

## **Annotated Professional Resources Part A**

### **Understanding Grief and Loss in Children and Their Families**

#### **WEBSITES**

**A Lion in the House – [Sibling Stories](#).** Password: sibs

Created with SuperSibs!, this module tells the story of several siblings as their brother or sister fights cancer. Sibling Stories provides an initial view of how it feels to be pushed aside, left in the dark, and perhaps even forbidden to speak about the stress and anxiety they face every day. Depression, anger, and a desire to rebel are some of the experiences common to these “shadow survivors.” The documentary revisits the siblings after the remission or death of the child with cancer to ask them to reflect on their life and their memories.

#### **Children’s Grief Education Association Navigating Children’s Grief**

<http://childgrief.org/childgrief.htm>

The CGEA is dedicated to serving the needs of grieving children and families and to providing education and support to those who serve them. This website offers great resources to support and care for children who are grieving the loss of a loved one.

#### **CureSearch for Children’s Cancer**

<http://curesearch.org/Coping-With-Cancer>

CureSearch provides a wide variety of [medical information](#), [clinical videos](#), [webinars](#), [a CancerCare app](#), and other resources for patients, parents, siblings, extended family members, friends, neighbors, teachers and many others who care about a child with cancer.

#### **Dana Farber Sibling Program**

<https://www.dana-farber.org/Pediatric-Care/Treatment-and-Support/Patient-and-Family-Support/Sibling-Program.aspx>

Dana-Farber's Sibling Program provides support to siblings and their families. Through high-level care and ongoing research, our unique program is committed to further exploring the impact of a cancer diagnosis on siblings and creating a better experience for all involved throughout the cancer journey.

#### **Grief Net Grace Happens**

[www.griefnet.org](http://www.griefnet.org)

An internet community of persons dealing with grief, death, and major loss. System that connects to a variety of resources related to death, dying, bereavement, and major emotional and physical losses. Offers information as well as discussion/support groups including a kids section.

#### **Journey of Hearts An Online Healing Place for Anyone Grieving a Loss**

<http://www.journeyofhearts.org/>

This site offers resources and support in the grief process following loss or life change. It combines elements of medicine, psychiatry, poetry, prose and images to provide resources and support to those who have experienced loss, be it acute or long- standing.

### **Childhood Cancer International**

[icccpo.org](http://icccpo.org)

This international network of parent support groups and survivor networks share information and experience in order to improve access to the best possible treatment and care for children with cancer everywhere in the world. The networks share a common goal of providing a voice for the needs of children with cancer and their families and advocating for increased awareness of childhood cancer at both a local and international level.

### **Healthychildren.org [Siblings of Children with Chronic Illnesses](#).**

Parents are not the only ones who must adjust to a child's illness or disability. The American Academy of Pediatrics' family focused Website healthychildren.org provides information for parents taking care of other children in the family.

### **The Dougy Center: The National Center for Grieving Children and Families.**

[www.dougy.org](http://www.dougy.org)

The Dougy Center provides a safe place for children, teens, young adults and their families who are grieving a death to share their experiences through peer support groups, education, and training.

### **[Kidsaid.com](http://Kidsaid.com)**

Kidsaid is a safe place for kids to help each other deal with grief and loss. It provides an email support group, share and view artwork and stories, a questions and answers sections.

### **Sibling Support Project: Our brothers, our sisters, ourselves...**

[www.siblingsupport.org](http://www.siblingsupport.org)

The first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. This site for parents and siblings of children with special needs provides information on sources of support, resources, and workshops for parents and siblings.

### **Serving Siblings of Children with Cancer SuperSibs!**

<http://www.alexlemonade.org/campaign/supersibs>

Brothers and sisters of cancer patients often face fear, anxiety, changes in daily routines, worry, grief and even jealousy as their family is thrown into the emotional turmoil of managing a child's cancer treatment. SuperSibs, a program of Alex's Lemonade Stand Foundation, is dedicated to comforting, encouraging, and empowering siblings during their family's battle against childhood cancer, so these children and teens can face the future with courage and hope.

### **American Cancer Society**

[www.cancer.org](http://www.cancer.org)

The American Cancer Society provides several resources regarding supporting children and their siblings diagnosed with cancer:

[Children Diagnosed with Cancer: Dealing with the Diagnosis](#),

[What helps kids with cancer and their brothers and sisters?](#)  
[How do children with cancer and their siblings react to a cancer diagnosis?](#)

### **CancerCare Counseling: Helping the Siblings of the Child with Cancer**

[http://www.cancercare.org/publications/50-helping\\_the\\_siblings\\_of\\_the\\_child\\_with\\_cancer](http://www.cancercare.org/publications/50-helping_the_siblings_of_the_child_with_cancer)

A cancer diagnosis has a profound effect on the entire family, especially when it is a child who is diagnosed. This factsheet provides some steps to ease a child's anxiety.

### **Association of Professional Chaplains: Healing through Spiritual Care**

<http://www.professionalchaplains.org/content.asp?contentid=100>

The online reading room provides a wealth of important resources, articles, and research in the field of professional chaplaincy.

### **HealthCare Chaplaincy Network Handbook of Patient's Spiritual and Cultural Values for Health Care Professionals**

[http://www.healthcarechaplains.org/docs/publications/landing\\_page/cultural\\_sensitivity\\_handbook\\_from\\_healthcare\\_chaplains\\_network\\_8\\_15\\_2014.pdf](http://www.healthcarechaplains.org/docs/publications/landing_page/cultural_sensitivity_handbook_from_healthcare_chaplains_network_8_15_2014.pdf)

As health care professionals we encounter patients of different faith and cultural backgrounds. This handbook is intended as an easy-to-use guide meant to describe beliefs and practices generally found within a particular cultural or religious group.

## **PRINT PROFESSIONAL RESOURCES**

**Alderfer MA, Hodges JA. Supporting siblings of children with cancer: A need for family-school partnerships. [School Ment Health](#) 2010; 2:72-81.**

This manuscript documents the mental health needs of siblings of children with cancer, describes their perceptions regarding amount of social support received, and the importance of social support across home and school sources, and reveals important associations between social support and more positive emotional, behavioral, and academic functioning.

**Gaab EM, Owens GR, MacLeod RD. Siblings caring for and about pediatric palliative care parents. [J Palliat Care](#) 2014; 17(1):62-67**

Interviews with siblings of children receiving palliative care revealed that siblings may benefit from participating in conversations about mortality and from providing direct care.

**Hancock, LJ. The camp experience for siblings of pediatric cancer patients. [Ped Oncol Nurs](#) 2011; 28:137-142.**

Siblings of pediatric cancer patients experience difficulties coping and adapting to the cancer diagnosis. A variety of emotional and behavioral changes as well as somatic complaints have been reported. Children describe many negative changes after their sibling is diagnosed with cancer. Many social supports and therapeutic interventions have been proposed, one of which is a camp experience. The literature has demonstrated that camps have a positive impact and offer siblings a supportive peer environment. Camp encourages discussion with peers and health care providers and facilitates participation in activities that improve knowledge, social confidence, and self-esteem.

**Rosenberg AR, Postier A, Osenga K, Kreicbergs U, Neville B, Dussel V, Wolfe J. Long-term psychosocial outcomes among bereaved siblings of children with cancer. [J Pain Symptom Manage](#) 2015; 49(1):55-65.**

58 siblings, an average of 12 years after the death of a brother or sister, completed a survey. Anxiety, depression, and illicit substance use increased during the year after their brother's/sister's death but then returned to baseline. Siblings who reported dissatisfaction with communication, poor preparation for death, missed opportunities to say goodbye, and/or a perceived negative impact of the cancer experience on relationships tended to have higher distress. Almost all siblings reported that their loss still affected them.

**Miller PJ, Rosengren KS, Gutierrez IT. Children's Understanding of Death: Toward a Contextualized and Integrated Account. [Monographs of the Society for Research in Child Development](#) 2014; 79.**

This series of several papers discusses a research project conducted in the Midwest among 3-6 year old children regarding their understanding of death. The authors explore death as part of a process of socialization in particular sociocultural contexts and provide an integrated vision of the multifaceted nature of the children's understanding of death, encompassing affective and cognitive dimensions.

**Murray, JS. Siblings of children with cancer: A review of the literature. [J Ped Oncol Nurs](#) 1999; 16:25-34 with multiple citations forward.**

Research on siblings of children with cancer has clearly shown that the childhood cancer experience is a stressor that may increase subjective feelings of anxiety by well siblings and in some cases lead to decreased psychosocial competencies and increased psychopathologies. Research has expanded from identifying psychosocial problems experienced by the sibling after the patient's death to identifying stressors during the illness experience. More recent studies have identified clinical interventions that can provide support to siblings of children with cancer. The principles inherent in coping with cancer are generalizable to many diseases.

**Sharp D, Rossiter L. Siblings of children with a chronic illness: A meta-analysis. [J Pediat Psychol](#) 2002; 27:699-710.**

Siblings of children with a chronic illness are at risk for negative psychological effects. Intervention programs should be developed.

**Sloper D, While D. Risk Factors in the adjustment of siblings of children with cancer. [J Ped Psychol Psychiatr](#) 1996;37:597-607.**

This study investigated the psychological adjustment of 99 siblings of children with cancer. At 6 months post-diagnosis, 24 siblings had scores in the borderline or clinical range on parent- and teacher-completed measures of behavioral adjustment and were reported to have shown negative changes in behavior since diagnosis. Problems in adjustment were related to the degree of disruption of family life occasioned by the illness, the resources available to the family to cope with the effects of such disruption on siblings, and siblings' perceptions of negative interpersonal effects on their lives.

**Wilkins KL, Woodgate RL. A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. [J Ped Oncol Nurs](#) 2005;22:305.**

This review discusses 27 qualitative research studies published between 1979 and 2005. Three themes emerged from an analysis of the primary findings: (1) changing lives, (2) intense feelings, and (3) unmet needs.

**Koenig H, Adams K. Religion and Health: Collaboration among healthcare discipline can shape future understandings of how person cope with religion. Association of Professional Chaplains *Healing Spirit* (Fall 2008)**

This article focuses on how people self-identify religion and whether it works for them as a coping method.

### **MULTIMEDIA RESOURCES**

**National Cancer Institute: When Your Brother or Sister Has Cancer: A Guide for Teens**  
<http://www.cancer.gov/publications/patient-education/sibling-has-cancer>

This guide (available in pdf, kindle, and epub) is for young people who have a brother or sister with cancer. It provides information and advice on; ways to deal with changes, finding support, what a sibling may be feeling, cancer treatments, etc.

**What Do I Tell My Children?** (Video)

Aquarius Productions, 31 Martin Road, Wellesley, MA, 02181 (617-237-0608)

**Dana Farber *Sibling Voices***

Sibling Voices was created on YouTube by and for siblings who have a brother or sister with cancer; and as a way to inform parents/guardians, educators, and others about the sibling experience. The section "Impact on the Family" includes tips and suggestions for parents as well as essays written by siblings.

**How to Help Children through a Parent's Serious Illness. Kathleen McCue**  
**New York: St. Martin's Press; 2011**

<http://www.amazon.com/Children-Through-Parents-Serious-Illness/dp/0312697686>

How to Help Children Through a Parent's Serious Illness has become the standard work on an important subject. A classic for over fifteen years, it continues to be a go-to book for supportive, practical advice, based on the lifetime experience and clinical practice of one of America's leading child life practitioners. The new edition also explores the major issues and developments from the last decade that affect children today, including the dangers and opportunities of the Internet, a deeper understanding of how hereditary diseases affect children, the impact of the nation's explosive growth in single-parent families, and new insights into how family trauma and a parent's mental illness may affect children.

**Living with Grief: Children, Adolescents, and Loss. Kenneth Doka. Hospice Foundation of America**

<http://www.amazon.com/Living-Grief-Children-Adolescents-Loss/dp/1893349012>

Living With Grief: Children, Adolescents, and Loss, (available in Kindle and print) features articles by leading educators and clinicians in the field of grief and bereavement. The chapters entitled "Voices"

are the writings of children and adolescents. The book includes a comprehensive resource list of national organizations and a useful bibliography of age-appropriate literature for children and adolescents.

**Preparing the Children: Information & Ideas for Families Facing Terminal Illness & Death Kathy Nussbaum**

<http://www.compassionbooks.com/preparing-the-children-information-and-ideas-for-families-facing-terminal-illness-and-death-revised-edition/>

This exceptional resource gives insight into the needs of children during a family member's terminal illness plus many detailed ideas on how those needs can be met.

**The Grieving Child: A Parent's Guide Helen Fitzgerald**

<http://www.amazon.com/The-Grieving-Child-Parents-Guide/dp/0671767623>

Explaining death to a child is one of the most difficult tasks a parent or other relative can face. The Grieving Child offers practical, compassionate advice for helping a child cope with the death of a parent or other loved one. Parents of children from preschool age to the teen years will find much-needed guidance.

**The Seasons of Grief: Helping Your Children Grow Through Loss Donna Gaffney**

<http://www.amazon.com/The-Seasons-Grief-Helping-Children/dp/0452262437>

This book provides detailed suggestions for helping children confront the trauma of death.

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