Websites

Life-Limiting Perinatal Diagnoses

- <u>Alexandra's House</u> Peer support perinatal hospice program
- <u>Anencephaly</u> Information, facts, personal stories, pictures submitted by families.
- <u>Be Not Afraid</u> Private non-profit corporation whose mission is to provide comprehensive, practical, and peer-based support to parents experiencing a prenatal diagnosis and carrying to term.
- <u>Caring Bridge</u> Free, personalized websites that parents can create to keep loved ones informed of their babies' progress.
- <u>Carrying To Term</u> Support and tools for carrying a pregnancy with a poor prenatal diagnosis to term.
- <u>Cherishing the Journey</u> Comfort and guidance to families carrying a pregnancy with a poor prenatal diagnosis.
- <u>Isaiah's Promise</u> Christian support for families with a poor prenatal diagnosis.
- <u>Made, Born, and Carried: Lessons from Porter Gray</u> Christian-based blog written by a family whose unborn baby was been diagnosed with Trisomy 13.
- <u>Now I Lay Me Down to Sleep</u> Bereavement photography group providing photo sessions for families and their newly born babies who are stillborn or have life-limiting conditions.
- <u>Perinatal Hospice & Palliative Care -</u> Resources, links, book suggestions. Offers expectant parents and family members support and grief counseling throughout the mother's pregnancy and the birth and death of the baby.
- <u>Poor Prenatal Diagnosis</u> Information for families facing decisions following a poor prenatal diagnosis.
- <u>Recapture My Heart</u> A palliative care journey for a family with a diagnosis of anencephaly.
- <u>The Little Green Family</u> Blog written by a family whose daughter was diagnosed with Trisomy 13.
- <u>Sufficient Grace Ministries</u> Christian support offering comfort, encouragement and hope following a poor prenatal diagnosis.
- <u>Tiny Treasure in Heaven</u> Christian-based blog site written by a couple whose son was born with Potter's Syndrome (bilateral renal agenesis).

Infant and Perinatal Loss (General)

- <u>Babies Remembered</u> Understanding, healing and information from author, Sherokee Ilse.
- <u>Bereaved Parents of the USA</u> National non-profit self-help group offering support and understanding for the loss of a child
- <u>Goodgrief App</u> Launched in 2018, new members create profiles based on the loss they suffered, and then can initiate or accept conversations with others via in-app texting. Their opening sentences often sound almost identical: "I'm here for support," is typical.

These are moms whose babies died during birth. Men whose wives didn't survive cancer. Sisters who found a sibling post-suicide. Spouses in the aftermath of divorce. Children who lost parents.

- <u>Grieve Out Loud</u> support from bereaved parents for bereaved parents, including a Pen Pal program.
- <u>H.A.N.D. (Helping After Neonatal Death)</u> Helps parents, their families, and their healthcare providers cope with the loss of a baby before, during or after birth.
- <u>HopeXchange</u> Offers information, educational and uplifting articles, booklets, pamphlets, books, miscarriage FAQs, extensive list of links and resources, and free monthly newsletter.
- <u>Love & Loss Project</u> The Love & Loss Project offers free virtual monthly Retreats, healing programs & private sessions for women and couples across the globe.
- <u>M.E.N.D.</u> (Mommies Enduring Neonatal Death) Works hand-in-hand with healthcare providers to improve patient encounters and care in the midst of the painful experience of a miscarriage, stillbirth or infant loss.
- <u>M.I.S.S. Foundation</u> Mothers In Sympathy and Support (MISS) Foundation is dedicated to supporting parents one to one after the death of an infant or young child. Referrals to peer contacts and ancillary organizations are offered.
- <u>Missing G.R.A.C.E. Foundation</u> A national nonprofit organization that provides education and bereavement materials for Professional Care Providers as well as resources and support for families that have experienced a pregnancy loss, infant loss, infertility or adoption. The heart of the mission of G.R.A.C.E. is helping families Grieve, Restore, Arise, Commemorate and Educate.
- <u>Pregnancy After Loss Support (PALS)</u> Non-profit organization and community support resource for women experiencing the confusing and conflicting emotions of grief mixed with joy during the journey through pregnancy after loss. We seek to help expectant mothers celebrate their current pregnancy by choosing hope over fear while still nurturing and honoring the grief over the loss of their deceased child.
- <u>Return to Zero Center for Healing</u> Transforming the culture of pregnancy and infant loss through: Healing Retreats, Outreach and Education, Peer Support and Community, and Empowerment.
- <u>Rock Goodbye Angel</u> Grief support videos are on their YouTube channel for free. A Facebook live support check in available on Wednesdays and Sunday's. Pastoral counseling services are also available via phone or FaceTime (at a reduced rate during the time of the COVID-19 pandemic).
- <u>Saying Goodbye</u> Information, advice and support for the loss of a pregnancy or infant (UK based website).
- <u>SHARE Pregnancy and Infant Loss (National)</u> Serving those whose lives are touched by the tragic death of a baby through pregnancy loss, stillbirth or in the first few months of life; providing support toward positive resolution of grief experienced at the time of or following the death of a baby. This support encompasses emotional, physical, spiritual, and social healing, as well as sustaining the family unit.
- <u>Stillbirthday</u> The mission of the Stillbirthday Global Network is to validate a pregnancy loss as the birth, and death, that it is. We do this in part through printable birth plans and doulas who can support families in person prior to, during, or after birth. We aim to come

alongside families from the very beginning of their parenting journey, whether through rearing or grieving, and provide support for birth in any trimester.

- <u>Still Standing Magazine</u> A collection of articles by bereaved parents with support for mothers, fathers, grandparents, and with topics including mental health and infertility.
- <u>Through the Heart</u> Online support and resources including comfort kits, education and remembrance wall.

Infant and Perinatal Loss (Blogs)

- <u>A Baby Carly Story</u> Mom who delivered her stillborn daughter at Northside.
- <u>A Blog for Fathers When a Baby Dies</u> for fathers who lose a baby.
- Chasing Rainbows, H.E.A.R.T.strings Perinatal Bereavement & Palliative Care Blog
- <u>Holding Harrison A mom's encouraging insight about the loss of her son.</u>
- <u>Pregnancy Journeys After Loss</u>: "The birth of a child isn't always a nine-month process."
- <u>Pregnant with Hope</u> Faith-based infertility and loss support.
- <u>Recapture My Heart</u> A palliative care journey for a family with a diagnosis of anencephaly.

Lactation After Loss

- <u>Helping Hands Milk Bank</u> Serves as a resource for donation across the United States.
- <u>Human Milk Banking Association of North America</u> Organization that believes in a world where all infants have access to human milk through support of breastfeeding and use of donor human milk.

Living Childless After a Loss

• <u>Still Mothers: Living Childless After a Loss</u> - Still Mothers is a community and support resource for women who are living a childless life after the death of their only child(ren). We support all mothers who have faced loss due to miscarriage, stillbirth, neonatal death, infant death, as well as any other form of child loss.

Loss of Multiple

- <u>C.L.I.M.B. (Center for Loss in Multiple Birth)</u> Parents throughout the United States, Canada, Australia, New Zealand and beyond who have experienced the death of one or more, both or all of our twins or higher multiples at any time from conception through birth, infancy and childhood.
- <u>Forever Angels: Loss in the Womb -</u> Discussion board for parents losing one, more or all multiple birth children.
- <u>TwinList.org</u> Support for parents who have lost one or all of a set of multiples.

Medical Termination

- <u>Baby Center: Termination for Medical Reasons Group</u> Online support group for those terminating a pregnancy based on medical reasons.
- <u>Ending a Wanted Pregnancy</u> Provides abortion grief support after pregnancy termination for medical reasons, whether a decision was based on a poor prenatal diagnosis or maternal health problems.
- <u>A Heartbreaking Choice</u> Offers complete, unconditional support for women who have terminated a much wanted pregnancy due to a poor prenatal diagnosis, a severe or terminal fetal anomaly, a selective reduction, or for the health of the mother.

Miscarriage

- <u>Baby Center: Understanding Miscarriage</u> This website has information on all kinds of loss. Trigger alert it is also a general pregnancy site.
- <u>Facts About Miscarriage: Information, Healing and Hope -</u> A mom's personal perspective on baby loss and miscarriage.
- <u>March of Dimes: Complications & Miscarriage -</u> Information from the March of Dimes on miscarriage.
- <u>Miscarriage Association</u> Information and support following miscarriage, molar pregnancy or ectopic. Also has remembrance page to add your baby's name to a star.

SIDS & Infant Loss

• <u>Infant Loss Resources</u> - SIDS/sleep related loss

Stillbirth

- <u>First Candle</u> Organization dedicated to reducing the rates of stillbirth and SIDS.
- <u>The International Stillbirth Alliance (ISA)</u> The International Stillbirth Alliance (ISA) is an alliance of member organizations and individual supporters working towards stillbirth prevention and improvement of bereavement care worldwide.
- <u>Star Legacy Foundation</u> Community of health professionals, researchers, families, policy makers and advocates dedicated to healthy pregnancy outcomes and stillbirth prevention.

Books

Infant and Perinatal Loss (General)

- <u>Abby: A Mother's Memoir of Losing One Daughter and Being Saved by</u> <u>Another</u> (Stember) Abby is an honest, introspective memoir of Abby's stillbirth and its emotional aftermath. Abby is also a celebration of the author's other daughter, Peyton, whose small voice and tender heart pulled her over incredible obstacles and gave her peace and hope during their family's darkest time.
- <u>A Broken Heart Still Beats: After Your Child Dies</u> (Hurcombe) Compilations of poetry, fiction, and essays eloquently expresses a parent's pain, stages of grief, and the coping and healing that follow (not specific to perinatal loss).
- <u>A Gift of Time</u> (Kubelbeck and Davis) A Gift of Time is a gentle and practical guide for parents who decide to continue their pregnancy knowing that their baby's life will be brief. When prenatal testing reveals that an unborn child is expected to die before or shortly after birth, some parents will choose to proceed with the pregnancy and to welcome their child into the world. With compassion and support, A Gift of Time walks them step-by-step through this challenging and emotional experience—from the infant's life-limiting prenatal diagnosis and the decision to have the baby to coping with the pregnancy and making plans for the baby's birth and death.
- <u>Anna, a Daughter's Life</u> (William Loizeaux) is a journal of memories and remembrances written by the father of a baby girl who died from VATER Syndrome when she was several months old.
- <u>Bittersweet...hello goodbye. A Resource in Planning Farewell Rituals when a Baby</u> <u>Dies</u> (edited by Lamb) Guidance and specific suggestions for creating a meaningful memorial service.
- <u>Couple Communication After a Baby Dies</u> (Sherokee Ilse and Tim Nelson) provides insight into the differences and similarities of men and women who grieve. The book includes the stories of two "imperfect couples" (the Ilse's and the Nelson's) who have endured 20+ years since their babies have died. The book also includes a mini-workbook of conversation starters. Ilse has written over 17 books and booklets on loss and has worked with numerous infant loss organizations. Nelson is the author of A Father's Story as well as "A Guide for Father's When a Baby Dies" and co-founded A Place to Remember publishing company.
- <u>Creating Meaningful Funeral Ceremonies: A Guide for Families</u> (Wolfelt) Practical ideas for creating authentic, personalized, and meaningful funeral ceremonies.
- Empty Cradle, Broken Heart (Davis) The heartache of miscarriage, stillbirth, or infant death affects thousands of U.S. families every year. Empty Cradle, Broken Heart offers reassurance to parents who struggle with anger, guilt, and despair after such tragedy. Deborah Davis encourages grieving and makes suggestions for coping. The book includes information on issues such as the death of one or more babies from a multiple birth, pregnancy interruption, and the questioning of aggressive medical intervention. There is also a special chapter for fathers as well as a chapter on "protective parenting" to help anxious parents enjoy their precious living children. Doctors, nurses, relatives, friends, and other support persons can gain special insight. Most importantly, parents facing the death of a baby will find necessary support in this gentle guide. If reading this book moves you to cry, try to accept this reaction. Your tears merge with those of other grieving parents. You are not alone!
- <u>Ended Beginnings</u> (Panuthos & Romeo) Infertility, miscarriage, sudden infant death, abortion, adoption, premature or traumatic birth, and help for grieving children.

- <u>Goodbye My Child</u> (Wheeler & Pike) Guide for newly bereaved parents. Talks about funeral planning, differences in losses, the five phases of mourning, men and women grief, grandparents, your other children, family and friends and picking up the pieces.
- <u>Help, Comfort, and Hope after Losing Your Baby in Pregnancy or the First</u> <u>Year</u> (Lothrop) Miscarriage, stillbirth, neonatal death, sudden infant death, and termination of pregnancy.
- <u>Hope is Like the Sun</u> (Church) Follow the author and four of her friends as they navigate the difficult journey through pregnancy loss.
- Losing Malcolm: A Mother's Journey Through Grief (Carol Henderson) tells the story of their son who was diagnosed three days after birth with a heart problem. Malcolm ends up dying after an emergency surgery. Along with her expression of intense grief, most readers will relate to Henderson's accompanying feelings of inadequacy and guilt. Along that path she experienced mindless numbness, frustration, resentment of other women with their children, fear of her own body, and rage at people who dismissed her loss. Even when she became pregnant again, she felt that the new baby was "floating in a womb of tears." And yet she had the wisdom to embrace all these reactions as natural aspects of the grieving process.
- <u>Mourning Sickness</u> (edited by Martin & Loren) 49 contributors (many of them awardwinning writers) share their personal journeys through miscarriage, stillbirth and infant death.
- <u>Planning a Precious Goodbye</u> (Ilse & Martinez) Specific suggestions for creating a meaningful memorial service for their baby who has died.
- <u>Silvie's Life: Biography of a Baby Girl</u> (Marianne Rogoff) Imagine a joyous, healthy pregnancy, a well-thought out birth plan, a normal labor, a baby who doesn't cry, who lies limp on her mother, and is raced by helicopter to a hospital with an intensive care nursery. There the nightmare becomes reality, a baby born with severe brain damage, with no identifiable cause. One week after Silvie's birth, her parents are advised to take her home to die. The doctors guessed that she would die in a few days; those days stretched into weeks, accumulated into months. Rogoff's luminous memoir details the conflicting emotions she and her husband felt as they continuously braced themselves for their baby's death. Her descriptions of living in limbo, trying to balance hope with reality, are powerful.
- <u>The Good Grief Club</u> (Novak) The Good Grief Club is the true story of seven women who discover that their new friendships have the power to heal the pain of losing their babies in miscarriage, stillbirth, and infant death. One by one, fate weaves their lives together in the wake of tragedy misunderstood by those around them. Set around support group meetings and restaurant rendezvous, these seven soul sisters find a new normal. Through tears and anger, compassion and laughter, late nights and French toast, the sun slowly emerges from the darkness bringing with it love, hope, and healing as, together, they rebuild their lives.
- <u>Waiting with Gabriel</u> (Amy Kuebelbeck) tells the journey of the author and her family as they prepare to deliver their baby boy who was diagnosed before birth with a fatal heart malformation.
- <u>When a Child Dies: A Resource for Families</u> (Charles & Ciepielinski) They cover everything from funeral & memorial planning to helping surviving siblings; from

announcements to thank you cards; from support for parents to tips on how family, friends, caregivers can actually be helpful.

• <u>When a Meeting is Also a Farewell</u> (Ingela Radestad) is about the author's first child Ellen who died shortly before birth. As a midwife and now mother of three, she wrote a book to help parents and those around them cope with the death of a very young child in a sensitive yet realist way. The book includes personal interviews, letters, and poems as well as guidelines and suggestions for healthcare providers.

Difficult Decisions During Pregnancy

Some of these books may be helpful during the decision-making process related to termination of pregnancy due to poor prenatal diagnosis (fetal abnormalities or life-limiting diagnoses).

- <u>A Time to Decide, A Time to Heal (Minnick)</u> For parents making difficult decisions about babies they love. Written by mothers and fathers who have faced the news of fetal anomaly with grief and courage. Looks at the steps involved in the decision to continue or to end the pregnancy, with the book's real strength (and largest portion) being in the comprehensive approach it takes to healing grief after a decision to terminate is made.
- <u>Beyond Prenatal Choice</u> (MacMillin) Written for individuals who find out, through prenatal diagnosis, that their baby has an abnormality, and who have made the difficult and selfless decision to terminate the pregnancy.
- <u>Ended Beginnings</u> (Panuthos & Romeo) Infertility, miscarriage, sudden infant death, abortion, adoption, premature or traumatic birth, and help for grieving children.
- <u>Loving and Letting Go</u> (Davis) This books is designed for parents who decide to reject aggressive medical intervention for their critically ill newborns. It includes chapters on facing the decision, the dilemmas of withdrawing artificial support and a gentle final chapter, "Letting Go With Love."
- <u>Our Heartbreaking Choices</u> (edited by Brooks) 46 women share their stories of terminating a much-wanted pregnancy.

Miscarriage

- <u>After Miscarriage: A Journey to Healing</u> (Leo): Women who have lost a child due to miscarriage are all too often expected to go quietly on with their lives and never speak of "it" again. Lori Leo was one of those women who struggled in silence with her grief. But after suffering 4 miscarriages in two years, Lori began to speak openly about her loss and reach out to women. She shares her journey into adoption and her advice on living life in a world full of children including responding to hurtful comments, using support groups and remembering your baby.
- <u>After Miscarriage: Medical Facts & Emotional Support</u> (Danielsson) Medical and emotional issues that may accompany miscarriage, including when to seek testing, how to choose the right doctor, when to try for another pregnancy, and how to deal with anxiety.
- <u>Embracing a Loss from Sorrow to Acceptance</u> (Elisa Carrillo Baldry) is a journal "companionway" that provides tools for working through grief. It includes the author's own poems and personal thoughts, but it also gives the reader journaling prompts. This may be particularly helpful to those who wish to journal but are not sure how to begin.

- <u>Hidden Loss : Miscarriage and Ectopic Pregnancy</u> (Edited by Hay) Personal accounts of a number of women, offering insight into the emotional and medical effects, and studying the processes of grieving and recovery.
- <u>Miscarriage, Medicine, & Miracles</u> (Young & Zavatto) Guide for women and their partners.
- <u>Motherhood after Miscarriage</u> (Diamond) Myths and realities associated with miscarriage, summaries of the known and suspected causes of single and recurrent miscarriage, the pros and cons of hormone treatments and in vitro fertilization, miscarriage risks for prospective mothers over 35.
- <u>Miscarriage: What Every Woman Needs to Know (Regan)</u> Professor Lesley Regan is the first woman to hold a chair on obstetrics and gynecology in the country and for the past decade she has worked to establish the biggest miscarriage clinic in the world. This book gives up-to-date information on the many causes of miscarriage and the latest treatments available.
- <u>Miscarriage: Women Sharing from the Heart</u> (Allen & Marks) The personal stories of 100 women talking about their miscarriage experiences, interviews with fathers on how they have been affected, and advice for partners, family members, and health care professionals.
- <u>Our Stories of Miscarriage</u> (edited by Faldet & Fitton) Fifty contributors, including four men, share vivid accounts of how miscarriage has affected their lives.
- <u>To Full Term: A Mother's Triumph Over Miscarriage (Klein)</u> The author's account of her pregnancy after experiencing three miscarriages

Stillbirth

- Forever Silent, Forever Changed (Davis) A mother writes about her son that was stillborn
- <u>Life Touches Life: A Mother's Story of Stillbirth and Healing</u> (Northrup) A mother's account of the birth of her full-term baby who was stillborn due to a Group-B Strep infection.
- <u>Ghostbelly</u> (Heineman) A mother writes about her full-term son unexpectedly still born.

Pregnancy After Loss

- <u>An Exact Replica of a Figment of My Imagination</u> (McCracken) Touching and often unexpectedly funny memoir about the author's life before and after losing her first child in the ninth month of pregnancy. "I'm not ready for my first child to fade into history," explains McCracken as she talks about her next pregnancy.
- <u>Another Baby? Maybe, Thirty Most Frequently Asked Subsequent Pregnancy</u> <u>Questions</u> (Ilse & Doerr) The authors who have lived through a number of pregnancies after their own losses, share the most common concerns, issues and questions parents face when considering another pregnancy and living through it.
- Journeys: Stories of Pregnancy After Loss (Abbey) The stories of almost a dozen families - how the families coped with loss and went on to have successful pregnancies
- <u>Pregnancy after a Loss</u> (Lanham) Helps women to prepare, both psychologically and physically, for a new pregnancy.

- <u>Pregnancy after Loss</u> (Warland) Addresses fears for those preparing or already pregnant after miscarriage, stillbirth, neonatal death or SIDS.
- <u>Someone Came Before You</u> (Schwiebert) For children when the baby they are waiting for dies and for the child who comes after the one who died.
- <u>Still To Be Born</u> (Schwiebert) Talks openly about whether or not to get pregnant again, and factors that should be considered before that decision is made
- <u>Trying Again: A Guide to Pregnancy After Miscarriage, Stillbirth, and Infant</u> <u>Loss (Douglas, Sussman, & Davis) Provides facts to help determine whether you, or your</u> partner, are emotionally ready for another pregnancy
- <u>When Pregnancy Follows a Loss: Preparing for the Birth of Your New Baby</u> (O'Leary & Thorwick) A compilation of families' experiences