

APPENDIX C

Resources

Books

These are books we've discovered, read, recommended to others, and in many cases, used ourselves. They all offer additional advice, wisdom, and encouragement in a variety of areas which you may encounter on your journey of parenting your preemie. When reading any book (including this one!), embrace what you find helpful, and pass by whatever isn't. This is not an exhaustive list—keep your eyes and ears open for other books that offer you support, insights, and solutions. And if you like a particular author, look into other books they may have written.

Books for Parents of Premies

While most of these books give a nod to the emotional elements, they mainly focus on the medical and caregiving issues you face with your preemie. Some focus on the time in the NICU; others focus on what you need to know after homecoming; some deal with both.

Bradford, N. *Your Premature Baby: 0 – 5 Years*. Westport, Conn.: Firefly Books, 2003.

Garcia-Prats, J. A. and S. S. Hornfischer. *What to Do When Your Baby Is Premature: A Parent's Handbook for Coping with High-Risk Pregnancy and Caring for the Preterm Infant*. New York: Times Books, 2000.

Harrison, H. with A. Kositsky. *The Premature Baby Book: A Parents' Guide to Coping and Caring in the First Years*. New York: St. Martin's Press, 1983. (A classic, the first big book for parents of preemies that invited them into the NICU and encouraged them to be an informed advocate for their babies.)

Klein, A. H. and J. A. Ganon. *Caring for Your Premature Baby: A Complete Resource for Parents*. New York: HarperCollins, 1998.

Linden, D. W., E. T. Paroli, and M. W. Doron. *Preemies: The Essential Guide for Parents of Premature Babies*. New York: PocketBooks, 2000.

Luddinton-Hoe, S. M. and S. K. Golant. *Kangaroo Care: The Best You Can Do to Help Your Preterm Infant*. New York: Bantam Doubleday Dell, 1993. (The classic that illuminates the origins, practice, and profound benefits of skin-to-skin contact between preemies and parents.)

Madden, S. L. *The Premie Parents' Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and through the First Years*. Cambridge: Harvard Common Press, 2000.

Manginello, F. P. and T. F. Digeronimo. *Your Premature Baby: Everything You Need to Know about the Childbirth, Treatment, and Parenting of Premature Infants*. Rev. ed. New York: John Wiley and Sons, 1998.

Resta, B. *Believe in Katie Lynn*. Nashville: Eggman Publishing, 1995. (A children's picture book—beautifully illustrated, heartfelt story about the powers of developmentally supportive care in the NICU. See also under “Books for Children.”)

Sears, W., R. Sears, J. Sears, and M. Sears. *The Premature Baby Book: Everything You Need to Know about Your Premature Baby from Birth to Age One*. Boston: Little, Brown and Company, 2004. (Taking care of your preemie, with an emphasis on “attachment parenting” and the responsive practices that strengthen your relationship with your baby.)

Tracy, A. E., D. I. Maroney, et. al. *Your Premature Baby and Child: Helpful Answers and Advice for Parents*. New York: Berkley, 1999. (A complete handbook on taking care of your preemie after hospital discharge.)

Zaichkin, J. *Newborn Intensive Care: What Every Parent Needs to Know*. Petaluma, Calif.: NICU Ink, 1996. (A big and thorough book detailing physical and developmental conditions associated with prematurity and medical treatments in the NICU.)

For Bereaved Parents

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.)

Chethik, N. *FatherLoss: How Sons of All Ages Come to Terms with the Deaths of Their Dads*. New York: Hyperion, 2001. (Beautiful, lucid exploration and accounts of men's experiences with grief. Written for men, about men, by a man. Affirming. See also under "General Emotional Adjustment.")

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.)

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 intertwine when a child is dying.)

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.)

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 preemie parent, author of *Born Too Soon*, which is listed in "Medical Ethics.")

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.)

Staudacher, C. *Men and Grief: A Guide for Men Surviving the Death of a Loved One*. Oakland, Calif.: New Harbinger Publications, 1991. (Examines the ways men grieve; encourages men to face feelings.)

Medical Ethics

These books support the parent's right to be involved in medical life-and-death decision making for their newborns, as well as the idea that some fates are worse than death. Many of them are beautifully written personal accounts that can offer you affirmation and reassurance around these heart-wrenching decisions.

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.)

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.)

Belkin, L. *First Do No Harm*. New York: Simon and Schuster, 1993. (Medical ethics and decision making.)

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.)

Davis, D. L. *Fly Away Home: For Bereaved Parents Who Turned Away from Aggressive Medical Intervention for Their Critically Ill Child*. Omaha: Centering, 2000. (A gentle, affirming book about making and living with the profound decision to refuse aggressive medical intervention for the terminally ill child. Includes a reassuring chapter on parenting the dying child.)

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 about making and living with the agonizing and heartfelt decision to refuse aggressive medical intervention in the NICU.)

Dubler, N. and D. Nimmons. *Ethics On Call: Taking Charge of Life-and-Death Choices in Today's Health Care System*. New York: Vintage Books, 1993. (Medical ethics and decision making. Chapters on newborns and children.)

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

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. She wrote the book from her baby's point of view—which is why it's listed as fiction by the publisher—about their experiences in a British neonatal intensive care unit. While it gives emotional depictions of infant and parent suffering in the NICU, it is also surprisingly comforting in terms of helping the reader see the hope, purpose, meaning, and love that prevails. Because the author imagines and showcases the baby's experience and acceptance of the NICU roller coaster and the medical decisions made, the book can be very reassuring if you are harboring any doubts, whatever your decision or the outcome. Ultimately, it offers the healing perspective that your baby's NICU 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 beautiful book and personal account of the life-and-death decision-making process with a critically ill newborn. 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.)

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.)

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

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.)

General Emotional Adjustment

These books deal more generally with your emotional needs around personal growth, spiritual searching, and your relationships. They support your awareness of your authentic self, and encourage you to reach for emotional health and balance. We've also included a popular women's magazine, because it addresses the search for fulfillment and meaning and encourages you to tap into your own power. For more support around emotional adjustment, also check out the books under "Personal Stories."

Emotional Health, Personal Growth, and Authentic Living

Beck, M. *Finding Your Own North Star: Claiming the Life You Were Meant to Live*. New York: Three Rivers Press, 2002. (How to reconnect with your essential self and regain the capacity to steer your own course toward happiness and fulfillment of your life's true purpose. One of the best "personal coaching" books.)

Boss, P. *Ambiguous Loss: Learning to Live with Unresolved Grief*. Cambridge: Harvard University Press, 1999. (Puts you in touch with the losses that are difficult to identify and mourn, and shows you how to find meaning and peace.)

Chethik, N. *FatherLoss: How Sons of All Ages Come to Terms with the Deaths of Their Dads*. New York: Hyperion, 2001. (Even though this book focuses on men's experiences with grieving the death of a father, it offers supportive insight into

how dads of premature babies react and cope with their losses. See also under “For Bereaved Parents.”)

Goldbart, S. and D. Wallin. *Mapping the Terrain of the Heart: Passion, Tenderness and the Capacity to Love*. Northvale, N. J.: Jason Aronson, Inc., 2001. (Psychodynamic approach, looking at how to form a healthy, fulfilling emotional connection and stay in a lifelong romantic relationship. Written primarily for a professional audience.)

Goleman, D. *Emotional Intelligence*. New York: Bantam, 1995. (The classic that identifies and describes emotional intelligence, a key to living a successful and fulfilling life.)

Hernandez-Hacker, P. and C. Ringo. *Early Passage: A Journal for Parents of Premies*. Petaluma, Calif.: NICU Ink, 2001. (A beautiful book for journaling, constructed specifically for parents of premature babies, with inspiring, comforting messages scattered throughout the pages.)

Krasnow, I. *Surrendering to Motherhood: Losing Your Mind, Finding Your Soul*. New York: Miramax, 1998. (If you can overlook the author’s ease in childbearing and focus on the more personal, developmental journey, this book is a gem about shifting your point of view toward the relative values of and balance between motherhood and career. In fact, a turning point for her was her first-born’s time in a pediatric intensive care unit when he was a toddler, an experience whose telling will resonate with premie parents. It explores the soul-searching evaluation of priorities experienced by many mothers (including the author, an exquisitely entertaining and honest storyteller) and the discovery that you can reorganize your life, focus on motherhood, and find personal fulfillment therein, ultimately realizing that it can actually be satisfying to let your career slow down or be put on hold. This book can inspire you to relax and enjoy the chaos and charm of parenting babies and young children, and stop feeling like you’re “missing out.”)

Krasnow, I. *Surrendering to Yourself: You Are Your Own Soulmate*. New York: Miramax, 2003. (In the author’s wonderful style of personal narrative woven with interviews of others, this book offers inspiring examples of the struggles and

successes of personal growth and discovery, inspiring you to listen to the deepest part of yourself, follow your passions, and live the life you were meant to live.)

Levoy, G. M. *Callings: Finding and Following an Authentic Life*. New York: Three Rivers Press, 1998. (Listening to the healthiest, most essential part of yourself, following your dreams and passions, and finding fulfillment. Full of encouragement and inspiring personal stories.)

Martin, T. L. and K. J. Doka. *Men Don't Cry, Women Do: Transcending Gender Stereotypes of Grief*. New York: Brunner-Routledge, 1999. (Written for professionals; focuses on instrumental and intuitive grieving styles.)

McClure, V. *The Path of Parenting: Twelve Principles to Guide Your Journey*. Novato, Calif.: New World Library, 1999. (A gentle, supportive book on becoming a conscious parent. The twelve principles get to the heart of what's important. Also listed under "Parenting Style and Caregiving.")

Moran, V. *Fit from Within: 101 Simple Secrets to Change Your Body and Your Life—Starting Today and Lasting Forever*. Chicago: Contemporary Books, 2002. (A nurturing, encouraging, empowering book on having a healthy relationship with food and your body.)

Ruiz, D. M. *The Four Agreements: A Practical Guide to Personal Freedom*. San Rafael, Calif.: Amber-Allen Publishing, 1997. (Four simple but empowering principles to help you live your life with love and freedom from unnecessary suffering.)

Seligman, M. E. P. *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*. New York: The Free Press, 2002. (The value of focusing on your signature strengths and optimism; insightful chapters on love and raising children.)

Seligman, M. E. P. *Learned Optimism: How to Change Your Mind and Your Life*. New York: PocketBooks, 1998. (A companion book to M. E. P. Seligman's *The Optimistic Child* (listed under "Supporting Your Premie's Development"), gives you tools you need to be resilient, especially in the face of adversity.)

Siegel, D. and M. M. Hartzell. *Parenting from the Inside Out: How a Deeper Self-Understanding Can Help You Raise Children Who Thrive*. New York: Jeremy P. Tarcher, 2003. (Fascinating book that helps you understand your own tendencies and how to build the kind of relationship with your child that helps him or her become compassionate and resilient. See also under “Supporting Your Premie’s Development” and “Parenting Style and Caregiving.”)

Winfrey, O., ed. *O, The Oprah Magazine*. (Contains many supportive, insightful articles that can help you live your life to the fullest, with emotional intelligence and spiritual awareness.)

Marriage

These books give honest and realistic descriptions of marriage and offer the comfort of knowing that you are not alone when you’re wondering about the state of your partnership. (For improving marriage, see “Relationship Skills.”)

Coleman, J. *Imperfect Harmony: How to Stay Married for the Sake of Your Children and Still Be Happy*. New York: St. Martin’s Press, 2003. (Insightful and supportive, this book offers alternatives to the devastation of divorce. It presents a realistic look at marriage, encourages you to let go of idealized images and unrealistic expectations, and suggests constructive ways to think about your relationship, your past, your needs, your abilities, and your pursuit of happiness.)

If you’re wondering, “Is this it?” or “What if?” these next books are for you:

Krasnow, I. *Surrendering to Marriage: Husbands, Wives, and Other Imperfections*. New York: Hyperion, 2001. (Through the author’s own experiences and interviews of others, she explores the unspoken truths about what it’s really like to be married—to build a life with another person who is ultimately so different from you, to be attracted to someone else, to consider parting—and all the challenge, reward, and compromise marriage entails.)

Viorst, J. *Grown-Up Marriage: What We Know, Wish We Had Known, and Still Need to Know about Being Married*. New York: The Free Press, 2003. (The author’s observations and interviews encourage you to ground your

expectations, endure the ebbs and flows of long-term relationships, and let go of the notion that the grass is greener on the other side.)

Divorce

Allison, S. *Conscious Divorce: Ending a Marriage with Integrity, A Practical and Spiritual Guide for Moving On*. New York: Three Rivers Press, 2001. (Begins with helping you get in touch with your intuition and what you really want, and then walks you through the ways to transform an unhealthy marriage into a healthy divorce.)

Ford, D. *Spiritual Divorce: Divorce as a Catalyst for an Extraordinary Life*. San Francisco: HarperSanFrancisco, 2001. (Empowering whether you're already divorced, in the process, or contemplating it—how to transform the breakdown of your relationship into an opportunity for personal growth, spiritual enlightenment, and emotional renewal.)

Widowhood

Feinberg, L. S. *I'm Grieving as Fast as I Can: How Young Widows and Widowers Can Cope and Heal*. Far Hills, N.J.: New Horizon Press, 1994.

Relationship Skills

Gottman, J. M. and J. DeClaire. *The Relationship Cure: A Five-Step Guide for Building Better Connections with Family, Friends, and Lovers*. New York: Crown Publishers, 2001. (Focuses on forging and maintaining healthy relationships.)

Gottman, J. M. and N. Silver. *The Seven Principles for Making Marriage Work: A Practical Guide from the Country's Foremost Relationship Expert*. New York: Crown Publishers, 1999. (Focuses on how successful marriages work and the ways of relating that build and maintain a healthy relationship.)

Heitler, S. *The Power of Two: Secrets to a Strong and Loving Marriage*. Oakland, Calif.: New Harbinger Publications, 1997. (Focuses on the communication skills that make marriage a supportive and rewarding partnership for both people—how to talk, how to listen, how to have constructive discussions, and how to deal with differences, anger, decision making, and conflict resolution. Rich in details and examples.)

Coping with Uncertainty and Difficult Circumstances; Spirituality

DeBecker, G. *Protecting the Gift: Keeping Children and Teenagers Safe (and Parents Sane)*. New York: Random House, 1999. (Encourages parents to examine their fears in light of the facts and to listen to and trust their intuitions about the safety or danger of particular situations as they arise.)

Jeffers, S. *Embracing Uncertainty: Breakthrough Methods for Achieving Peace of Mind When Facing the Unknown*. New York: St. Martin's Press, 2003. (How to let go of the outcome and trust the process when you are facing change or entering uncharted territory; accepting your destiny, finding treasures in adversity, following your intuition, finding meaning and purpose.)

Katie, B. *Loving What Is: Four Questions That Can Change Your Life*. New York: Harmony Books, 2002. (How to accept reality and live with it in peace. If this approach works for you, it may help you come to terms with the disappointing aspects of delivering and parenting your preemie.)

Remen, R. N. *Kitchen Table Wisdom: Stories That Heal*. New York: Riverhead Books, 1996. (A book of touching true stories that can inspire you to find treasure in adversity.)

Shelton, M. M. *Guidance from the Darkness: The Transforming Power of the Divine Feminine in Difficult Times*. New York: Jeremy P. Tarcher, 2000. (Spirituality; finding meaning in adversity; supportively encourages you to listen to your heart, trust the process, and let go of trying to control the outcome. Inspiring.)

Zukav, G. *The Seat of the Soul*. New York: Simon and Schuster, 1989. (Spiritual searching, meaning of life, basic truths.)

Personal Stories

All of these books are beautifully written by gifted writers, and while they may bring you to tears, they are healing to read. Besides making you feel less alone, these books are honestly written, filled with perspectives and insights that can help you cope with your own struggles. While not all of these books deal specifically with prematurity, they all carry childbearing and parenting themes that you may be dealing with and grieving over, and many come with

the recommendation of other parents of preemies. Keep in mind that even if the details of your situation differ from the author's, the theme of "personal growth" can be meaningful to you. This is not an exhaustive list, so if reading this kind of book helps, we encourage you to find other personal stories that speak to you.

Barsuhn, R. *Growing Sophia: The Story of a Premature Birth*. St. Paul: deRuyter-Nelson Publications, 1996. (The roller coaster of birth, NICU, and homecoming.)

Beck, M. *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*. New York: Times Books, 1999. (Prenatal diagnosis, coming to terms with a child's disability, and learning to find treasures in differences from "the norm.")

Berstein, J. *Loving Rachael: A Family's Journey from Grief*. Pittsburgh: Coyne and Chenoweth, 1988. (Coming to terms with a baby's unfolding disabilities.)

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.)

Gill, B. *Changed by a Child: Companion Notes for Parents of a Child with a Disability*. New York: Doubleday, 1998. (A mom describes her own journey, giving reassurance and guidance to readers along the way.)

Keller, H. *The Story of My Life*. Reissue Edition. New York: Bantam Classics, 1991. (The inspiring story of Helen Keller's triumph in spite of her disabilities and the brilliant instruction, discipline, and support of her teacher, Anne Sullivan, whose high expectations and refusal to pity Helen spurred her to emerge from her dark, silent prison and find her way in the world.)

Kephart, B. *A Slant of Sun: One Child's Courage*. New York: W. W. Norton, 1998. (Becoming a special kind of parent to a child who is "different," dealing with diagnoses of autism and pervasive developmental disorder.)

Seroussi, K. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*. New York: Simon and Schuster, 2000.

(Explores the controversial link between autism and food cravings/sensitivities, but the other focus is on how this mother followed her instincts and became her child's best advocate and detective. See also under "Parenting Challenges.")

Westby, J. *They Will Know They Are Loved: A Family's Life with Premature Twins*.

New York: Kirk House Publishing, 2002. (A father's memoir. Honest, heartfelt, focuses on his baby boys' early birth and his relationships with them as well as with his wife.)

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.)

Zimmermann, S. *Grief Dancers: A Journey into the Depths of the Soul*. Golden,

Colo.: Nemo Press, 1996. (Coming to terms with her child's disabilities.)

Collections of Personal Stories

Some of these collections are written by the parents themselves and put together by an editor; others are written by an author and based on observations and interviews with parents or health care providers. All of these books sensitively present a wide variety of situations and outcomes within the focus.

Brown, A. B. and K. R. McPherson, eds. *The Reality of Breastfeeding: Reflections by Contemporary Women*. Westport, Conn.: Bergin and Garvey, 1998. (Moving

and entertaining short essays by moms, speaking honestly and opening about breast-feeding struggles, wonders, disappointments, and triumphs. A wide range of experiences and outcomes and all the attendant tears, joy, frustration and relief. See also under "Breast-Feeding.")

Humes, E. *Baby E.R.: The Heroic Doctors and Nurses Who Perform Medicine's Tiniest Miracles*. New York: Simon and Schuster, 2000. (Stories from the front lines in the NICU, real and varied.)

Kennedy, N. J. and D. Pegher. *Baby Hands and Baby Feet: Poems and Drawings from the Nursery*. Petaluma, Calif.: NICU Ink, 1995. (Written by nurses, touching emotional and visual snapshots. Rich and affirming for health care providers, and a window into the NICU for uninitiated friends and relatives.)

Marsh, J. D. B., ed. *From the Heart: On Being the Mother of a Child with Special Needs*. Bethesda, Md.: Woodbine House, 1995. (Mothers in a variety of situations talk about coping emotionally with the challenges that arise—organized according to themes such as “Being Heard,” “Life Amplified,” and “Healing.”)

McCarty, R., ed. *You Are Not Alone: 20 Stories of Hope, Heroism, Heartache, and Healing as Told by the Parents of Children Treated in the NICU*. South Weymouth, Mass.: Children’s Medical Ventures, 1998.

Meyer, D. J., ed. *Uncommon Fathers: Reflections on Raising a Child with a Disability*. Bethesda, Md.: Woodbine House, 1995. (The companion book to Marsh’s book *From the Heart*. Fathers in a variety of situations talk about coping emotionally with the challenges that arise.)

Naseef, R. *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*. Baltimore: Brookes Publishing, 2001 (Insightful, supportive, practical, comprehensive guide based on the author’s personal experiences with his son who has autism, as well as interviews with other parents of children with disabilities. See also under “Parenting Challenges.”)

Powell K. A. and K. Wilson, eds. *Living Miracles: Stories of Hope from Parents of Premature Babies*. New York: St. Martin’s Press, 2000. (Inspirational stories from parents whose preemies survived; a variety of outcomes are represented.)

Simons, R. *After the Tears: Parents Talk about Raising a Child with a Disability*. New York: Harcourt-Brace, 1987. (Reinforces that this child is precious and you will survive.)

Smith, T. *Miracle Birth Stories of Very Premature Babies: Little Thumbs Up!* Westport, Conn.: Bergin and Garvey, 1999. (Based on interviews, detailed accounts of

parents' experiences with their preemies' early arrivals and hospitalizations.) Sullivan, T. *Special Parent, Special Child: Parents of Children with Disabilities Share Their Trials, Triumphs, and Hard-Won Wisdom*. New York: G. P. Putnam's Sons, 1995. (Interviews with parents who have learned to reframe their initial discouragement and have come to see disability as a small part of who their child is.)

Breast-Feeding

All these books support, encourage, and advocate for breast-feeding, and it wouldn't hurt to have more than one on hand.

Brown, A. B. and K. R. McPherson, eds. *The Reality of Breastfeeding: Reflections by Contemporary Women*. Westport, Conn.: Bergin and Garvey, 1998. (Moving and entertaining short essays by moms, speaking honestly and openly about breast-feeding struggles, wonders, disappointments, and triumphs. A wide range of experiences and outcomes, and all the attendant tears, joy, frustration, and relief. Also listed under "Collections of Personal Stories.")

Bumgarner, N. J. *Mothering Your Nursing Toddler*. Schaumburg, Ill.: La Leche League International, 2000. (Supportive and encouraging, promotes the idea of child-led weaning and the benefits of continuing to breast-feed beyond the first year.)

Mohrbacher, N. and J. Stock. *The Breastfeeding Answer Book*. Rev. ed. Schaumburg, Ill.: La Leche League International, 1997. (Written for health care providers, so it tends to be dry and clinical, but it's packed full of data and information, including a comprehensive chapter on prematurity.)

Neifert, M. *Dr. Mom's Guide to Breastfeeding*. New York: Penguin, 1998. (A comprehensive, supportive guide; excellent chapters on problems and on preemies.)

Newman, J. and T. Pitman. *The Ultimate Breastfeeding Book of Answers: The Most Comprehensive Problem-Solution Guide to Breastfeeding from the Foremost Breastfeeding Expert in North America*. Roseville, Calif.: Prima Publishing, 2000. (This big book is full of information and support for breast-feeding, advocating and uncovering myths—especially when it comes to preemies. It also has an excellent,

encouraging chapter on tips for “when baby refuses the breast.”)

Sears, W. and M. Sears. *The Breastfeeding Book: Everything You Need to Know about Nursing Your Child*. Boston: Little, Brown and Company, 2000.

Parenting Books

These are not your typical “how-to” parenting books. Rather than telling parents what they should do, these books guide you toward positive, healthful action while empowering you to figure out solutions that will work for you and your children. They recognize that every parent and every child is unique, and suggest different ways of thinking about, coping with, and handling your most important, complicated, and creative role—that of parent. They consider the emotional as well as the physical/biological components of development, behavior, and parent-child interaction. Recognizing that your needs and your child’s needs are sometimes at odds, these books are flexible and empathic, and encourage you to find the balance that’s right for you. By acknowledging the importance of uncovering underlying problems, they are able to offer useful guidance and ideas to help you find real solutions that can work for you and your child.

We’ve included our favorite books that explain ways to support your child’s development, that help you think about your parenting style, that explore positive approaches to discipline, and that address the more challenging aspects of parenting, whether you have a “high-need” child, a child with disabilities, or a child who simply marches to the beat of a different drummer.)

Supporting Your Premie’s Development

Well-written and informative, these books offer insights into the connections between a child’s development and the brain, inborn temperament, and relationships with caregivers. Filled with guidance and support, these books can help you foster your premie’s development and identify the real sources of difficulties, enabling you to find real and holistic solutions that strengthen your relationship with your child.

Eliot, L. *What’s Going on in There? How the Brain and Mind Develop in the First Five Years of Life*. New York: Bantam, 2000. (A comprehensive overview of current scientific knowledge about infant and early childhood brain development,

with a focus on how you, the parent, can affect this complex process. Detailed, scientific, yet accessible.)

Greenspan, S. with N. B. Lewis, *Building Healthy Minds: The Six Experiences That Create Intelligence and Emotional Growth in Babies and Young Children*. Cambridge, Mass.: Perseus Books, 1999. (Shows parents how to nurture a rewarding relationship with their infant and use their baby's budding abilities to build on their emotional and cognitive development. The case studies are especially helpful in pointing out ways to relate with babies who have sensitivities and weaknesses by building on their strengths. Also listed under "Parenting Style and Caregiving.")

Gottman, J. *The Heart of Parenting: Raising an Emotionally Intelligent Child*. New York: Simon and Schuster, 1997. (See also under "Parenting Style and Caregiving.")

Sears, W. and M. Sears with E. Pantley. *The Successful Child: What Parents Can Do to Help Kids Turn out Well*. Boston: Little, Brown and Company, 2002.

Seligman, M. E. P. *The Optimistic Child: A Proven Program to Safeguard Children against Depression and Build Lifelong Resilience*. New York: HarperPerennial, 1996. (See also under "Parenting Challenges.")

Siegel, D. and M. M. Hartzell. *Parenting from the Inside Out: How a Deeper Self-Understanding Can Help You Raise Children Who Thrive*. New York: Jeremy P. Tarcher, 2003. (Fascinating book that draws the connection between brain development, attachment, and interpersonal relationships. Helps you understand your own tendencies and how to build the kind of relationship with your child that helps him or her become compassionate and resilient. See also under "Parenting Style and Caregiving" and "Emotional Health, Personal Growth, and Authentic Living.")

Stern, D. *Diary of a Baby: What Your Child Sees, Feels, and Experiences*. New York: Basic Books, 1992. (This fascinating book is the imaginary diary of a child from the age of six weeks to four years, based on the latest infant development and brain research.)

Developmental Challenges

Berk, L. *Awakening Children's Minds: How Parents and Teachers Can Make a Difference*. New York: Oxford University Press, 2001. (Also listed under "Parenting Challenges.")

Greene, R. W. *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, "Chronically Inflexible" Children*. New York: HarperCollins, 1998. (Also listed under "Parenting Challenges.")

Greenspan, S. I. *The Challenging Child: Understanding, Raising, and Enjoying the Five "Difficult" Types of Children*. Reading, Mass.: Addison-Wesley, 1995. (Also listed under "Parenting Challenges.")

Koplewicz, H. S. *It's Nobody's Fault: New Hope and Help for Difficult Children*. New York: Times Books, 1996. (Also listed under "Parenting Challenges.")

Kranowitz, C. S. *The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction*. New York: Perigee, 1998. (Also listed under "Parenting Challenges.")

Kurcinka, M. S. *Raising Your Spirited Child: A Guide for Parents Whose Child Is More Intense, Sensitive, Perceptive, Persistent, Energetic*. New York: HarperPerennial, 1992. (Also listed under "Parenting Challenges.")

Levine, M. *A Mind at a Time: America's Top Learning Expert Shows How Every Child Can Succeed*. New York: Simon and Schuster, 2002. (Explains how the eight neurodevelopmental systems evolve, interact, and contribute to a child's success in school. Advocates for identifying and teaching to a child's strengths.)

Sears, W. and M. Sears. *Parenting the Fussy Baby and High-Need Child: Everything You Need to Know—From Birth to Age Five*. Boston: Little, Brown and Company, 1996. (Also listed under "Parenting Style and Caregiving")

Sears, W. and L. Thompson. *The A.D.D. Book: New Understandings, New Approaches to Parenting Your Child*. Boston: Little, Brown and Company, 1998. (Also listed under "Parenting Challenges.")

Parenting Style and Caregiving

Brazelton, T. B. and S. I. Greenspan. *The Irreducible Needs of the Child: What Every Child Must Have to Grow, Learn, and Flourish*. Cambridge, Mass: Perseus Books, 2000. (Written more for professionals and policymakers, this book is full of Dr. Brazelton's and Dr. Greenspan's accumulated experience, research, and wisdom.)

Brazelton, T. B. and J. D. Sparrow. *Touchpoints: Both Volumes of the Nation's Most Trusted Guide to the First Six Years of Life*. Cambridge, Mass.: Perseus, 2002. (Originally in two volumes: birth to age three and ages three to six. Explores the developmental strides, growth spurts, and typical regressions that babies and children experience to help parents understand and empathize with their child's ups and downs, progress and setbacks.)

Davis, L. and J. Keyser. *Becoming the Parent You Want to Be: A Sourcebook of Strategies for the First Five Years*. New York: Broadway Books, 1997. (A warm, open-minded book that offers lots of ideas, suggestions, and encourages you to figure out what's best for you and your child.)

Douglas, A. *The Mother of All Baby Books: The Ultimate Guide to Your Baby's First Year*. Indianapolis, Ind.: Hungry Minds, 2002. (Down-to-earth and informative, this book tackles topics that are off-limits to many other baby books, such as prematurity. You can pick up this "mainstream baby book" and get support for the postpartum, breast-feeding, sleeping, equipment and routine baby care issues that you have in common with full-term parents *and* also feel acknowledged and accounted for in the special sections devoted to prematurity issues.)

Gottman, J. *The Heart of Parenting: Raising an Emotionally Intelligent Child*. New York: Simon and Schuster, 1997. (Teaches and supports parents in how to honor feelings and approach parenting and discipline in emotionally healthy ways, which is what makes parents most effective. Also listed under "Supporting Your Premie's Development.")

Greenspan, S. with N. B. Lewis, *Building Healthy Minds: The Six Experiences That Create Intelligence and Emotional Growth in Babies and Young Children*. Cambridge, Mass.: Perseus Books, 1999. (Also under "Supporting Your Premie's Development.")

Klaus, M. H., J. H. Kennell, and P. H. Klaus. *Bonding: Building the Foundations of Secure Attachment and Independence*. Reading, Mass.: Addison-Wesley, 1995. (A supportive book that reassures and encourages parents in their efforts to form a bond with their infant. Includes an excellent chapter on prematurity.)

McClure, V. *Infant Massage: A Handbook for Loving Parents*. New York: Bantam Books, 2000. (Teaches the advantages and techniques of infant massage.)

McClure, V. *The Path of Parenting: Twelve Principles to Guide Your Journey*. Novato, Calif.: New World Library, 1999. (A gentle, easy-to-read, practical book that focuses on parents and examines emotionally healthy principles that can ground your parenting in the conscious decisions you make about how you want to live your life and what kind of relationship you want with your child through the years. See also under “General Emotional Adjustment.”)

McKay, M., ed., et al. *When Anger Hurts Your Kids: A Parent's Guide*. New York: MJF Books, 1996. (A practical, supportive book that offers ways to identify and talk back to anger triggers, enabling parents to be more effective.)

Pantley, E. *The No-Cry Sleep Solution: Gentle Ways to Help Your Baby Sleep through the Night*. New York: McGraw-Hill/Contemporary Books, 2002. (Work with your baby toward good sleep habits. Presents a variety of solutions so you can choose what works best for you and your baby. Endorsed by William Sears, pediatrician and author of *Nighttime Parenting*.)

Rose, L. *Learning to Love: The Developing Relationships between Mother, Father, and Baby During the First Year*. Camberwell, Victoria: Acer Press, 2000. (Ideas and support for attuning to, interacting with, and connecting with your baby.)

Rosenfeld, A. *Hyper-Parenting: Are You Hurting Your Child by Trying Too Hard?* New York: St. Martin's Press, 2000. (Examines the tendency for parents to strive to raise perfect kids in perfect ways and encourages them to relax, enjoy, simplify, do what feels right, trust their abilities, and accept imperfection—in the children and themselves.)

Samalin, N. *Loving without Spoiling and 100 Other Timeless Tips for Raising Terrific Kids*. Chicago: Contemporary Books, 2003. (A nice overview of responsive, nurturing parenting.)

Sears, W. *Nighttime Parenting: How to Get Your Baby and Child to Sleep*. Rev. ed. New York: Plume, 1999. (Encourages parents to be as responsive to a baby's needs at night as they are during the day and shows the advantages and how-tos of cosleeping.)

Sears, W. and M. Sears. *The Attachment Parenting Book: A Commonsense Guide to Understanding and Nurturing Your Baby*. Boston: Little, Brown and Company, 2001. (The definitive guide to attachment parenting, an approach that emphasizes responding to your child's needs, figuring out what works best for both of you, and strengthening the connection between you and your child from infancy onward. Excellent section on the benefits of attachment parenting for premies and their parents.)

Sears, W. and M. Sears. *The Baby Book: Everything You Need to Know about Your Baby from Birth to Age Two*. Boston: Little, Brown and Company, 2003. (Responsive parenting; informative supportive chapter on "Babywearing: The Art and Science of Carrying Your Baby.")

Sears, W. and M. Sears. *Parenting the Fussy Baby and High-Need Child: Everything You Need to Know—From Birth to Age Five*. Boston: Little, Brown and Company, 1996. (A supportive book, encouraging parents to become attuned to their high-need baby or child. Also listed under "Developmental Challenges.")

Siegel, D. and M. M. Hartzell. *Parenting from the Inside Out: How a Deeper Self-Understanding Can Help You Raise Children Who Thrive*. New York: Jeremy P. Tarcher, 2003. (See under "Supporting Your Premie's Development" and "Emotional Health, Personal Growth, and Authentic Living.")

Small, M. *Our Babies, Ourselves: How Biology and Culture Shape the Way We Parent*. New York: Anchor Books, 1998. (Looks at parenting and nurturing across cultures, thereby encouraging parents to question the culturally ingrained practices that don't work or feel right and to reach for ones that do.)

Thevenin, T. *The Family Bed: An Age-Old Concept in Child Rearing*. Wayne, N.J.: Avery, 1987. (Looks at sleeping practices across the ages and cultures, and opens the mind toward the idea of having a family bed.)

Discipline

Brazelton, T. B. and J. Sparrow. *Discipline: The Brazelton Way*. Cambridge, Mass.: Perseus Publishing, 2003. (Concise, practical, empathic.)

Faber, A. and E. Mazlish. *Siblings without Rivalry: How to Help Your Children Live Together So You Can Live Too*. Expanded ed. New York: Avon, 1998. (Full of practical examples; teaches parents how to view sibling relationships realistically and how to cultivate healthy relationships between your kids.)

Kurcinka, M. S. *Kids, Parents and Power Struggles: Winning for a Lifetime*. New York: HarperCollins, 2000. (How to use “emotion coaching” to build a warm, nurturing, effective relationship with your child.)

Nelson, J. *Positive Discipline: The Classic Guide for Parents and Teachers to Help Children to Develop Self-Discipline, Responsibility, Cooperation, and Problem-Solving Skills*. Rev. ed. New York: Ballantine, 1996. (Offering many pearls of wisdom, this warm, practical book shows parents and other caregivers how to look for the underlying needs that aren't being met when children misbehave. Reframes “discipline” as gentle and firm guidance and encouragement that makes children feel better, which naturally and intrinsically motivates them to behave better.)

Samalin, N. and M. M. Jablow. *Loving Your Child Is Not Enough: Positive Discipline That Works*. New York: Penguin, 1998. (Another book that focuses on solving underlying problems and reframing discipline in positive ways.)

Parenting Challenges

Berk, L. *Awakening Children's Minds: How Parents and Teachers Can Make a Difference*. New York: Oxford University Press, 2001. (Academic but insightful and instructive with plenty of examples, this book highlights principles of child development, the overall importance of early childhood education, and how to structure home and school environments. Supportive and informative

chapter on children with disabilities, focusing on ADHD. Also listed under “Developmental Challenges.”)

Bryan, E. M. *Twins, Triplets, and More: Their Nature, Development, and Care*. New York: St. Martin’s Press, 1998. (Addresses many unique parenting concerns, including managing the logistics, emotional coping, bonding, disability, death, and selective reduction.)

Greene, R. W. *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, “Chronically Inflexible” Children*. New York: Harper-Collins, 1998. (How to reclaim your sanity—and your child. Excellent guide that looks at parenting a child with challenging temperamental qualities who has frequent “meltdowns” and doesn’t respond to typical or even skillful parenting. Offers insights into what’s going on with the child’s brain chemistry and physiology, with suggestions for repairing and strengthening your relationship with your child and teaching him or her self-regulation. Also listed under “Developmental Challenges.”)

Greenspan, S. I. *The Challenging Child: Understanding, Raising, and Enjoying the Five “Difficult” Types of Children*. Reading, Mass.: Addison-Wesley, 1995. (An insightful, supportive guide to acquiring a unique parenting style that suits your child’s unique personality and needs. Also listed under “Developmental Challenges.”)

Greenspan, S. I., and R. Weider. *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*. Cambridge, Mass.: Perseus Press, 1998. (How to enlist your child’s strengths to help him overcome weaknesses. Also listed under “Developmental Challenges.”)

Harwell, J. *Ready-to-Use Tools and Materials for Remediating Specific Learning Disabilities*. West Nyack, N.Y.: The Center for Applied Research in Education, 1995.

Koplewicz, H. S. *It’s Nobody’s Fault: New Hope and Help for Difficult Children*. New York: Times Books, 1996. (Looks at the biochemical basis for children who present with challenging behaviors—the brain-behavior connection. Also listed under “Developmental Challenges.”)

Kranowitz, C. S. *The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction*. New York: Perigree, 1998. (For parents of kids who are under- or overwhelmed by sensory stimulation, the classic book on sensory integration dysfunction. Also listed under “Developmental Challenges.”)

Kurcinka, M. S. *Raising Your Spirited Child: A Guide for Parents Whose Child Is More Intense, Sensitive, Perceptive, Persistent, Energetic*. New York: HarperPerennial, 1992. (How to work with, not against, your child’s inborn temperament and enjoy him or her. Also listed under “Developmental Challenges.”)

Lavin, J. L. *Special Kids Need Special Parents: A Resource for Parents of Children with Special Needs*. New York: Berkley, 2001. (A practical and supportive book that covers emotional issues, family dynamics, and behavioral challenges, as well as advocating for your child in medical settings and at school, and dealing with pain and mobility issues.)

Miller, N. B. *Nobody’s Perfect: Living and Growing with Children Who Have Special Needs*. Baltimore: Paul H. Brookes Publishing Company, 1994. (A warm, supportive book that identifies and describes four overlapping processes of adaptation to parenting a child with any kind of special needs, helping parents make sense of their unique experiences.)

Miller, N. B. and C. C. Sammons. *Everybody’s Different: Understanding and Changing Our Reactions to Disabilities*. Baltimore: Paul H. Brookes Publishing Company, 1994.

Naseef, R. *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*. Baltimore: Paul H. Brookes Publishing Company, 2001. (Focuses on the emotions and grieving process of parents struggling to accept and raise a child with special needs. Supportive, insightful guide to coping and balancing needs. Great for fathers. See also under “Collections of Personal Stories.”)

Noel, B. and A. Klein. *The Single Parent Resource*. Beverly Hills, Calif.: Champion Pr Ltd, 1998.

Pruitt, D. B., ed. *Your Child: What Every Parent Needs to Know about Childhood Development from Birth to Preadolescence—What's Normal, What's Not and When to Seek Help*. New York: HarperCollins, 1998. (A general guide that can help you differentiate between normal developmental struggles and difficulties that call for professional intervention.)

Rothbart, B. *Multiple Blessings: From Pregnancy through Childhood, A Guide for Parents of Twins, Triplets, or More*. New York: Hearst Books, 1994.

Sears, W. and L. Thompson. *The A.D.D. Book: New Understandings, New Approaches to Parenting Your Child*. Boston: Little, Brown and Company, 1998. (A supportive, informative book that looks at the neurological basis for Attention Deficit Disorder, examines the child's positive traits, and offers suggestions for alternative treatments, including neurofeedback, that build on the child's strengths, instead of relying solely on drug therapies. (Also listed under "Developmental Challenges."))

Segal, M. *In Time and with Love: Caring for the Special Needs Baby*. Rev. ed. New York: Newmarket Press, 2001. (Gentle, supportive, affirming.)

Seligman, M. E. P. *The Optimistic Child: A Proven Program to Safeguard Children against Depression and Build Lifelong Resilience*. New York: HarperPerennial, 1996. (Guiding your child toward holding an optimistic view of life, people, and events, which fortifies the ability to bounce back from disappointment, frustration, rejection, discouragement, and misfortune—and find authentic happiness. See Seligman's other books in "General Emotional Adjustment.")

Seroussi, K. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*. New York: Simon and Schuster, 2000. (Explores the link between autism and food cravings/sensitivities. A story of advocating for your child. See also under "Personal Stories.")

Trozzi, M. and Massimini, K. *Talking With Children about Loss: Words, Strategies, and Wisdom to Help Children Cope with Death, Divorce, and Other Difficult Times*. New York: Perigree, 1999. (Sensitive, helpful guide. Includes an example about premie twins and how to talk to the child who survived about the one who died in infancy.)

School Advocacy

Siegel, L. *The Complete IEP Guide: How to Advocate for Your Special Ed Child*. Berkeley, Calif.: Nolo Press, 2001.

Wright, P. W. D. and P. D. Wright. *Wrightslaw: From Emotions to Advocacy—The Special Education Survival Guide*. Hartfield, Va.: Harbor House Law Press, 2001.

Books for Children

Collins, P. L. *Waiting for Baby Joe*. Niles, Ill.: Albert Whitman and Company, 1990. (Explores the emotions families feel when their baby is born prematurely and they have to wait for the baby to get better and come home.)

Lafferty, L. and N. Flood. *Born Early: A Premature Baby Story*. Minneapolis: Fairview, 1998. (Shows the NICU, explains medical procedures, simply written and illustrated with gentle photographs. Covers birth to homecoming.)

Murphy-Melas, E., D. Tate, and W. Troyer. *Watching Bradley Grow: A Story about Premature Birth*. Atlanta, Ga.: Longstreet Press, 1996. (Deals with feeling left out when you can't visit the baby in the hospital, and your parents are spending a lot of time there.)

Resta, B. *Believe in Katie Lynn*. Nashville: Eggman Publishing, 1995. (A beautifully illustrated, heartfelt story about a baby in the NICU; good explanation of a special beginning to show your growing premie or your other children. See also under "Books for Parents of Premies.")

Health, Pregnancy, Fertility

Alcaniz, L. *Waiting for Bebé: A Pregnancy Guide for Latinas*. New York: One World/Ballentine, 2003. (Available in Spanish and English.)

Chism, D. M. *The High-Risk Pregnancy Sourcebook: Everything You Need to Know*. Los Angeles: Lowell House, 1997. (Looks at risk factors, complications, and what you can do to have the best chance for a healthy baby.)

Douglas, A. and J. R. Sussman, *Trying Again: A Guide to Pregnancy after Miscarriage, Stillbirth, and Infant Loss*. Dallas: Taylor Trade Publishing, 2000. (A thorough, supportive book detailing pregnancy, testing, complications, and coping for anxious parents.)

Douglas, A. and J. R. Sussman. *The Unofficial Guide to Having a Baby*. New York: MacMillan, 1999. (An empowering book packed full of information to help you make sound decisions during pregnancy.)

Dunwold, A. and D. G. Sanford. *Postpartum Survival Guide*. Oakland, Calif.: New Harbinger, 1994. (Examines postpartum reactions with suggestions on how to cope.)

Kleiman, K. and V. D. Raskin, *This Isn't What I Expected: Overcoming Postpartum Depression*. New York: Bantam, 1994. (Compassionate and supportive, provides a comprehensive description of postpartum depression, treatments, and advice around this misunderstood and often misdiagnosed condition.)

Luke, B. *Every Pregnant Woman's Guide to Preventing Premature Birth: A Program for Reducing the Sixty Proven Risks That Can Lead to Prematurity*. New York: Times Books, 1995. (Looks at risk factors and what you can do about them.)

McIntyre, A. *The Complete Woman's Herbal: A Manual of Healing Herbs and Nutrition for Personal Well-Being and Family Care*. New York: Henry Holt, 1995.

Moran, V. *Fit from Within: 101 Simple Secrets to Change Your Body and Your Life—Starting Today and Lasting Forever*. Chicago: Contemporary Books, 2002. (A nurturing, encouraging, empowering book on having a healthy relationship with food and your body.)

Murkoff, H., A. Eisenberg, and S. Hathaway, *What to Expect When You're Expecting*. New York: Workman Publishing, 2002. (Newly updated, packed with information.)

Peoples, D. and H. R. Ferguson. *Experiencing Infertility: An Essential Resource*. New York: W. W. Norton, 1998. (Focuses on emotions as well as practical matters such as seeking treatment, adoption. Written in easy-to-read question-and-answer style.)

Rothman, B. K. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York: Penguin Books, 1986. (Takes a look at what prenatal diagnostic testing can mean for parents who may hesitate to invest in a baby until the tests come back “normal,” or who must now face decisions they never imagined.)

Salzer, L. P. *Surviving Infertility: A Compassionate Guide through the Emotional Crisis of Infertility*. New York: HarperPerennial, 1991. (Supportive; focuses mostly on the emotional aspects and coping strategies.)

Sears, W. and M. Sears. *The Pregnancy Book: Month by Month, Everything You Need to Know from America's Baby Experts*. Boston: Little, Brown and Company, 1997. (Comprehensive and supportive.)

The Staff of RESOLVE with Diane Aronson, Executive Director. *Resolving Infertility: Understanding the Options and Choosing Solutions When You Want to Have a Baby*. New York: HarperCollins, 1999. (Informative, focuses on treatment options.)

Tracy, A. E. and R. H. Schwarz. *The Pregnancy Bed Rest Book: A Survival Guide for Expectant Mothers and Their Families*. New York: Berkley Publishing Group, 2001. (Practical tips and emotional support.)

Videos

The March of Dimes is developing a program, including videos, to offer comprehensive support to parents in the NICU. Contact The March of Dimes Resource Center (See “Resource Organizations” below.)

Parents on the Threshold: You Are Not Alone, produced by the Colorado Collective for Medical Decisions (CCMD) and Nickel’s Worth Productions in 1999, a 30-minute videotape that supports parents who face

life-and-death decisions in the NICU. To obtain an order form, contact Nickel's Worth Productions at NickelTV@aol.com. See Appendix D for more on the video and CCMD's Neonatal Guidelines.

Special Beginnings introduces families to the NICU with an overview of care and validation of emotions that parents experience. Contact the Centering Corporation (See "Resource Organizations" below.)

Resource Organizations

These organizations publish a variety of supportive books and materials for parents experiencing crisis during pregnancy or after delivery, including bed rest, prematurity, raising a child with special needs (including difficulty feeding), and death of a baby. Some also distribute resources from other publishers, including books for parents, siblings, NICU baby books. Contact them to order catalogs or to explain your special needs.

A Place to Remember
Publisher and distributor:
deRuyter-Nelson Publications, Inc.
1885 University Avenue, Suite 110,
Saint Paul, MN
(800) 631-0973
www.APlaceToRemember.com

Brookes Publishing
P.O. Box 10624, Baltimore, MD
21285-0624
(800) 638-3775 | Fax: (410) 337-8539
www.brookespublishing.com

Centering Corporation
Publisher and distributor
P.O. Box 4600, Omaha, NE 68134
(402) 553-1200
www.centering.org

Children's Medical Ventures
Products developed specifically for
preemies and NICU care providers
www.childmed.com/

The March of Dimes
Resource center and developer of the
NICU Family Support Program for
hospitals nationwide
(888) MODIMES
www.marchofdimes.com

Woodbine House
Special Needs Collection
Books for Parents, Professionals,
and Children
(800) 843-7323
www.woodbinehouse.com

Internet

The quantity and variety of Web sites and Listservs on the Internet are endless. Listed are some central sites providing links to many other sites that you can look into to meet your needs for information, ideas, and support. As always, use your judgement, and look for Web sites that are legitimate and reliable sources of information and comfort, or Listservs that are well-run communities of mutual respect, sharing, and support.

Community

www.preemie-l.org

Parents of Premature Babies

Preemie-L (“L” stands for “list”)

The premier Listserv for parents of premature babies, a virtual community sharing ideas, information, and support. In addition to participation in the discussion groups, parents can request that they be put in touch with another family whose situation is similar to theirs and whose preemies are now older. Parents have volunteered, and been trained to be mentors. Check out their links to other resources, including *The Early Edition* newsletter, Recommended Booklist, and Selected Resources.

www.prematurity.org

Premature Baby – Premature Child

Provides articles, resources and support from parents and doctors for parents of children born prematurely. This site includes a mailing list, information on parenting your premature child, the long-term impacts of prematurity, the special needs of children, celebrating and coping with prematurity, an e-mail support group, and an Internet forum.

www.preemie-hearts.com

Home of Preemie Purple Hearts, beautiful blown-glass pendant/pins for parents and others who journey with prematurity. “An outward sign of unity among a special group of people ... the Heart can be with you when you feel alone, remind you there are hundreds of others who keep you in their hearts.”

www.thepreemieplace.org/

The Preemie Place

A smaller board for parents of premature children.

Emotional Support

www.parentingyourprematurebaby.com

Parenting Your Premature Baby and Child: The Emotional Journey
Short articles written by Davis and Stein (authors of this book) and
some links to other preemie and parenting sites

<http://members.aol.com/KBone91/tbone.html>

T-Bone's Survival Tips for New Preemie Parents

www.premature-infant.com

Parenting in the NICU and Beyond

A resource for parents of preemies and for health care professionals
by Dianne Maroney, a former NICU nurse, coauthor of *Your Premature
Baby and Child*, and mother of a preemie.

Fathers

www.jeffslife.net

Heartfelt, beautifully written essays by writer Jeff Stimpson, father of
Alex (preemie) and Ned.

Breast-Feeding

www.lalecheleague.org

La Leche League International

Multiples

www.mostonline.org/

Mothers of Supertwins Online

www.groups.yahoo.com/group/specpar/join

SPECPAR (for parents of multiples where one or more of the children
has special needs)

www.synspectrum.com/multiplicity.html

Multiplicity: The Special Challenges of Parenting Twins and More
Loss, Prematurity and Special Needs

Designed and maintained by Elizabeth A. Pector, M.D., a family
practitioner and parent to a surviving preemie twin.

NICU and Medical Information

www.pediatrics.wisc.edu/childrenshosp/parents_of_preemies/

Answers to commonly asked questions; Web site developed by Jane E.
Brazy, M.D., neonatologist. Available in Spanish and English.

www.hhs.gov/ocr/hipaa

U.S. Department of Health and Human Services
Office for Civil Rights – HIPAA Medical Privacy Rules –
National Standards

This government Web site provides information about laws regarding medical records and getting access to them.

Family-Centered Care

www.familycenteredcare.org

The Institute for Family-Centered Care, a nonprofit organization, provides essential leadership to advance the understanding and practice of family-centered care. The Institute serves as a central resource for both family members and members of the health care field, providing information, education, training, and networking.

www.theschwartzcenter.org

The Kenneth B. Schwartz Center
Promotes collaborative and healing relationships between families and caregivers. Provides consultation and a model of hospital rounds that supports and builds community for health care providers.

101 Merrimac Street, Suite 603
Boston, MA 02114-2792
(617) 724-4746

Resource Listings for Premie Parents

<http://members.aol.com/MarAim/preemie.htm>

Resources for Parents of Premies

www.prematurity.org/preemiepgs.html

<http://kingproductions.com/babylink.htm>

Tommy's Cybernursery Premie Web

Daddy's Link Library, comprehensive listing of Internet sites

www.storknet.com/cubbies/index.html

Storknet.com

Comprehensive pregnancy and parenting site, including special topics such as neonatal intensive care and pregnancy/infant loss support.

www.pregnancy.org/topics.php

Pregnancy.org: Preconception, Pregnancy, and Parenting
Comprehensive site and community, topics include preemies, infertility, grief and loss, special needs, twins and multiples; run by parents who've been there.

www.sidelines.org

Sidelines provides emotional support and practical suggestions during pregnancy bed rest.

<http://fpb.cwru.edu/bedrest/>

From Judith Maloni, RN, Ph.D. regarding the latest medical information about pregnancy bed rest.

Feeding Issues

www.members.iinet.net.au/~scarffam/serve/cache/1.html

Support group for G-tube, NG-tube, J-tube and GJ-tube users and their caregivers. Members range from parents trying to make the decision to have a tube placed in their children to those who are veterans.

www.network54.com/Hide/Forum/109925

GERD Word: A board for parents of children with reflux

www.feedingcenter.org/discussion.html

Center for Pediatric Feeding and Swallowing Disorders

www.health.groups.yahoo.com/group/feeding/

The feeding group on Yahoo

<http://hometown.aol.com/Lmwill262/>

Small Wonders – Premie Place

Premie-related issues, particularly “Feeding and Premies.”

Postpartum Depression

www.depressionafterdelivery.com/

Depression After Delivery

www.postpartum.net/

Postpartum Depression International

Childbearing Losses

www.climb-support.org

CLIMB: Center for Loss in Multiple Birth

Provides support by and for parents of twins, triplets, or higher multiple birth children who have experienced one or more of their children's deaths during pregnancy, at birth, in infancy, or in childhood.

<http://health.groups.yahoo.com/group/elimbo/>

LIMBO Loss in Multiple Birth Outreach

www.plida.org/

PLIDA Pregnancy Loss and Infant Death Alliance

A nationwide, collective community of professionals and bereaved parents that promotes awareness, advocacy, parent support, and resources for grieving parents and their families.

www.nationalshareoffice.com

SHARE Pregnancy and Infant Loss Support

Provides a national list of parent support groups and other resources
(800) 821-6819

www.resolve.org/main/national/index.jsp?name=home

RESOLVE The National Infertility Association

A nationwide network of chapters providing education, advocacy, and support.

Family Medical Leave Laws

www.dol.gov/esa/whd/fmla/

U.S. Department of Labor Web site that provides compliance assistance for the Family Medical Leave Act (FMLA)

Education Advocacy

www.wrightslaw.com/

Accurate, up-to-date information about special education law and advocacy for children with disabilities.

www.allkindsofminds.org/

A nonprofit institute for understanding differences in learning. This is a comprehensive Web site for families, educators, and clinicians.

www.ideapractices.org

The Individuals with Disabilities Education Act Web site will provide you with information on the laws that govern early intervention and special education services.

www.ldanatl.org

Learning Disabilities Association

Resources and information on learning disabilities, including ADD.

www.copaa.net/

The Council of Parent Attorneys and Advocates

Tools and information for effective advocacy.

Children with Special Needs

www.geocities.com/heartland/plains/8950

The Cerebral Palsy Network

Parents improving the lives of their children who have CP.

www.oneaddplace.com

One ADD Place

Resources on attention deficit disorder, including links to online support.

www.our-kids.org

Our Kids: Devoted to Raising Special Kids with Special Needs

An e-mail support group for parents, caregivers, and others who are working with children with physical and/or mental disabilities and delays.

www.childrensdisabilities.info

Children's disabilities information.

<http://childrenwithspecialneeds.com/ipw-web/bulletin/bb/index.php>

Community for families of children with special needs.

<http://groups.yahoo.com/group/KidPower/>

Kid Power: A board for parents of children with mild CP.

www.childdevelopmentnet.com/clinical/general/milestonesa.html#3

A resource for developmental milestones.

www.eparent.com

Exceptional parent magazine.

www.familyvillage.wisc.edu

Family Village is a huge Web site with a wealth of parenting and disability information.

www.rarediseases.org

The National Organization for Rare Disorders (NORD)

www.cheshire-med.com/forums/cldforum.html

Chronic lung disease forum. This is really designed for adults but is a great resource for those with pulmonary issues.

www.nichcy.org

NICHY is the National Information Center for Children and Youth with Disabilities. English and Spanish.

www.tash.org/

TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.

www.bridges4kids.org/HelpForKids-US.html

Bridges for Kids: “Building partnerships between families, schools, and communities”

A nonprofit parent organization providing a comprehensive list of resource and referral centers for parents looking for any kind of help for children from birth through transition to adult life.

www.yellowpagesforkids.com/

Yellow Pages for Kids with Disabilities

www.normemma.com/

Professional Development on Disability and Non-Coercive Practices

www.specialchild.com/bulletin.html

Special Child: lists equipment for sale/giveaway, and items wanted.

Financial and Health Care Access Assistance

www.familyvoices.org

Family Voices is a national organization devoted to helping families with their health care and insurance concerns.

www.challengedamerica.com

Challenged America: offers grants up to \$500 for equipment purchase.

www.dcrf.com

Disabled Children’s Relief Fund

Offers assistance to obtain medical care and equipment for disabled children.

www.npath.org/

Patient Travel

You can call twenty-four hours a day, seven days a week:

(800) 296-1217

www.miracleflights.org

Miracle flights for kids—free flights for medical care on commercial and private planes.

www.angelflight.com

Angel Flight—offers free flights for medical care.