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.

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.


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.


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.


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.


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.


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


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.


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.


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)


### 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.


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.

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.


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)


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.

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.


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.


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.


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.


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.


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.


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.

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.


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.


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.

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 with 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.


**Subsequent Pregnancy and Parenting**

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


~ 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

- A comprehensive reference list on perinatal hospice is available at
  www.perinatalhospice.org

- For paper copies of extensive bibliographies on perinatal death and bereavement issues, contact Wisconsin Stillbirth Service Project, 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

- 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
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](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](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.”*


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.


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.juns.nursing.arizona.edu/articles/Fall%202006/horning.htm


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.


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


**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](http://www.cdc.gov/nchs/hus.htm)


**Canada**

Statistics Canada
Vital Statistics - Stillbirth Database Table 8
[http://www.statcan.ca/english/freepub/84F0210XE/2005001/technote5.htm](http://www.statcan.ca/english/freepub/84F0210XE/2005001/technote5.htm)

List of summary tables
[http://cansim2.statcan.ca/cgi-win/cnsmcgi.pgm?Lang=E&SP_Action=Result&SP_ID=3871&SP_TYP=5&SP_Sort=1](http://cansim2.statcan.ca/cgi-win/cnsmcgi.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](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](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

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

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

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 BridgeTo Hope*
Produced by Bereavement Services, 2006, 7 mins.
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

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*

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. 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%20Users%20Guide.pdf](http://www.parentingyourprematurebaby.com/CCMD%20Neonatal%20Video%20Users%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](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

~ 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](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  
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  
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  
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  
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  
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**
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
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
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.nowilaymewedontosleep.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
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
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.

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

Professional, Educational, and Advocacy Organizations

American Academy of Pediatrics (AAP)
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

American Academy of Hospice and Palliative Medicine (AAHPM)
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

Children's Hospice and Palliative Care Coalition
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
Provides advocacy, education and research to assist families, healthcare practioners & 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
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.

End-of-Life Nursing Education Consortium (ELNEC)
www.aacn.nche.edu/elnec
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
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
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

Institute for Family-Centered Care
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
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
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
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
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
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  
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  
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  
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  
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.sidscouncil.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  
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  
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  
A nonprofit membership organization the 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  
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/webpaq11.htm](http://www.wisc.edu/wissp/webpaq11.htm)