

Children and Families in the Face of Illness and Death

- ❖ The types of loss children and families experience
 - Death
 - Chronic Illness
 - Divorce
 - Sense of Belonging / Family Unit / Normalcy

- ❖ Family Dynamics in the face of illness and death
 - Changes in parental behavior
 - Changes in family structure & roles
 - Special issues related to divided families

- ❖ The role of spirituality in illness and death
 - Spirituality in the context of a particular family
 - Religious context
 - Meaning of life and death for the child and family
 - Role of rituals

- ❖ Resource information to assist children and families
 - Memory making
 - Grief Materials (books, sibling bags, journals, etc.)
 - Grief support centers
 - Counseling services

Memory Making Ideas

Photostory & Illustory

Hand Molds & Hand Prints

Scrapbooking

Journals

Letters

Photo Collages

Video recordings

Shadow Boxes & Memory Boxes

Make a Wish Trips

Family Web page

Plant a tree or flower

CD of favorite songs

Grief Resources

Ted E Bear Hollow – A center for grieving children and teens located in Omaha, Ne.
www.tedebearhollow.org

Mourning Hope – A center for grieving children, teens, young adults and their families located in Lincoln, Ne
www.mourninghope.org

Faith's Lodge – A place located in Wisconsin where families coping with a serious illness or death of a child can make memories, find hope and strength for the future.
www.faithslodge.org

Centering Corporation – A nonprofit grief support center located in Omaha that offers resources for purchase to help aid professionals and families.
www.centering.org

Dougy Resource Center – National center for grieving children and families. This site offers a database for support centers listed by state.
www.dougy.org/grief-support-programs

National Alliance for Grieving Children – National center for grieving children and families. This site offers a database for support centers listed by state.
www.nationalallianceforgrievingchildren.org

The Initiative for Pediatric Palliative Care (IPPC) – Educational resource for professionals and families.
www.ippcweb.org

Partnership for Parents – A support network for parents of children with special needs.
www.partnershipforparents.org

NHCPO's Caring Connection – Provides information on hospice and palliative care.
www.nhpco.org

Care Pages - CarePages offers websites for free that feature patient blogs that connect friends and family during a health challenge.
www.carepages.com

Counseling Services – Vary by location.

Resource Books for Children

(Please be advised that these books are commonly used by several organizations, however, all of these have not been reviewed by Children's Hospital and Medical Center.)

- *A Birthday Present for Daniel* by Juliet Rothman, A girl loses her brother to death and she tells how her family helped her cope.
- *A Terrible Thing Happened* by Margaret M Holmes, A boy experiences something terrible and begins anxiety which results in him feeling bad, getting stomach aches and having bad dreams. (Doesn't say what the bad thing is – good for several experiences)
- *Beyond the Rainbow* by Marge Eaton Heegard, A book to help a child suffering from a serious illness cope.
- *Chicken Soup for the Grieving Soul* by Jack Canfield and Mark Victor Hansen, Stories of grief and coping.
- *Gentle Willow* by Joyce Mills, A girl is upset that she is going to lose her friend, Gentle Willow, but the Tree Wizards help her understand memories and that there are special ways of saying goodbye.
- *I Miss You: A first look at Death* by Pat Thomas, Help understand death and the normal feelings of grief.
- *I Know I Made It Happen* by Lynn Blackburn, A young girl thinks certain things are her fault. She learns that no one is to blame.
- *If Nathan Were Here* by Mary Bahr, A story of children mourning the loss of a friend.
- *Lifetimes* by Bryan Mellonie & Robert Ingpen, A gentle way to explain death to a child and how all living things reach the end of a lifetime.
- *Little Tree: A Story for Children with Serious Medical Problems* by Joyce C. Mills, A story for children about the changes they may experience and how they are still the same person.
- *Living Well with My Serious Illness* by Marge Eaton Heegaard, An activity book that helps a child deal with their serious illness.
- *Lost and Found: Remembering a Sister* by Ellen Yeomans, A girl recounts her confusing thoughts and feelings after the death of her sister.
- *Mama does the Mambo* by Kathleen Lenier, A mother and father used to dance. When the father dies the mother stops dancing and the little girl notices and is sad. The mom soon finds a new partner and enjoys dancing again.

- *Ocho Loved Flowers* by Anne Fontaine, A little girl takes care of her cat who is dying from a tumor.
- *Someone Special Died* by Joan Singleton Prestine, A girl describes the anger and sadness she feels after someone she loves dies. She makes a scrapbook to remember the things that they did together.
- *Stacy Had A Little Sister* by Wendie Old, A girl loses her baby sister to Sudden Death Syndrome.
- *Sunflowers and Rainbows for Tia: Saying Goodbye to Daddy* by Alesia Greene, Tells how a young girl feels when her father dies and how the family expresses it.
- *That Summer* by Tony Johnston, A dying child and his family sew a quilt of memories.
- *The Bug Cemetery* by Francis Hill, Some neighborhood friends have funerals for dead bug's they find. However, when one experiences the death of a pet it is a different matter.
- *The Empty Place* by Roberta Temes, A boy opens up to a babysitter who also lost a sibling and talks about the emotions he has as he deals with his sister's death.
- *The Giving Tree* by Shel Silverstein, A book open to many interpretations.
- *The Next Place* by Warren Hanson, Simple text take one on a journey to a place where earthly hurts are left behind.
- *Tough Boris* by Mem Fox, A young boy sneaks into a Pirate's ship and finds that even tough Pirates cry.
- *When Dinosaurs Die: A Guide to Understanding Death* by Laurie Krasny Brown, Answers the basic questions about death such as why do people die and what does dead mean.
- *When Families Grieve* by Sesame Street, Helps a family sort through tough emotions.
- *When Someone Dies* by Sharon Greenlee, Explains that when someone dies many things stop, but the memories go on.
- *When the Wind Stops* by Charlotte Zolotow, A young boy is reluctant for his day to end, but his mother assures him that nothing in the natural world ends. "It begins in another place, or in a different way."

Resource Books for Adults

(Please be advised that these books are commonly used by several organizations, however, all of these have not been reviewed by Children's Hospital and Medical Center.)

- *A Grief Unveiled: One Father's Journey Through The Death of a Child* by Gregory Floyd, A father copes after a tragic loss of his child.
- *A Different Dream for My Child* by Jolene Philo, A family facing the life threatening birth defect of their child and the support given.
- *A Time to Decide, A Time to Heal* by Molly Minnick, A book for parents making difficult decisions about their babies
- *Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness* by Barbara M. Sourkes, A therapist talks about the sessions she has with children.
- *Chicken Soup for the Grieving Soul* by Jack Canfield and Mark Victor Hansen, Stories of grief and coping.
- *Empty Cradle, Broken Heart: Surviving the Death of Your Baby* by Deborah L. Davis, Helps with the heartache of miscarriages, stillbirths and infant deaths.
- *Gone From My Sight: The Dying Experience* by Barbara Karnes, explains in a simple, gentle yet direct manner the process of dying from disease
- *Grandparents Cry Twice: Help for Bereaved Grandparents* by Mary Lou Reed, (Grandparents) A book about grandparents dual sorrow when a grandchild dies. They cry for their lost grandchild and they also cry for the terrible grief they see their own child having to bear.
- *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-threatening Illness* by Hank Dunn, a guide to help patients and families with end-of-life decisions.
- *Lean On Me Gently: Helping the Grieving Child* by Doug Manning, Doug provides answers and assurances for anyone who is concerned about a child in grief.
- *Loving and Letting Go* by Deborah Davis, For parents who decided to turn away from aggressive medical intervention for their critically ill newborn
- *Never Too Young to Know: Death in Children's Lives* by Phyllis Rolfe Silverman, A good explaining how children understand death.
- *Notes Left Behind* by Brooke and Keith Desserich (Parents and Children), A true story of a six-year-old girl named Elena and her battle against pediatric brain cancer.

- *Shadows in the Sun: The Experiences of Sibling Bereavement in Childhood* by Betty Davies, A book that reflects on short and long term bereavement of siblings.
- *Waiting with Gabriel* by Amy Kuebelbeck, A book reflecting on the struggles faced by a mom finding out early in pregnancy of her unborn child having a hypoplastic heart and her decision in limiting care.
- *When Courage Lies in Letting Go* by Deborah Davis, A book affirming parents who are considering palliative care, or have already decided against continued aggressive medical intervention for their dying child
- *25 Things to Do: When Grandpa Passes Away, Mom and Dad Get Divorced or the Dog Dies* by Laurie A. Kanyer, A resource of tools to help you cope.

Developmental Understanding and Reactions to Death

Developmental Level	Child's Understanding	Related Behaviors	Helpful Interventions
Birth to Age 2	<ul style="list-style-type: none"> - Need nurtured and supported. Can be affected by the loss of physical touch and nurturing - Primarily affected from the emotions of caregivers - Do not understand death 	<ul style="list-style-type: none"> - Crying - Clingy - Distress - Infantile behaviors 	<ul style="list-style-type: none"> - Allow family and friends to help provide support and nurturing for you and your infant in times of separation - Spend one on one time providing loving physical touch - Keep the routine as normal as possible
Ages 2-5	<ul style="list-style-type: none"> - Have misconceptions about death - Death is seen as reversible and temporary - Do not understand the permanency of death - Death can be seen as punishment - Think they can catch it - Egocentric thinking, they believe somehow it is related or caused by them 	<ul style="list-style-type: none"> - Confused. Need repetition, may need to talk about death multiple times and at random times - May go back and forth between showing concern and showing no concern - May regress in behaviors such as baby talk, bedwetting, thumb sucking, etc. - Clingy to caregivers 	<ul style="list-style-type: none"> - Explain what to expect and the changes within the home - Use the word death or dead instead of words with multiple meanings - Keep explanations short, simple and honest - Offer ways to express feelings
Ages 6-8	<ul style="list-style-type: none"> - Death is possible but not for them - Begin to understand that death is not reversible and that it is universal and final 	<ul style="list-style-type: none"> - Crying - Mad at the deceased - Lack ability to maintain attention - Curious about death - Headaches and stomach aches - Withdrawn - Higher anxiety - Guilt 	<ul style="list-style-type: none"> - Explain that everyone reacts differently to death - May need to readdress around holidays - Give permission to cry and validate the feelings they have - Be honest - Listen to them - Offer ways to express feelings
Ages 8-12	<ul style="list-style-type: none"> - Understand that death can involve them as well - Understand death is universal and final 	<ul style="list-style-type: none"> - Mad at the deceased - Curious about the biology of death - Conforms more to peers - Sleep disturbances - Anxiety and emotional roller coasters 	<ul style="list-style-type: none"> - Listen to them - Help them build their self esteem - Provide reassurance - Offer ways to express feelings
Ages 12-18	<ul style="list-style-type: none"> - Starting to think more like an adult - Can think abstractly, which helps them understand death - Can understand life can be fragile 	<ul style="list-style-type: none"> - Tries to assume the adult role - Anger - Risk Taking behaviors - Critical of others - Conform to peers - Insecure about the future and may question their belief system - Academic difficulties 	<ul style="list-style-type: none"> - Encourage communication - Discuss role changes - Explain that everyone reacts differently - Listen to them - Be honest - Validate their feelings - Build self esteem - Redefine expectations

