



Pediatric Resources for Families

While by no means a definitive list, these are some of the resources recommended by members of the Children's Project on Palliative/Hospice Services (ChiPPS).

ChiPPS is a group of professionals who are working together to enhance the science, practice, and availability of pediatric palliative and hospice care. Since its inception in 1998, ChiPPS has made valuable contributions to the field, including the development of educational materials that can help organizations serve the needs of children more effectively. In addition to these resources, visit the ChiPPS section of NHPCO's Web site: www.nhpc.org/pediatrics.

Web Sites

Aiding Mothers and Fathers Experiencing Neonatal Death (www.amendgroup.org).

Offers a free counseling service to parents who have experienced the loss of an infant through miscarriage, stillbirth, or neonatal death. Its main purpose is to offer support and encouragement to parents having a normal grief reaction to the loss of their baby.

Alliance of Grandparents, A Support in Tragedy (www.agast.org).

Produces a quarterly newsletter, and features a section on resources and a place to post memorials.

BabySteps (www.babysteps.com).

Provides resources for parents, siblings and other family members, including a remembrance room, bereavement sharing rooms, and bereavement resource rooms with a section on "do's and don'ts." Other sections of site list literature for adults and literature for children—each offering short descriptions/comments on the many titles listed.

Bereaved Families of Ontario (www.bereavedfamilies.net).

This site of Bereaved Families of Ontario—a longstanding, well-established organization—offers many types of support groups and activities for many different types of family bereavement situations (children, adolescents, parents, etc.). BFO has numerous affiliates throughout the Canadian province of Ontario.

Candlelighters Childhood Cancer Foundation (www.candlelighters.org).

This web site serves as a support group for parents whose children are living with or have died from cancer.

Caring Connections (www.caringinfo.org).

A program of the National Hospice and Palliative Care Organization that offers consumer information for parents of ill children.

Children's Hospice and Palliative Care Association (www.partnershipforparents.org).

This association offers a support network for parents of children with serious illnesses, with access to handouts and discussion forums for parents. Information is available in Spanish.



Children's Hospice and Palliative Care Coalition (www.childrenshospice.org).

This California partnership advocates for legislation and has developed the Partnership for Parents web sites—see the *Partnership for Parents* entry below.

The Compassionate Friends (www.compassionatefriends.org).

This national nonprofit self-help support organization offers friendship and understanding to bereaved parents, grandparents, and siblings.

Dougy Center (www.grievingchild.org).

A nonprofit organization that provides peer and professional support to grieving children. The Dougy Center's mission is to provide a safe place for children and families to share their experiences.

Grief and Loss (www.aarp.org/griefandloss).

The AARP Grief and Loss Program has been in existence since 1973 and offers eCards, online journals, a discussion area, and articles on coping with the loss of specific loved ones.

Hygeia® (www.hygeia.org).

Brings together an international community of families who have endured the tragedy of miscarriage, stillbirth and neonatal/infant loss. Online since 1995 and with over 28,000 members, Hygeia® has become the most enduring program of compassion, empathy and support pertaining to Perinatal loss. There are poems and a place for memories and mementos. There is a 24-hour, toll-free support line, and links to journaling opportunities for healthcare providers. The large database of families allow links between families whose fetus/newborn has a rare condition. Information is accessible in Spanish as well.

Mothers in Sympathy and Support (www.misschildren.org).

A nonprofit, international organization which provides immediate and ongoing support to grieving families, empowerment through community volunteerism opportunities, public policy and legislative education, and programs to reduce infant and toddler death through research and education. Provides information in Spanish.

National SIDS/ Infant Death Resource Center (www.sidscenter.org).

Provides information and resources (professional and non-professional) about Sudden Infant Death Syndrome, stillbirths, and miscarriages. Provides information in Spanish.

National Organization of Parents of Murdered Children, Inc. (www.pomc.com).

Provides the ongoing emotional support needed to help parents and other survivors facilitate the reconstruction of a "new life" and to promote a healthy resolution. Not only does POMC help survivors deal with their acute grief, but also with the criminal justice system.

Partnership for Parents/Padres Compadres (www.PartnershipforParents.org/
www.PadresCompadres.org). Excellent online resources for parents whose children have been diagnosed with a life-threatening or life-shortening illness, are receiving treatment, or have died.

SHARE Pregnancy and Infant Loss Support (www.nationalshareoffice.com).

SHARE's mission is to serve those who are touched by the tragic death of a baby through miscarriage, stillbirth or newborn death. Its web site offers a packet of grief literature, information on local chapters, bimonthly newsletter, and resources.



Subsequent Pregnancy After a Loss Support (www.spals.com).

SPALS features an e-mail based, self-help listserv service for people who are pregnant or hoping to be pregnant after an infant or prenatal loss.

Sudden Infant Death Syndrome Alliance (www.sidsalliance.org).

Another good general resource on SIDS.

Survivors of Suicide (www.afsp.org).

This is a comprehensive site for survivors of loss from suicide. It contains a directory of SOS chapters, excerpts from the organization's quarterly newsletter, and suggestions for suicide survivors. Local and national programs, tips for coping, and information about the causes of suicide, etc. are all presented in a clear and easily navigatable site.

Winston's Wish (www.winstonswish.org.uk).

The premier British support group center for bereaved children and their families. Runs weekend residential camps, offers telephone and online resources, works in collaboration with educators and members of the community, and has a splendid book by J. A. Stokes: *Then, Now and Always—Supporting Children as They Journey Through Grief: A Guide for Practitioners*.

Books

Schrauger, B. (2001) *Walking Taylor Home* [ISBN 0-8499-1703-4].

Ash, L. (2004). *Life Touches Life: A Mother's Story of Stillbirth and Healing*.

Beggins, Jeanne P. (2004). *A Book of James*.

Bramblett, J. (1991). *When Good-Bye Is Forever: Learning to Live Again after the Loss of a Child*.

Crider, T. (1996). *Give Sorrow Words: A Father's Passage Through Grief*.

Daher, D. (2003). *And the Passenger was Death: The Drama and Trauma of Losing a Child*.

eFord, F. (1997). *Alex, the Life of a Child*.

Fleming, D. (2005). *Noah's Rainbow: A Father's Emotional Journey from the Death of His Son to the Birth of His Daughter*.

Koppelman, K. L. (1994). *The Fall of a Sparrow: Of Death and Dreams and Healing*.

Leach, C. (1981). *Letter to a Younger Son*.

Orloff, S. & Huff, S., editors. (2003). *Home Care for Seriously Ill Children*.

Smith, G. H. (2006). *Remembering Garrett*.

Stinson, R., & Stinson, P. (1983). *The Long Dying of Baby Andrew*.

Wagner, S. (1994). *The Andrew Poems*.

Sarnoff Schiff, Harriet – *The Bereaved Parent*. Penguin Books.

Kushner, H. *When Bad Things Happen to Good People*.