Baltimore: Icarus Books, 1993. Poetry written by the author, who is grieving after her newborn's death. Gets to the heart of a mother's grief.

\* Baseman, C. *Love, Mom: A Mother's Journey From Loss to Hope*. AuthorHouse, 2006. After her daughter was stillborn, this mother found solace, healing, and meaning through writing letters to her daughter and connecting with nature. Chronicles the struggles of the shock and medical mysteries of stillbirth, explaining death to her toddler son, and maintaining her marriage and other relationships. An honest, detailed portrait of grief and recovery.

Brooks, C. (Ed.) *Heartbreaking Choices: Forty-six women share their stories of interrupting a much-wanted pregnancy*. iUniverse, 2008. Heartfelt narratives, chronicling a wide variety of experiences and timelines, describing their love for their babies, their agonizing decision-making process, their grief, their struggles, and their healing.

Brunner, S. H. *Perfect Vision: A Mother's Experience with Childhood Cancer*. Fuquay-Varina, N. C.: Research Triangle, 1996. Coping with raising a child with chronic illness and unknown prognosis, and eventually, death.

Butler, M. *Born to Die?* Dublin: Marino Books, 1995. A mother's personal account: making difficult medical decisions; overcoming ambivalent feelings toward her baby whose prognosis is poor.

Faldet, R. & Fitten, K. (Eds.) *Our Stories of Miscarriage: Healing With Words*. Minneapolis, MN: Fairview Press, 1997. A collection of essays, poetry, and journal excerpts by mothers and a handful of fathers. Resources and suggested readings listed in back matter.

Hander, J. *A Place of Peace: One Mother's Inspirational Journey to Reclaim Life after the Death of Her Daughter*. iUniverse, 2007. A bereaved mother chronicles her emotional journey with the premature birth of twin girls after TTS; Alexa survives after a long NICU stay, but Alysa dies after 28 days, when her parents make the heartwrenching decision to withdraw aggressive medical intervention.

[www.aplaceofpeace.net](http://www.aplaceofpeace.net)

Housden, M. *Hannah's Gift: Lessons from a Life Fully Lived*. New York: Bantam, 2002. A mom shares the transformative lessons she received during her three-year-old daughter's last year of life. Shows how joy and sorrow can intertwine when a child is dying.

Kay, R. *Saul*. New York: St. Martin's Press, 2000. A memoir based on the author's own experiences with her son, who was born extremely prematurely, and died four months later. While it does not shy away from the challenges and suffering in the NICU, the author imagines and describes her baby's acceptance of the NICU roller coaster and the medical decision-making. This book offers the reassuring perspective that your baby's experience was part of his or her unique and ultimately spiritual path.

Kuebelbeck, A. *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life*. Chicago: Loyola Press, 2002. A tremendous personal account of the life-and-death decision-

making process after prenatal diagnosis of a fatal condition. It covers medical ethics, prenatal diagnosis, heart-wrenching decision-making before and after birth, letting nature take its course as the way to give a baby the best quality of life; parenting, bonding, grieving.

Lammert, C. & Friedeck, S. (Eds.) *Angelic Presence -- Short Stories of Solace and Hope After the Loss of a Baby*. Salt Lake City, UT: Richard Paul Evans Publishing, 1997. A compilation of essays written by bereaved parents.

Loizeaux, W. *Anna: A Daughter's Life*. New York: Arcade Publishing, 1993. Parenting a baby through multiple hospitalizations, surgeries, and procedures; coping with death and grief.

■ McCracken, E. *An Exact Replica of a Figment of My Imagination: A Memoir*. Boston, Mass: Little, Brown & Company, 2008. Celebrated writer McCracken explores love and grief in this non-fiction memoir about her first baby, a son, who was stillborn, and the journey of her subsequent pregnancy.

Mehren, E. *Born Too Soon: The Story of Emily, Our Premature Baby*. New York: Doubleday, 1991. Parenting a premature baby in the NICU; the joys and challenges of the roller coaster; dealing with doctors, nurses, and hospital policies; medical ethics and advocating for their baby's best interests; decision making and letting nature take its course. A story of hope, courage, and love.

Mirren, E. (Ed.) *Our Children—Coming to Terms with the Loss of a Child: Parents' Own Stories*. London: Hodder and Stoughton, 1985. A collection of parents' personal experiences.

■ Moore, S. (Ed.) *25 Stolen Angels: 25 Stories of Hope After Pregnancy or Infant Loss*. Clarksville, Tenn.: Dynasty Publishers, 2007. Mothers and fathers write about their experiences of grief and healing following the death of their babies. Miscarriage, prematurity, stillbirth, SIDS, fatal birth defects, and more. [www.stolenangels.com](http://www.stolenangels.com).

■ Novak, M. *The Good Grief Club: A True Story about the Power of Friendship and French Toast*. Inkwell Productions, 2007. Written by a bereaved mother who draws the reader into her group of seven mothers who came together in grief. Relays their heartaches and coping; struggles with more loss and infertility; their triumphs with subsequent pregnancy; and their recovery and healing.

Ryan, A. *Silent Love: Personal Stories of Coming to Terms with Miscarriage*. New York: Marlowe and Company, 2001. A wide range of personal stories from mothers, fathers, and grandparents.

■ Vigour, T. *Mourning Sarah: A Case for Testing Group B Strep*. Radcliffe Publishing, 2008. A bereaved mother powerfully recounts her infant daughter's death, her inquiry into this treatable condition, her grief, advocacy, and healing. [www.radcliffe-oxford.com](http://www.radcliffe-oxford.com)

Woodwell, W. H. *Coming to Term: A Father's Story of Birth, Loss, and Survival*. Jackson, Miss.: University of Mississippi Press, 2001. A dad's account of HELLP syndrome, extremely premature delivery, death of one twin, the NICU experience.

## Dying and Death

*These books take a broader view and can answer questions parents might have about the physical or spiritual processes of dying and death.*

■ Lynch, T. *The Undertaking: Life Studies from the Dismal Trade*. New York: Penguin, 1998. A book of essays by third-generation funeral director who is also a gifted writer, his incisive, witty, compassionate observations on death and its attendant rituals, relationships and how the living respond to death.

Nuland, S. B. *How We Die: Reflections on Life's Final Chapter*. New York: Knopf, 1993. A strangely comforting book demystifying the physical realities of dying and death.

Quill, T.E. *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life*. Baltimore, MD: The Johns Hopkins University Press, 1996. Through the stories of nine patients with terminal conditions, the physician author illustrates a better way to die, focusing on partnership, commitment and collaborative decision-making.

Sharp, J. *Living Our Dying: A Way to the Sacred in Everyday Life*. New York: Hyperion, 1996. A compassionate and practical book, a spiritual exploration of becoming conscious of one's own mortality, and cultivating life's preciousness through an awareness of death.

## Medical Ethics, Decision-Making, Palliative Care, Hospice Care

*These books support the parents' right to be involved in medical life-and-death decision-making for their babies, and affirm the idea that sometimes, end-of-life palliative care can be the kinder course.*

Anspach, R. R. *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*. Berkeley: University of California Press, 1997. Medical ethics and decision making in the NICU.

Carter, BS, Levetown M (Eds.) *Palliative Care for Infants, Children, and Adolescents*. Baltimore: Johns Hopkins University Press, 2004. Case-based clinical handbook, including psycho-social support for families and health care practitioners.

Children's Project on Palliative/Hospice Services (ChiPPS.) *Compendium of Pediatric Palliative Care*. Alexandria, VA: NHPCO, 2002. A comprehensive guide to pediatric palliative care for professionals, including many tools, resource lists, models and best practices, plus contact information for national leading programs. Available online at [www.nhpco.org](http://www.nhpco.org); click on Marketplace, item # 810030.

Dailey AA, Zarbock S (Eds.) *Hospice Care for Children* (2<sup>nd</sup> edition.) New York: Oxford University Press, 2001. Focuses on psycho-social aspects of working with children and families, with a chapter on newborn death and decision-making.

Davis, D. L. *Loving and Letting Go: For Bereaved Parents Who Turned Away from Aggressive Medical Intervention for Their Critically Ill Newborn*. Rev. ed. Omaha: Centering, 2002. A gentle, affirming book written for parents about making and living with the agonizing and heartfelt decision to refuse aggressive medical intervention in the NICU.

Davis, D. L. *When Courage Lies in Letting Go: Turning Toward End-of-Life Palliative Care for Your Child*. (Rev. ed.; Formerly *Fly Away Home*.) Omaha: Centering, 2000; 2007. A gentle, affirming book for parents about making and living with the profound decision to refuse aggressive medical intervention and choose palliative care for their terminally ill child. Includes a reassuring chapter on parenting the dying child.

Goldman A, Hain R, Liben S. *Oxford Textbook of Palliative Care for Children*. Oxford: Oxford University Press, 2006. Comprehensive book on the philosophy and medicine of palliative care, educating and supporting palliative care providers, and working with families when a child is dying. Includes a chapter on the effects of ethnicity, culture, and religion on the experience of and rituals surrounding death of a child.

Ellenchild Pinch, W. J. *When the Bough Breaks: Parental Perceptions of Ethical Decision-Making in NICU*. Lanham, Md.: University Press of America, 2002. An academic textbook describing parents' experiences in the NICU and beyond.

Guyer, R.L. *Baby at Risk: The Uncertain Legacies of Medical Miracles for Babies, Families, and Society*. Sterling, Virginia: Capital Books, 2006. An exploration of assisted reproduction and neonatal intensive care technologies and the questions they raise about quality of life, risks and benefits-- and the burgeoning population of imperiled newborns.

Ilse, S. *Precious Lives, Painful Choices: A Prenatal Decision-Making Guide*. Long Lake, MN: Wintergreen Press, 1993. For parents who face decisions after prenatal tests detect serious problems in the baby. Non-judgemental, covers emotions, decision-making process, gathering information and support, and examines both options of continuing or terminating the pregnancy.

Lantos, J. D. *The Lazarus Case: Life-and-Death Issues in Neonatal Intensive Care*. Baltimore: Johns Hopkins University Press, 2001. A composite malpractice case that illustrates the ambiguities, misunderstandings and responsibilities in life-and-death decision making in the NICU.

Lantos JD, Meadow WL. *Neonatal Bioethics: The Moral Challenges of Medical Innovations*. Baltimore: Johns Hopkins University Press, 2006. Examines the creation and development of neonatology, along with the ethical challenges it presented and the relationships between scientific progress, medical innovation, bioethical reflection, and political regulation.

Lyon, J. *Playing God in the Nursery*. New York: W. W. Norton, 1985. Medical ethics and decision-making in the NICU.

## Relationship-Based Care

*These books provide information, suggestions, and support for health care practitioners in their efforts to provide **relationship-based care** to bereaved families. While these references are not confined to perinatal bereavement, they are especially pertinent to the kinds of support and training practitioners need in order to do this important and often challenging work.*

Benner, P. & Wrubel, J. *The Primacy of Caring: Stress and Coping in Health and Illness*. Boston, MA: Addison-Wesley, 1989. First-person accounts from practicing nurses demonstrate how their caring made a critical difference for patients and their families. Winner of two American Journal of Nursing Book of the Year Awards.

Gerteis, M, Edgman-Levitan, S, Daley, J, & Delbanco, TL. (Eds.) *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care (Rev. ed.)* New York: Jossey-Bass Health Series, 2002. Comprehensive, research-based look at the experiences and needs of patients and how patient-centered care can make hospitalization more humane and enhance quality of care. Provides insights into why some hospitals are more patient-centered than others, how patient-centered quality can be integrated into health care policy, standards, and regulations, and how practitioners can become advocates of this model.

Goleman, D. *Social Intelligence: The New Science of Human Relationships*. New York: Bantam, 2007. Goleman's companion to his masterpiece, *Emotional Intelligence*. In this book he explores the benefits to our brain chemistry when we connect with others, how we are wired for compassion and rapport, and how relationships have the power to mold not only human experience but also human biology. Social intelligence is key to providing relationship-based care.

Goleman, D., Boyatzis, R.E., & McKee, A. *Primal Leadership: Learning to Lead with Emotional Intelligence*. Cambridge, MA: Harvard Business School Press, 2004. Goleman, author of *Emotional Intelligence* and *Social Intelligence*, explores the art and science of effective, inspirational, "resonant" leadership. The experiences of leaders in a wide range of work environments lend real-life examples to much of the advice Goleman et al. offer, from developing the motivation to change and creating an improvement plan based on learning rather than performance outcomes, to experimenting with new behaviors and nurturing supportive relationships that encourage change and growth.

Koloroutis M. (Ed.) *Relationship-Based Care: A Model for Transforming Practice*. Minneapolis: Creative Health Care Management, 2004. The seminal work on providing relationship-based care in health settings, and winner of the 2004 *American Journal of Nursing* Book of the Year Award. Provides a practical framework for addressing current challenges in health care, fulfilling a strong commitment to patient care, improving patient, staff and physician satisfaction, recruiting, retaining, and developing talented staff members, and providing a caring and healing environment with collaborative work relationships.

Raines C, Ewing L *The Art of Connecting: How to Overcome Differences, Build Rapport, and Communicate Effectively with Anyone*. New York: Amacom, 2006. A general book

on basic ideas and skills that will aid you in your efforts to build rapport with families in crisis.

Remen, N. *Kitchen Table Wisdom: Stories that Heal*. New York: Riverhead Books, 1996. Physician Naomi Remen explores the healing aspects of the mind-body connection in this collection of vignettes about her dealings with patients. While most of her stories are about her interactions cancer patients, she clearly demonstrates the universal themes and features of relationship-based care. An easy and riveting read.

Robb, M., Barret, S., Komaromy, C., and Rogers, A. *Communication, Relationships and Care: A Reader*. New York: Brunner-Routledge, 2003. A collection of writings that reflect on communication and relationships in health and social care settings, including improving interpersonal communication, developing participatory relationships with patients/clients, working more closely in partnership with other practitioners, issues of power and diversity, and the emotional dimension of care work.

Wiley, E. & Pincus, C. *There Are No Mistakes: Becoming Comfortable With Life As It Is, Not As It Should Be*. Newburyport, MA: Conari Press, 2006. A supportive book about letting go of the “shoulds” and what might have been, and instead accepting what is, in spite of the challenges you face, so that you can move through the world with a sense of grace and ease. Encourages self-knowledge, reflection, taking care of yourself, letting go of perfectionism, not fixing others, finding community, creating a toolbox, and going with the flow. Includes personal stories from others, along with specific and simple exercises to do at the end of each chapter. An easy, comforting read.

Wright, S.G. & Sayre- Adams, J. *Sacred Space: Right Relationship and Spirituality in Health Care*. Edinburgh: Churchill Livingstone, 2001. Examines the nature of disconnection, stress, and burnout among caregivers. Offers practical strategies for dealing with stress and burnout and ways of reintegrating the sacred and spirituality into personal and working lives.

## **Subsequent Pregnancy and Parenting**

*These books support bereaved parents who are considering or have embarked on another pregnancy.*

Abbey, A.L. (Ed.) *Journeys: Stories of Pregnancy After Loss*. Boulder, CO: Woven Word Press, 2006. A collection of essays by mothers and fathers who've experienced the death of a baby, describing their emotional experiences with the next pregnancy (sometimes pregnancies) and usually, new healthy baby. Wide variety of situations, honest, hopeful, and truly demonstrates that you're not alone.

Douglas, A. & Sussman, J.R. *Trying Again: A Guide to Pregnancy After Miscarriage, Stillbirth, and Infant Loss*. Dallas, TX: Taylor Trade Publishing, 2000. Focuses on medical information and comprehensive prenatal care, including fertility issues and high risk pregnancy. Also covers the emotional aspects of preparing for, conceiving, and carrying a subsequent pregnancy.

Jeffers, S. *Embracing Uncertainty: Breakthrough Methods for Achieving Peace of Mind When Facing the Unknown*. New York: St. Martin's Press, 2003. Helpful for parents who face the natural anxiety of subsequent pregnancy.

Lanham, C.C. *Pregnancy after a Loss: A Guide to Pregnancy After Miscarriage, Stillbirth, and Infant Death*. New York: Berkeley Publishing, 1999. Focuses on the emotional journey of subsequent pregnancy, and includes the author's experiences and those of other parents she interviewed.

O'Leary, J. & Thorwick, C. *When Pregnancy Follows a Loss: Preparing for the Birth of Your New Baby*. Published by the authors, 2006. Available at [www.centering.org](http://www.centering.org) or [www.aplacetoremember.com](http://www.aplacetoremember.com) A small book -28 pages- that gives a concise overview of the subsequent pregnancy experience, including quotes from parents.

Schwiebert, P. & Kirk, P. *Still to be Born: A Guide for Bereaved Parents who are Making Decisions about their Future*. Portland, OR: Grief Watch, 1989. A concise and thorough book about when (or if) to try again, medical considerations, and coping during subsequent pregnancy, delivery, and postpartum.

## ~ Professional Journal Articles ~

There are many articles in the professional literature on perinatal grief, parent support, medical ethics, perinatal hospice, subsequent pregnancy, and relationship-based care. For comprehensive reference lists pertaining to special topics, see the following websites.

- The National SIDS/Infant Death Resource Center website collects and displays the latest relevant journal abstracts  
<http://www.sidscenter.org/JournalAlerts.aspx?fromparent=parent&id=6&heading=JournalAlerts>
- A comprehensive reference list on perinatal hospice is available at [www.perinatalhospice.org](http://www.perinatalhospice.org)
- For paper copies of extensive bibliographies on perinatal death and bereavement issues, contact Wisconsin Stillbirth Service Project, [www.wisc.edu/wissp](http://www.wisc.edu/wissp)
- For resources on the death of one or more babies in a multiple pregnancy, the Center for Loss in Multiple Birth has an exhaustive list, including journal articles, on their website [www.climb-support.org](http://www.climb-support.org)
- For relationship-based care consulting and resources, go to Creative Health Care Management's website, <http://www.chcm.com/index.htm>
- For the latest literature on perinatal mortality, etiology, grief, and other topics, see First Candle's "Research Studies" page, which includes links to abstracts:  
[http://www.firstcandle.org/research/res\\_rs.html](http://www.firstcandle.org/research/res_rs.html)

- For more information pertaining to PLIDA's Position Statements, each document contains a Resources list and a Contributors list, where you can find the books, articles, researchers, educators, and advocates that have informed our organization's position on various topics. <http://www.plida.org/positions.php>
- To do your own search for professional research articles pertaining to your special interests or needs, **PubMed** provides a user-friendly online search engine with access to a database that includes over 17 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s. From the National Center for Biotechnology Information (NCBI), and a service of the National Library of Medicine (NLM) and the National Institutes of Health (NIH,) PubMed includes links to abstracts, full text articles, and related articles. <http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed>

## PLIDA's Selected Journal Articles

**This is a selection of professional journal articles that focus on the emotional aspects of perinatal bereavement, parent support, relationship-based care, and subsequent pregnancy/parenting. To see available abstracts for any of these references, put the article's title in the PubMed search engine (see above.) You can also gather more articles on the specific topic by clicking on "related articles."**

Alexander KV. "The one thing you can never take away." *MCN Am J Matern Child Nurs.* 2001;26(3):123-7. (*bereavement photography*)

Armstrong DS. Perinatal loss and parental distress after the birth of a healthy infant. *Adv Neonatal Care.* 2007 Aug;7(4):200-6.

Ayers S. Thoughts and emotions during traumatic birth: a qualitative study. *Birth.* 2007 Sep;34(3):253-63.

Badenhorst W, Riches S, Turton P, Hughes P. The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatic Obstetrics & Gynecology,* 2006; 27(4):245 - 256.

Badenhorst W, Hughes P. Psychological aspects of perinatal loss. *Best Pract Res Clin Obstet Gynaecol.* 2007 Apr;21(2):249-59.

Ballweg DD. Implementing developmentally supportive family-centered care in the newborn intensive care unit as a quality improvement initiative. *J Perinat Neonatal Nurs.* 2001;15(3):58-73.

Barnsteiner JH, Gillis-Donovan J. Being related and separate: A standard for therapeutic relationships. *Maternal Child Nursing Journal.* 1990;15(4):223-4;226-8.

Barr P. Relation between grief and subsequent pregnancy status 13 months after perinatal bereavement. *J Perinat Med.* 2006;34(3):207-11.

\*Barr P, Cacciatore J. Problematic emotions and maternal grief. *Omega (Westport)*. 2007-2008;56(4):331-48.

\*Brier N. Grief following miscarriage: a comprehensive review of the literature. *J Womens Health (Larchmt)*. 2008 Apr;17(3):451-64.

\*Brosig CL, Pierucci RL, Kupst MJ, Leuthner SR. Infant end-of-life care: the parents' perspective. *J Perinatol*. 2007 Aug;27(8):510-6.

Brown MS, Ohlinger J, Rusk C, Delmore P, Ittmann P; CARE Group. Implementing potentially better practices for multidisciplinary team building: creating a neonatal intensive care unit culture of collaboration. *Pediatrics*. 2003;111(4 Pt 2):e482-8.

Bruns DA, McCollum JA. Partnerships between mothers and professionals in the NICU: caregiving, information exchange and relationships. *Neonatal Netw*. 2002;21(7):15-23.

Buchi S, Morgeli H, Schnyder U, Jenewein J, Hepp U, Jina E, Neuhaus R, Fauchere JC, Bucher HU, Sensky T. Grief and post-traumatic growth in parents 2-6 years after the death of their extremely premature baby. *Psychother Psychosom*. 2007; 76(2):106-14.

\*Cacciatore J. Effects of support groups on post traumatic stress responses in women experiencing stillbirth. *Omega (Westport)*. 2007;55(1):71-90.

\*Cacciatore J, Bushfield S. Stillbirth: the mother's experience and implications for improving care. *J Soc Work End Life Palliat Care*. 2007;3(3):59-79.

Caelli K, Downie J, Letendre A. Parents' experiences of midwife-managed care following the loss of a baby in a previous pregnancy. *J Adv Nurs*. 2002 Jul;39(2):127-36.

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. 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 Law Med*. 1997; 13(2):125-143.

Callister LC. Perinatal loss: a family perspective. *J Perinat Neonatal Nurs*. 2006 Jul-Sep;20(3):227-34.

Cameron J, Taylor J, Greene A. Representations of rituals and care in perinatal death in British midwifery textbooks 1937-2004. *Midwifery*. 2007 Jan 20; [Epub ahead of print]

Capitulo KL. Evidence for healing interventions with perinatal bereavement. *MCN Am J Matern Child Nurs*. 2005;30(6):389-96.

Carr D, Knupp SF. Grief and perinatal loss. A community hospital approach to support. *J Obstet Gynecol Neonatal Nurs*. 1985;14(2):130-9.

■ Carter D, Misri S, Tomfohr L. Psychologic aspects of early pregnancy loss. *Clin Obstet Gynecol*. 2007 Mar;50(1):154-65.

■ Chan MF, Lou FL, Arthur DG, Cao FL, Wu LH, Li P, Sagara-Rosemeyer M, Chung LY, Lui L. Investigating factors associate to nurses' attitudes towards perinatal bereavement care. *J Clin Nurs*. 2008 Feb;17(4):509-18.

Chan MF, Lou FL, Zang YL, Chung YF, Wu LH, Cao FL, Li P. Attitudes of midwives towards perinatal bereavement in Hong Kong. *Midwifery*. 2007;23(3):309-21

Corr CA, Corr DM, Goldman C, Jupp P, Lattanzi-Licht M, Papadatou D, Rybarik MF, Skeen J, Smeding R, Sourkes B, Thompson N. International Work Group on Death, Dying, and Bereavement; Caregivers in death, dying, and bereavement situations. *Death Stud*. 2006 Sep; 30(7):649-63

■ Côté-Arsenault D, Donato KL. Restrained expectations in late pregnancy following loss. *J Obstet Gynecol Neonatal Nurs*. 2007 Nov-Dec;36(6):550-7.

■ Côté-Arsenault D. Threat appraisal, coping, and emotions across pregnancy subsequent to perinatal loss. *Nurs Res*. 2007 Mar-Apr;56(2):108-16.

Côté-Arsenault D, Donato K, Earl SS. Watching and worrying: Early pregnancy after loss experiences. *MCN Am J Matern Child Nurs*. 2006;31:356-363.

Côté-Arsenault D, Freije MM. Support groups helping women through pregnancies after loss. *West J Nurs Res*. 2004;26:650-670.

Côté-Arsenault, D. Weaving babies lost in pregnancy into the fabric of the family. *J Fam Nurs*. 2003;9:23-37.

Côté-Arsenault, D., & Marshall, R. (2000). One foot in-one foot out: Weathering the storm of pregnancy after perinatal loss. *Res Nurs Health*. 2000;23:473-485.

Cuisinier MCJ, Kuijpers JC, Hoogduin CAL, deGraauw CPHM, Janssen HJEM. Miscarriage and stillbirth: Time since loss, grief intensity and satisfaction with care. *Eur J Ob Gyn Reprod Biol*. 1996, 993;52(3):163-168.

■ Cumming GP, Klein S, Bolsover D, Lee AJ, Alexander DA, Maclean M, Jurgens JD. The emotional burden of miscarriage for women and their partners: trajectories of anxiety and depression over 13 months. *BJOG*. 2007 Sep;114(9):1138-45.

Davis, DL . Providing Emotionally Supportive Care to Parents as They Face Decisions After Prenatal Diagnosis of a Baby's Life-Limiting Condition. *CHiPPS Pediatric Palliative Care Newsletter*. 2007;7, 22-5.

Davis, DL. Reflections on the Lancet Stillbirth Study. *The Forum, Association for Death Education and Counseling*. 2004;30:2, 4-5.

Davis DL, Stewart M, Harmon RJ. Postponing pregnancy after perinatal death: Perspectives on doctor advice. *J Am Acad Child Adolesc Psychiatry*. 1989;28:481-487.

Davis DL, Stewart M, Harmon RJ. Perinatal loss: Providing emotional support for bereaved parents. *Birth*. 1988;15(4):242-246.

\*Doran G, Downing Hansen N. Constructions of Mexican American family grief after the death of a child: An exploratory study. *Cultur Divers Ethnic Minor Psychol*. 2006 May;12(2):199-211.

\*Engelkemeyer SM, Marwit SJ. Posttraumatic growth in bereaved parents. *J Trauma Stress*. 2008 Jun;21(3):344-6.

\*Fenwick J, Jennings B, Downie J, Butt J, Okanaga M. Providing perinatal loss care: satisfying and dissatisfying aspects for midwives. *Women Birth*. 2007 Dec;20(4):153-60. Epub 2007 Oct 25.

\*Gaudet C, Séjourné N, Allard MA, Chabrol H. [Women and the painful experience of therapeutic abortion.] *Gynecol Obstet Fertil*. 2008 May;36(5):536-542.

\*Glaser A, Bucher HU, Moergeli H, Fauchère JC, Buechi S. Loss of a preterm infant: psychological aspects in parents. *Swiss Med Wkly*. 2007 Jul 14;137(27-28):392-401.

Geerinck-Vercammen CR. With a positive feeling: The grief process after stillbirth in relation to the role of the professional caregivers. *Eur J Ob Gyn Reprod Biol*. 1999;87(2):119-121.

\*Gold KJ, Dalton VK, Schwenk TL. Hospital Care for parents after perinatal death. *Obstet Gynecol*. 2007 May;109(5):1156-66.

\*Gold KJ. Navigating care after a baby dies: a systematic review of parent experiences with health providers. *J Perinatol*. 2007 Apr; 27(4):230-7.

\*Hale B. Culpability and blame after pregnancy loss. *J Med Ethics*. 2007 Jan;33(1):24-7. PMID: 17209106]

\*Howard LM, Kirkwood G, Latinovic R. Sudden infant death syndrome and maternal depression. *J Clin Psychiatry*. 2007 Aug;68(8):1279-83.

Gordin P, Johnson BH. Technology and family-centered perinatal care: conflict or synergy? *J Obstet Gynecol Neonatal Nurs*. 1999;28(4):401-8.

Heaman M. Psychosocial impact of high risk pregnancy: Hospital and home care. *Clin Obstet Gynecol*. 1998;41(3):626-639.

Heermann JA, Wilson ME. Nurses' experiences working with families in an NICU during implementation of family-focused developmental care. *Neonatal Netw*. 2000; 100;19(4):23-29.

Hochberg T. Touching souls: Healing with bereavement photography. *The Forum, Association for Death Education and Counseling*. 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. [www.iuns.nursing.arizona.edu/articles/Fall%202006/horning.htm](http://www.iuns.nursing.arizona.edu/articles/Fall%202006/horning.htm)

Hughes P, Riches S. Psychological aspects of perinatal loss. *Curr Opin Obstet Gynecol*. 2003 Apr;15(2):107-11.

Hughes PM, Turton P, Evans CDH. Stillbirth as risk factor for depression and anxiety in subsequent pregnancy: A cohort study. *BMJ*. 1999; 318:1721-4.

Hughes P, Turton P, Hopper E, Evans CD. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet*. 2002 Jul 13;360(9327):114-8.

Jansen JL. A bereavement model for the intensive care nursery. *Neonatal Netw*. 2003 May-Jun;22(3):17-23.

Johnson BH, Abraham MR, Parrish RN. Designing the neonatal intensive care unit for optimal family involvement. *Clin Perinatol*. 2004;31(2):353-382.

Kavanaugh K, Hershberger P. Perinatal loss in low-income African American parents. *J Obstet Gynecol Neonatal Nurs*. 2005 Sep-Oct;34(5):595-605.

Kavanaugh K, Moro T. Supporting parents after stillbirth or newborn death: There is much that nurses can do. *Am J Nurs*. 2006 Sep;106(9):74-9.

Kavanaugh K, Moro TT, Savage T, Mehendale R. Enacting a theory of caring to recruit and retain vulnerable participants for sensitive research. *Res Nurs Health*. 2006 Jun;29(3):244-52. Review.

Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decisions for extremely premature infants: report of a pilot study. *J Pediatr Nurs*. 2005 Oct;20(5):347-59.

Kavanaugh K, Trier D, Korzec M. Social Support Following Perinatal Loss. *J Fam Nurs*. 2004 Feb;10(1):70-92.

■ Kersting A, Kroker K, Steinhard J, Lüdorff K, Wesselmann U, Ohrmann P, Arolt V, Suslow T. Complicated grief after traumatic loss: a 14-month follow up study. *Eur Arch Psychiatry Clin Neurosci*. 2007 Dec;257(8):437-43.

Kobler K, Limbo R, Kavanaugh K. Meaningful Moments: The Use of Ritual in Perinatal and Pediatric Death. *MCN Am J Matern Child Nurs*. 2007 September/October;32(5):288-295.

■ Korenromp MJ, Page-Christiaens GC, van den Bout J, Mulder EJ, Hunfeld JA, Potters CM, Erwich JJ, van Binsbergen CJ, Brons JT, Beekhuis JR, Omtzigt AW, Visser GH. A

prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenat Diagn.* 2007 Aug;27(8):709-16.

■ Kuebelbeck A. Perinatal Hospice: A Holistic Approach 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).

[www.perinatalhospice.org/uploads/Kuebelbeck-ADEC.pdf](http://www.perinatalhospice.org/uploads/Kuebelbeck-ADEC.pdf)

Lasker JN, Toedter LJ. Satisfaction with hospital care and interventions after pregnancy loss. *Death Stud.* 1994;18(1):41-64.

Leduc L, Farine D, Armson BA, Brunner M, Crane J, Delisle MF, Gagnon R, Keenan-Lindsay L, Morin V, Mundle RW, Scheider C, Van Aerde J. Maternal-Fetal Medicine Committee; Clinical Practice Obstetrics Committee; Stillbirth and bereavement: Guidelines for stillbirth investigation. *J Obstet Gynaecol Can.* 2006 Jun;28(6):540-52.

Leon, IG. Providing versus packaging support for bereaved parents after perinatal loss. *Birth.* 1992 Jun;19(2):89-91.

Leon IG. Perinatal Loss: A Critique of Current Hospital Practices. *Clin Pediatr.* 1992;31(6):366-374.

Lewis E, Page A. Failure to mourn a stillbirth: An overlooked catastrophe. *Brit J Med Psychology.* 1978;51,237-241.

Lok IH, Neugebauer R. Psychological morbidity following miscarriage. *Best Pract Res Clin Obstet Gynaecol.* 2007 Feb 19.

Mander R, Marshall RK. An historical analysis of the role of paintings and photographs in comforting bereaved parents. *Midwifery.* 2003 Sep;19(3):230-42.

■ McCreight BS. Perinatal loss: a qualitative study in Northern Ireland. *Omega (Westport).* 2008;57(1):1-19.

McCreight BS. A grief ignored: narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness.* 2004; 26(3):326-350.

McGrath JM. Building relationships with families in the NICU: exploring the guarded alliance. *J Perinat Neonatal Nurs.* 2001;15(3):74-83.

McGreal D, Evans, BJ, Burrows GD. Gender differences in coping following loss of a child through miscarriage or stillbirth: a pilot study. *Stress Med.* 1997; 13(3):159-165.

Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study. *Pediatr Crit Care Med.* 2005 Jul;6(4):420-7.

Miron J, Chapman J. Supporting: Men's experience with the event of their partners' miscarriage. *Can J Nurs Res.* 1994; 26(2):61-72.

Moore KA, Coker K, DuBuisson AB, Swett B, Edwards WH. Implementing potentially better practices for improving family-centered care in neonatal intensive care units: successes and challenges. *Pediatrics*. 2003;111(4 Pt 2):e450-60.

Moro T, Kavanaugh K, Okuno-Jones S, Vankleef JA. Neonatal end-of-life care: a review of the research literature. *J Perinat Neonatal Nurs*. 2006 Jul-Sep;20(3):262-73.

Morrissey MV. Our first child was incompatible with life: understanding miscarriage as a lived experience. *Int J Psychiatr Nurs Res*. 2007 Jan; 12(2):1415-28.

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.

Nordstrom P, Lasby K. Journey of change: Building a bridge between neonatal nursing education and practice. *J Perinat Neonatal Nurs*. 1994;8(3):58-68.

O'Leary, J. Pregnancy and infant loss: supporting parents and their children. *Zero to Three*. 2007;27(6):42-49.

O'Leary, J. (2004) Grief and its impact on prenatal attachment in the subsequent pregnancy. *Arch Womens Ment Health*. 2004;7(1):1-15.

O'Leary JM, Gaziano C, & Thorwick C. Born after loss: the invisible child in adulthood. *J Prenat Perinat Psych Health*. 2006; 21(1):3-23.

O'Leary, J. & Thorwick, C. (2006) Fathering perspective during pregnancy post perinatal loss. *J Obstet Gynecol Neonatal Nurs*. 2006;35(1):78-86.

Osborne M. Photographs and mementos. The emergency nurse's role following sudden infant death. *Emerg Nurse*. 2000 Feb;7(9):23-5.

Paredes SD, Frank DI. Nurse/parent role perceptions in care of neonatal intensive care unit infants: Implications for the advanced practice nurse. *Clin Excell Nurs Pract*. 2000;4(5):294-301.

Petersen MF, Cohen J, Parsons V. Family-Centered Care: Do we practice what we preach? *J Obstet Gynecol Neonatal Nurs*. 2004;33(4):421-427.

Pidgeon C. Life after stillbirth: a father's story. *RCM Midwives*. 2007 Jun;10(6):288-9.

Primeau MR, Recht CK. Professional bereavement photographs: one aspect of a perinatal bereavement program. *J Obstet Gynecol Neonatal Nurs*. 1994 Jan;23(1):22-5.

Puddifoot JE, Johnson MP. The legitimacy of grieving: The partner's experience at miscarriage. *Soc Sci Med*. 1997; 45(6):837-845.

Puddifoot JE, Johnson MP. Active grief, despair, and difficulty coping: Some measured characteristics of male response following their partners miscarriage. *J Reprod Infant Psychol*. 1999; 17(1):89-92.

\*Rees DI, Sabia JJ. The relationship between abortion and depression: new evidence from the fragile families and child wellbeing study. *Med Sci Monit.* 2007 Oct;13(10):CR430-6.

Riley LP, LaMontagne LL, Hepworth JT, Murphy BA. Parental grief responses and personal growth following the death of a child. *Death Stud.* 2007 Apr; 31(4):277-99.

Riches G, Dawson P. Lost children, living memories: the role of photographs in processes of grief and adjustment among bereaved parent. *Death Stud.* 1998;22(2):121-40.

\*Romesberg TL. Building a case for neonatal palliative care. *Neonatal Netw.* 2007 Mar-Apr;26(2):111-5. Review.

\*Roy DJ. When newborn babies have to die...perinatal palliative care? *J Palliat Care.* 2007 Summer;23(2):67-8.

Robinson T, Marwit SJ. An investigation of the relationship of personality, coping, and grief intensity among bereaved mothers. *Death Stud.* 2006 Sep;30(7):677-96.

Rushton CH, Reder E, Hall B, Comello K, Sellers DE, Hutton N. Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. *J Palliat Med.* 2006 Aug;9(4):922-33.

Saflund K, Sjogren B, Wredling R. Physicians' attitudes and advice concerning pregnancy subsequent to the birth of a stillborn child. *J Psychosom Obstet Gynaecol.* 2002 Jun;23(2):109-15.

Saflund K, Sjogren B, Wredling R. The role of caregivers after a stillbirth: views and experiences of parents. *Birth.* 2004 Jun;31(2):132-7.

Saflund K, Wredling R. Differences within couples' experience of their hospital care and well-being three months after experiencing a stillbirth. *Acta Obstet Gynecol Scand.* 2006; 85(10):1193-9.

Saunders RP, Abraham MR, Crosby MJ, Thomas K, Edwards WH. Evaluation and development of potentially better practices for improving family centered care in neonatal intensive care units. *Pediatrics.* 2003;111(4pt2):e437-49.

\*Séjourné N, Callahan S, Chabrol H. [Psychological consequences of miscarriage: A review.] *J Gynecol Obstet Biol Reprod (Paris).* 2008 May 26.

\*Serrano F, Lima ML. Recurrent miscarriage: psychological and relational consequences for couples. *Psychol Psychother.* 2006 Dec;79(Pt 4):585-94.

Simmons RK, Singh G, Maconochie N, Doyle P, Green J. Experience of miscarriage in the UK: Qualitative findings from the National Women's Health Study. *Soc Sci Med.* 2006 Jun 14.

St John A, Cooke M, Goopy S. Shrouds of silence: three women's stories of prenatal loss. *Aust J Adv Nurs.* 2006 Mar-May;23(3):8-12.

Stratton K, Lloyd L. Hospital-based interventions at and following miscarriage: literature to inform a research-practice initiative. *Aust N Z J Obstet Gynaecol.* 2008 Feb;48(1):5-11.

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.

Swanson KM, Connor S, Jolley SN, Pettinato M, Wang TJ. Contexts and evolution of women's responses to miscarriage during the first year after loss. *Res Nurs Health.* 2007 Jan 22; 30(1):2-16.

Theut SK, Pedersen FA, Zaslow MJ, Rabinovich BA. Pregnancy subsequent to perinatal loss: Parental anxiety and depression. *J Am Acad Child Adolesc Psychiatry.* 1988;27:289-292.

Tschetter L, Hildreth M. Grief enriched us: a model of perinatal loss support. *J Perinat Educ.* 2005 Fall;14(4):3-4.

Tully MR. Donating human milk as part of the grieving process. *J Hum Lact.* 1999 Jun;15(2):149-51.

Vennemann MM, Rentsch C, Bajanowski T, Zimmer G. Are autopsies of help to the parents of SIDS victims? : A follow-up on SIDS families. *Int J Legal Med.* 2006 May 10.

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):30-5.

Wheeler SR, Limbo RK. Blueprint for a perinatal bereavement support group. *Pediatr Nurs.* 1990 Jul-Aug;16(4):341-4, 377.

Wijngaards-de Meij L, Stroebe M, Schut H, Stroebe W, van den Bout J, van der Heijden PG, Dijkstra I. Patterns of attachment and parents' adjustment to the death of their child. *Pers Soc Psychol Bull.* 2007 Apr;33(4):537-48.

Williams C, Munson D, Zupancic J, Kirpalani H. Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end-of-life care - A North American perspective. *Semin Fetal Neonatal Med.* 2008 May 9.

Wojnar D. Miscarriage experiences of lesbian couples. *J Midwifery Womens Health.* 2007 Sep-Oct;52(5):479-85.

Wood D. Preparing Expectant Parents for Perinatal Death. *AMN Healthcare Nursing News*, 2007. <http://www.nursezone.com/Nursing-News-Events/more-news.aspx?ID=17080>

Workman E. Guiding parents through the death of their infant. *J Obstet Gynecol Neonatal Nurs.* 2001 Nov-Dec;30(6):569-73.

Worth, N. (1997). Becoming a father to a stillborn child. *Clin Nurs Res.* 1997; 6(1):71-89.

Wright PM. Childbirth education for parents experiencing pregnancy after perinatal loss. *J Perinat Educ.* 2005 Fall;14(4):9-15.

Zeanah C. Adaptation following perinatal loss: A critical review. *J Am Acad Child Adolesc Psychiatry.* 1998;28(3):467-480.

Zeanah CH, Dailey JV, Rosenblatt MJ, Saller DN Jr. Do women grieve after terminating a pregnancy for fetal abnormalities? A controlled investigation. *Obstet Gynecol.* 1993 Aug;82(2):270-5.

Zengerle FS. The controversy over pastoral care of parents after a stillbirth. *J Pastoral Care Counsel.* 2007 Fall;61(3):243-6.

Zhang B, El-Jawahri A, Prigerson HG. Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *J Palliat Med.* 2006 Oct; 9(5):1188-203.

Zwelling E, Phillips CR. Family-centered maternity care in the new millennium: Is it real or is it imagined? *J Perinat Neonat Nurs.* 2001;15(3):1-12.

## \*Mortality Statistics

For the latest population statistics on infant and fetal mortality in North America, here are several sources and their links.

**United States**  
**Centers for Disease Control**  
Dept. of Health and Human Services  
National Center for Health Statistics  
<http://www.cdc.gov/nchs/hus.htm>

**National Vital Statistics Reports**, Vol. 55, No. 6, February 21, 2007

**Canada**  
**Statistics Canada**  
Vital Statistics - Stillbirth Database Table 8  
<http://www.statcan.ca/english/freepub/84F0210XIE/2005001/technote5.htm>

List of summary tables  
<http://cansim2.statcan.ca/cgi-win/cnsmcqi.pgm?Lang=E&SP Action=Result&SP ID=3871&SP TYP=5&SP Sort=1>

Infant mortality  
<http://cansim2.statcan.ca/cgi-win/CNSMCGI.PGM>

## ~ Films on DVD~

Some of these films were produced for practitioners, some for parents, and some for the general public. All contain information, insights, and/or support on specific perinatal bereavement issues. Some practitioner videos are available as online continuing education courses. Programs produced for parent viewing are not intended to substitute for direct communication, but rather to open the door for sensitive discussions between parent and practitioner. Accompanied by empathic support from health care practitioners, videos can help parents formulate questions, verbalize their thoughts, process emotions, clarify decisions, and feel reassured & less alone.

Films are divided into the following categories:

- Personal Stories
- Perinatal Bereavement
- Pediatric Hospice
- Neonatal Medical Ethics
- Subsequent Pregnancy

### Personal Stories

#### ***Losing Layla***

Produced by Hatchling Productions, 2002, 50 mins.

<http://www.vanessagorman.com/documentary.htm>

A documentary by an Australian filmmaker and writer, Vanessa Gorman, who began filming her own video diary to document the process of having a baby and its effect on a relationship, only to deliver Layla stillborn at term. The camera stays on her and her partner Michael, as they hold their baby and face their grief in the months following. It became an award-winning film shown on television networks around the world. The DVD also contains a postscript to this story, a 30 minute film *Regarding Raphael*, where she welcomes a baby son. Extraordinarily beautiful, raw and honest, a journey from joy to heartbreak, and then to bittersweet gratitude. Shows bereaved parents that they are not alone, and they too can survive; shows practitioners the inside story on how bereaved parents experience their baby's death and what helps them cope.

#### ***Capturing a Short Life***

Produced by Sheona McDonald, Dimestore Productions, 2008, 54 mins.

[www.dimestore.ca](http://www.dimestore.ca)

An award-winning documentary by a Canadian filmmaker, writer, and producer, who follows several families who face the death of a baby shortly after birth or in early infancy. It explores the depths of the parents' grief, affirms their desire to honor their baby's life, informs the viewer about the emotional landscape and the importance of remembering.

## Perinatal Bereavement

### ***Infant Mortality: From a Parent's Perspective***

Produced by Nicole Alston, 2006, 57 mins.

[www.theskyefoundation.org](http://www.theskyefoundation.org)

Features interviews conducted with African American and Latino women (and families) who share stories of the birth and death of their babies. Shows that despite varying income and education levels, the common emotional threads of despair, guilt, and devastation persisted. Also includes commentary from medical professionals.

### ***Grieving in the NICU: Mending Broken Hearts When a Baby Dies***

Produced by DIA Productions in collaboration with SHARE Pregnancy & Infant Loss Support, Washington University School of Medicine, St. Louis Children's Hospital and Stepstone Productions, 2006, 90 mins.

[www.grievingforbabies.org](http://www.grievingforbabies.org)

Members of families whose babies died in the NICU share their experiences. To grieving parents, the comforting message threaded throughout the video is that "you are not alone." Nationally acclaimed experts participate in the discussions and offer their helpful insights and suggestions.

### ***Grieving in the NICU: Supporting Families and the Health Team When a Baby Dies***

Produced by DIA Productions in collaboration with SHARE Pregnancy & Infant Loss Support, Washington University School of Medicine, St. Louis Children's Hospital and Stepstone Productions, 2007, 80 mins.

[www.grievingforbabies.org](http://www.grievingforbabies.org)

This chaptered DVD is designed to help health care practitioners meet the challenges of providing care for families whose babies will not survive to "graduate" from the NICU. The five chapters cover (1) supporting parents as they spend time with their dying baby and then (2) after their baby dies; (3) grandparent and sibling grief; (4) practitioner grief and coping; (5) responding with sensitivity to cultural and religious diversity. Features grieving parents, as well as doctors, nurses, a grief counselor, and a chaplain. Also available as an Individual Learning Model for online CEUs for physicians, nurses, social workers, and chaplains, the course streams the video from the DVD, contains text, self administered quizzes, and on-line certification.

### ***A Bridge To Hope***

Produced by Bereavement Services, 2006, 7 mins.

[www.bereavementservices.org](http://www.bereavementservices.org)

An introduction to perinatal bereavement care, for teaching in the classroom or building awareness in organizations. Dramatized story captures the hopes and dreams of parenthood devastated by the tragedy of loss. Illustrates how professional care serves as a bridge between the death of a precious baby and hope for tomorrow.

### ***...voices...NICU Caregivers on Religion and Self Care***

Produced by Bereavement Services, 2008, 23 mins.

[www.bereavementservices.org](http://www.bereavementservices.org)

In two separate chapters, nurses, physicians, and chaplains talk about self-care (13 minutes) and understanding families' religious beliefs (10 minutes.) For education and awareness for presentations at staff meetings, interdisciplinary rounds, workshops, trainings, and more.

## Pediatric Hospice

### ***When a Child is Dying***

Produced by Beth Seyda and Erica Rothman, 2002, 58 mins.

[www.compassionatepassages.org](http://www.compassionatepassages.org)

An award winning film featuring four bereaved families, one of which experienced the death of a 2 month-old twin baby daughter in the NICU. Parents discuss their emotional journeys and what they found supportive. Instructive for health care practitioners, and especially speaks to those who've experienced perinatal death themselves, as the parents of the dying twin were also physicians and struggled with straddling the worlds of parent and practitioner.

## Neonatal Medical Ethics

### ***Parents on the Threshold: You Are Not Alone***

Produced for the Colorado Collective for Medical Decisions (CCMD) by Nickel's Worth Productions, 1999. 30 mins.

This documentary shows babies and their parents who are facing difficult decisions in the NICU, as well as the practitioners who support and counsel them. Some parents choose hospice care, some choose intensive care. Can be used to educate practitioners, or as a tool to enhance communication with and support of parents who are facing life-and-death decisions in the NICU for their babies whose prognosis is unclear. To order, contact Nickel's Worth Productions at [NickelTV@aol.com](mailto:NickelTV@aol.com). To download a copy of CCMD's *Neonatal Video Users Guide*, which includes the *CCMD Neonatal Guidelines*, go to <http://www.parentingyourprematurebaby.com/CCMD%20Neonatal%20Video%20User%27s%20guide.pdf>

### ***Born Too Soon: Life and Death in the NICU***

Produced by DIA Learning, 2004

Individual Learning Model 78 mins.

Group Learning Model 30 mins.

The Individual Learning Model is an on-line healthcare ethics course, accredited by the AMA, ACCME and AMA's Physician's Recognition Award as a provider of category 1 CMEs. The course is also accredited by the major nursing organizations. Offering 12 CMEs for physicians and 14.4 contact hours for nurses, this is a comprehensive look at the world of neonatology in the 21st Century with a focus on neonatal medical ethics, including decision-making and helping parents deal with life and death issues in the NICU. For more information, to view a preview, and to order, go to [http://dialearning.com/program\\_list/p5/index.asp](http://dialearning.com/program_list/p5/index.asp).

The Group Learning Model is designed for a classroom or group setting, accredited for 2 CMEs and 2.4 contact hours, and comes with a DVD/CD ROM and downloadable facilitator guide. To purchase and download the guide, go to <http://fac.ethicsprograms.com>.

## Subsequent Pregnancy

***After Loss: Journey of the Next Pregnancy*** (28 mins)

***Labor and Birth: Rebuilding Trust*** (18 mins)

Produced by Abbott Northwestern Hospital, Parent Education Department, Minneapolis, MN, 1995; 1997.

Supports parents who are planning or coping with a new pregnancy after the death of their babies. Shows parents on their journeys. Available from Joann O'Leary, [jandj@pro-ns.net](mailto:jandj@pro-ns.net)

## ~ Websites ~

The Internet holds a vast collection of websites. Included here are the websites of well-established organizations that provide non-denominational support, services, materials, resources, information, or advocacy for bereaved families, and/or the practitioners who work with them. While most of these organizations are not-for-profit, some for-profits are included because they provide an array of services or products that meet the needs of bereaved parents or perinatal practitioners. Sites are listed in two categories: Parent Support Organizations and Resource Centers.

There are many other websites that you may find helpful in your journey or your work. Many of the sites listed here provide links to others that may meet your needs for information, ideas, and support. You can also type keywords, such as special topics of interest or book titles into your favorite search engine. Many authors and other professionals maintain their own websites, and those may be good sources of additional information, support, or networking. Some blogs written by bereaved parents can also be well worth reading (for instance, there are a number of bereaved mothers who keep journals on pregnancy.org. Go to <http://www.pregnancy.org/phpBB2/viewforum.php?f=224> and click on topics that pique your interest, and you may find a narrative that gives you special insight or if you're a parent, reassurance that you're not alone.)

As always, use your judgement, and look for websites that are legitimate and reliable sources of information and comfort, or Listservs that are well-run communities of mutual respect, sharing, and support.

Finally, be aware that some websites with appropriate-sounding titles or addresses may contain disturbing content that bears no relation to your needs. If you are a practitioner, please regularly visit and check the content of sites you recommend to parents, and remember that domain names can change hands overnight, without warning.

¶ Websites are divided into the following categories and subcategories:

Parent Support

Photography & Keepsakes

Multicultural Support

Resource Centers

Book Distributors & Specialty Publishers

Disposition, Funeral, & Memorials

Professional, Educational, & Advocacy Organizations

## Parent Support

*These organizations offer bereaved parents information, services, keepsakes, or emotional support around perinatal death and grief.*

### **Caring Bridge**

[www.caringbridge.org](http://www.caringbridge.org)

Provides free, personalized, easy to use websites for families who are experiencing a medical crisis, so that they can keep others informed without being barraged with queries. Friends and relatives can check in and get the latest update, as well as leave messages of support. Also a good outlet for creativity and expression, and a legacy for babies who die.

### **CLIMB: Center for Loss in Multiple Birth**

[www.climb-support.org](http://www.climb-support.org)

Provides parent-to-parent support and a newsletter for those who've experienced the death of one or more of twins or higher multiple birth children at any time from conception through birth, infancy and early childhood. Also promotes awareness as to the extent of multiple birth loss, education on the needs of bereaved parents, and research on prevention.

### **The Compassionate Friends**

[www.compassionatefriends.org](http://www.compassionatefriends.org)

Assists families towards the positive resolution of grief following the death of a child of any age and provides information to help others be supportive. Local chapters provide support groups where seasoned grievers reach out to the newly bereaved.

### **The MISS Foundation**

[www.missfoundation.org](http://www.missfoundation.org)

Provides crisis support and long term aid to families after the death of a child from any cause, with a focus on death during pregnancy and infancy. MISS also participates in legislative and advocacy issues, community engagement and volunteerism, culturally competent, multidisciplinary, education opportunities, and is committed to building interdisciplinary communities that provide long-term support to families after a child's death.

### **Faith's Lodge**

[www.faithslodge.org](http://www.faithslodge.org)

A retreat center in Wisconsin that provides opportunities for bereaved parents to get away from daily demands, connect with others in similar circumstances, and be intentional in their grief process. Offers a weekly supportive discussion group and referrals to resources if desired. For parents who are seeking this type of experience, it can have a profound impact on their healing journey.

### **Pregnancy.org: Dealing with Childbearing Complications**

<http://www.pregnancy.org/crisispreg.php>

A pregnancy information and support site founded by mothers who also know the heartache of having a baby die, so this website acknowledges that childbearing can be

complicated. This page looks at the emotional aspects, with questions posed by parents and answered by two authors of supportive books for parents.

### **SANDS Stillbirth and Neonatal Death Support Australia**

[www.sands.org.au/](http://www.sands.org.au/)

For more than two decades SANDS has provided sensitive support to parents and families who experience reproductive loss.

### **SANDS Stillbirth and Neonatal Death Support United Kingdom**

[www.uk-sands.org](http://www.uk-sands.org)

Established in the UK in 1975, SANDS promotes quality bereavement care, awareness, education, and research.

### **Share: Pregnancy and Infant Loss Support**

*Touching lives, healing hearts, giving hope*

[www.nationalshareoffice.com](http://www.nationalshareoffice.com)

Founded in 1977, **Share** is dedicated to supporting parents and families who've experienced the death of a baby during pregnancy or infancy. Sponsors **Share** support groups throughout North America and England.

### **StorkNet: Pregnancy/Infant Loss**

[www.storknet.com/cubbies/pil](http://www.storknet.com/cubbies/pil)

For perinatally bereaved parents, a special supportive "cubby" in this pregnancy and parenting website, which was founded by Maribeth Doerr, the bereaved mother who started PenParents and then graduated to the Internet.

### **StorkNet: Pails of Hope—**

#### **Pregnancy/Parenting After Infertility and/or Loss Support**

[www.storknet.com/cubbies/pailsofhope/index.html](http://www.storknet.com/cubbies/pailsofhope/index.html)

For bereaved parents, another StorkNet cubby. This one recognizes the tender feelings associated with contemplating pregnancy, being pregnant, or raising a child following the death of a baby or after the challenges of infertility.

### **String of Pearls**

[www.stringofpearlsonline.org](http://www.stringofpearlsonline.org)

Supports families seeking perinatal hospice. Aims to provide guidance, compassion and practical suggestions for parents after prenatal diagnosis of their baby's fatal condition. Denver-area coordination of care, but parent narratives, memory-making kits, birth plans, memorial planning, resources list, and consultation are available to anyone in North America.

### **Unexplained Stillbirth Support**

[www.stillbirthsupport.org](http://www.stillbirthsupport.org)

This website, by Australian obstetrician Steve Robson, MD, is dedicated to providing accurate, up-to-date information about stillbirth in general, and unexplained stillbirth in particular.

## Photography and Keepsakes

### **The Comfort Company**

[www.thecomfortcompany.net](http://www.thecomfortcompany.net)

Bereavement and condolence gifts, carefully selected or custom designed, including sympathy poems and cards.

### **Heartprints Photo Retouching**

<http://personal.nbnet.nb.ca/crempel/Heartprints/index.htm>

Heartprints is a digital photo retouching service for families who've experienced the death of a baby through stillbirth or prematurity, correcting the esthetics that can take away from the natural beauty of a tiny baby. Sensitive to parents' needs, Heartprints restores photos to depict the child parents remember and allows them to share with friends and family without worrying about disapproving reactions.

### **My Forever Child: Child Loss Keepsakes**

[www.myforeverchild.com](http://www.myforeverchild.com)

Unique acknowledgement and memorial keepsakes, remembrance jewelry, and sympathy gifts to comfort those touched by the loss of a child, no matter what age, including babies who died during pregnancy or infancy.

### **Now I Lay Me Down To Sleep: Infant Remembrance Photography**

[www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org)

A national network of photographers who volunteer their services to parents experiencing the death of a baby as early as 20 weeks gestation or at the discretion of medical personnel. At parents' request, an affiliated photographer comes to their location and conducts a sensitive portrait session. An archival quality DVD or CD is given to parents free of charge.

### **Timeless Traditions: Tear Bottle Keepsakes**

[www.timelesstraditionsgifts.com](http://www.timelesstraditionsgifts.com)

The leading wholesale supplier of historically-inspired tear bottles, which are small, exquisite glass bottles that are used to symbolize deep emotion and are a unique and personal gift choice for the bereaved.

### **Touching Souls: Healing with Bereavement Photography**

[www.toddhochberg.com](http://www.toddhochberg.com)

Todd Hochberg is known for his beautiful, heartfelt, evocative black & white documentary photography with grieving parents as they spend private time with their precious babies. While he makes images about their experience, he works inobtrusively—a quiet, observant, supportive, advocating presence. Parents treasure their photographs; health care practitioners and photographers are inspired by his informative workshops.

## Multicultural Support

### **Colorado Pregnancy and Newborn Loss**

[www.coloradopregnancyloss.org](http://www.coloradopregnancyloss.org)

Support services based in Colorado. Good source for services and resources in Spanish.

### **Family A-Z**

[www.azrodina.cz](http://www.azrodina.cz)

A website from the **Czech Republic**, contains a translation of excerpts from the book, *Empty Cradle, Broken Heart*, for grieving parents.

[http://www.azrodina.cz/article/detail/1?aid=1849&art\\_type=4&cid=15](http://www.azrodina.cz/article/detail/1?aid=1849&art_type=4&cid=15)

## Resource Centers

*These organizations offer books and other written materials, videos, educational programs, information, advocacy, and/or professional development specific to their chosen focus.*

## Book Distributors and Specialty Publishers

### **A Place to Remember**

[www.APlaceToRemember.com](http://www.APlaceToRemember.com)

Publisher and distributor of supportive materials for parents who've experienced crisis in pregnancy or the death of a baby, including books by other publishers, booklets, sympathy cards, and keepsakes.

### **Centering Corporation Grief Resource Center**

[www.centering.org](http://www.centering.org)

1-866-218-0101

Publisher and distributor of grief resources, including books from other publishers, as well as their own line of smaller books and booklets that focus on specific topics in pregnancy loss and infant death. Some books available in Spanish.

### **Grief Watch**

[www.griefwatch.com](http://www.griefwatch.com)

Home of Perinatal Loss, which publishes, creates, distributes written materials, including the books *Still to be Born*, and *We Were Gonna Have a Baby, But We Had an Angel Instead*, plus keepsakes, urns, certificates of life, and grief support cards.

### **GriefWorks**

[www.griefworks.org](http://www.griefworks.org)

Serves as a bereavement resource providing education and support for people grieving a death or seeking to understand the grief process.

### **Quality of Life Publishing**

[www.QOLpublishing.com](http://www.QOLpublishing.com)

Specializes in books and newsletters that help ease the way for patients and families dealing with terminal illness, death, and grief. Offers substantial discounts to hospices and other organizations.

### **Wintergreen Press**

[www.wintergreenpress.com](http://www.wintergreenpress.com)

Publisher of the classic “Empty Arms” and other titles. Along with a catalog, this website provides links to other organizations, resources, articles, and advocacy campaigns.

## **Disposition, Funeral, Memorials**

### **Heaven’s Gain**

<http://www.heavensgain.com/index.html>

Specializes in providing small baby caskets and burial products for families suffering the loss of a child through miscarriage or early stillbirth.

### **Olivia Raine Foundation**

<http://oliviaraine.org/>

Financial assistance for funeral-related expenses for infants.

### **Trappist Caskets**

[www.trappistcaskets.com/childcasket.asp](http://www.trappistcaskets.com/childcasket.asp)

Monks from Iowa’s New Melleray Abbey (established in 1849) build beautiful infant-sized caskets out of sustainable red oak harvested from the abbey’s forest. As a living memorial, they also plant a Red Oak tree in honor of every child who is buried in one of their handcrafted caskets, and a special mass is said in the child’s name.

### **Cherokee Child Caskets**

[www.cherokeechildcaskets.com](http://www.cherokeechildcaskets.com)

Since 1941, this company has specialized in caskets made for children and infants, including the tiniest babies. With sensitivity and attention to detail, this company offers quality and value, and its caskets can be ordered 7 days a week through any licensed funeral home, casket manufacturer, or funeral supply company.

### **The Green Funeral Site**

[www.thegreenfuneralsite.com](http://www.thegreenfuneralsite.com)

Information on a soothing alternative to traditional embalming and burials practices.

## **Professional, Educational, and Advocacy Organizations**

### **American Academy of Pediatrics (AAP)**

[www.aap.org](http://www.aap.org)

Committed to the attainment of optimal physical, mental and social health and well-being for all infants, children, adolescents, and young adults. American Academy of Pediatrics, Policy Statement on Palliative Care for Children:

[www.aappolicy.aappublications.org/cgi/content/full/pediatrics;106/2/351](http://www.aappolicy.aappublications.org/cgi/content/full/pediatrics;106/2/351)

### **American Academy of Hospice and Palliative Medicine (AAHPM)**

[www.aahpm.org](http://www.aahpm.org)

Organization of physicians and other medical professionals that is dedicated to excellence in palliative medicine, the prevention and relief of suffering among patients

and families by providing education and clinical practice standards, fostering research, facilitating personal and professional development of its members, and public policy advocacy.

**American College of Obstetricians and Gynecologists**

[www.acog.org](http://www.acog.org)

Advocacy, education, information, and practice management guidelines for women's reproductive health care.

**Association of Death Education and Counseling (ADEC)**

[www.adec.org](http://www.adec.org)

A professional organization dedicated to promoting excellence and recognizing diversity in death education, care of the dying, grief counseling, and research in thanatology (the study of dying, death, and bereavement.) Based on quality research and theory, the association provides information, support and resources to its international, multicultural, multidisciplinary membership and through it, to the public. Past issues of the ADEC newsletter, *The Forum*, are available online, [www.adec.org/publications/archive.cfm](http://www.adec.org/publications/archive.cfm)

**Association of Women's Health, Obstetric and Neonatal Nurses**

[www.awhonn.org](http://www.awhonn.org)

AWHONN professional resources and support empower nurses to provide superior evidence-based care to newborns and to women throughout the lifespan.

**Association of SIDS and Infant Mortality Programs (ASIP)**

[www.asip1.org](http://www.asip1.org)

Promoting leadership in bereavement services and maternal and child health since 1987, ASIP directs the National SIDS and Infant Death Project IMPACT to help disseminate risk-reduction and bereavement information across the country, house massive amounts of information on their website, produce provider guidelines that are distributed nationwide, and provide networking opportunities for their members via conferences and newsletters.

**Bereavement Services (RTS)**

[www.bereavementservices.org](http://www.bereavementservices.org)

Provides over 50 support materials (24 are also in Spanish) to facilitate compassionate bereavement care for families who've experienced early pregnancy loss, stillbirth, or newborn death. Bereavement Services also offers training for health professionals in all disciplines who interact with bereaved parents.

**Canadian Network of Palliative Care for Children**

[www.CNPCC.ca](http://www.CNPCC.ca)

This network addresses issues unique to palliative and end-of-life care for children. Facilitates standards development, advocacy, and education, and raises awareness of pediatric palliative care.

**Children's Project on Palliative/Hospice Services (ChiPPS)**

[www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)

Initiated by the National Hospice and Palliative Care Organization, this project is working to concretely enhance the science and practice of pediatric hospice and palliative care, and to increase the availability of state of the art services to families. Quarterly

newsletter. Issues in 2007 focus on perinatal death and bereavement.

<http://www.nhpc.org/i4a/pages/Index.cfm?pageID=4657>

### **Children's Hospice and Palliative Care Coalition**

[www.childrenshospice.org](http://www.childrenshospice.org)

Places priority on the holistic needs of the entire family when a child is diagnosed with a life-threatening condition. They collaborate with hospitals and community organizations in the work to ensure that children get comprehensive medical treatment, including palliative care at all stages, and that families receive the emotional and spiritual support they need to hold onto hope, whether they are hoping for a cure or for a peaceful death. Membership is free and networking encouraged.

### **Compassionate Passages**

[www.compassionatepassages.org](http://www.compassionatepassages.org)

Provides advocacy, education and research to assist families, healthcare practitioners & students, and the community in being supportive during and after the death of a child. Contact to order the award-winning educational film, *When a Child is Dying*, and *The Supportive Care Handbook*.

### **Creative Health Care Management**

<http://www.chcm.com/index.htm>

Creative Health Care Management provides consulting services on an international level, specializing in the design and implementation of resource-driven, evidence-based patient care delivery systems. They provide leadership, staff and team development and work process improvements consistent with ANCC Magnet status and JCAHO standards. Check out their website for services, conferences, workshops, resources, and ideas for increasing quality care and patient satisfaction, staff collaboration and retention, inspired leadership, and cost efficiency.

### **DIA Learning**

[www.dialearning.com](http://www.dialearning.com)

An Internet based continuing education service, producers of a set of medical ethics DVD programs, including "Born Too Soon: Life and Death in the NICU." DIA is accredited by the AMA, ACCME and AMA's Physician's Recognition Award as a provider of category 1 CMEs. Companion website [www.grievingforbabies.org](http://www.grievingforbabies.org).

### **End-of-Life Nursing Education Consortium (ELNEC)**

[www.aacn.nche.edu/elneec](http://www.aacn.nche.edu/elneec)

A comprehensive, national education program to improve end-of-life care by nurses. The project's goals are to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care.

### **First Candle**

[www.firstcandle.org](http://www.firstcandle.org)

A national nonprofit health organization uniting parents, caregivers, and researchers nationwide with government, business, and community service groups to advance infant health and survival.

### **Grieving for Babies**

[www.grievingforbabies.org](http://www.grievingforbabies.org)

From DIA Learning, Grieving for Babies offers DVDs that are designed to support and inform grieving families and the practitioners who work with them.

### **Human Milk Banking Association of North America**

Education and advocacy about the value of human donor milk banking, including the therapeutic value for some bereaved mothers. For a mother's account, see page 4 in this newsletter link: [http://www.hmbana.org/downloads/2006Jan\\_newsletter.pdf](http://www.hmbana.org/downloads/2006Jan_newsletter.pdf)

### **Institute for Family-Centered Care**

[www.familycenteredcare.org](http://www.familycenteredcare.org)

Promotes the understanding and practice of patient- and family-centered care, and seeks to ensure that principles of family-centered care are reflected in all systems providing care and support to individuals and families including health, education, mental health, and social services. Provides services, workshops, annual conference, and resources.

### **International Stillbirth Alliance (ISA)**

[www.stillbirthalliance.org](http://www.stillbirthalliance.org)

Coalition of organizations dedicated to understanding the causes and prevention of stillbirth, raising awareness, and facilitating research

### **The Kenneth B. Schwartz Center**

[www.theschwartzcenter.org](http://www.theschwartzcenter.org)

Initiated at Massachusetts General Hospital in 1997, The Schwartz Center Rounds are a multidisciplinary forum where health care practitioners gather to discuss important emotional and relational issues and share their experiences, thoughts, and feelings about working with seriously ill patients. The Center conducts pioneering programs to educate, train and support caregivers in the art of compassionate health care, and has successfully replicated the at dozens of hospitals around the country.

### **March of Dimes**

[www.marchofdimes.com](http://www.marchofdimes.com)

Since 1958, this organization's mission has been to improve the health of babies by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy.

### **National Association of Neonatal Nurses**

[www.nann.org](http://www.nann.org)

The advocate and leading change agent for the neonatal nursing profession to optimize care for neonates and their families.

### **National Association of Perinatal Social Workers**

[www.napsw.org](http://www.napsw.org)

Incorporated in 1980 as a community of social workers sharing knowledge about the psychological issues that emerge during the period of pregnancy through the first year of life, and striving for excellence in practice for the benefit of families.

### **\*National Association of Black Social Workers**

[www.nabsw.org](http://www.nabsw.org)

NABSW was established in 1968 to advocate and address important social issues that impact the health and welfare of the Black community.

### **\*National Society of Genetic Counselors**

[www.nsgc.org](http://www.nsgc.org)

The leading voice, authority and advocate for the genetic counseling profession, focusing on health care delivery, education, research and public policy.

### **\*National Black Nurses Association**

[www.nbna.org](http://www.nbna.org)

Founded in 1971, the NBNA's mission is to provide a forum for collective action by black nurses to investigate, define and advocate for the health care needs of African Americans and to implement strategies that ensure access to health care, equal to, or above health care standards of the larger society.

### **\*National Perinatal Association**

[www.nationalperinatal.org](http://www.nationalperinatal.org)

NPA is dedicated to the promotion of health care and public policy which ensures the optimal health and long-term development for mothers, infants and children.

### **National SIDS/Infant Death Resource Center**

[www.sidscenter.org](http://www.sidscenter.org)

Carries out clearinghouse activities on sudden infant death syndrome, including the collection and dissemination of information to the public, health and educational institutions, professional organizations, and voluntary groups.

### **National Hospice & Palliative Care Organization (NHPCO)**

[www.nhpco.org](http://www.nhpco.org)

A nonprofit membership organization representing hospice and palliative care programs and professionals in the United States, and committed to improving end-of-life care and expanding access to hospice care.

### **Perinatal Hospice**

[www.perinatalhospice.org](http://www.perinatalhospice.org)

Offers a list of perinatal hospice programs in North America and Europe, FAQ's, and other resources for parents and practitioners.

### **Pregnancy Loss and Infant Death Alliance (PLIDA)**

[www.plida.org](http://www.plida.org)

A nonprofit membership organization that promotes awareness about the emotional aspects of perinatal bereavement, advocates for comprehensive and compassionate care for parents, and offers information and support for practitioners who work with bereaved families.

### **PubMed**

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed>

From the National Center for Biotechnology Information, a service of the National Library of Medicine and the National Institutes of Health, PubMed includes over 17 million citations from MEDLINE and other life science journals for biomedical articles back to

the 1950s. PubMed includes links to abstracts, full text articles, and other related resources. A great place to search for professional articles pertaining to your area of interest.

**Wisconsin Stillbirth Service Program**

[www.wisc.edu/wissp](http://www.wisc.edu/wissp)

Promotes awareness, education, and research on stillbirth, and offers information and support to parents and health care practitioners. The resource bibliography is available in a paper copy and can be sent to anyone requesting it.

Inquire at <http://www.wisc.edu/wissp/webpag11.htm>