

How to Help Siblings Cope:

A resource guide for understanding how siblings deal with grief & loss



Publication of the Batten Disease Support & Research Association
2009

WELCOME

NOTICE TO THE READER

This Batten Disease Handbook is compiled with information from many sources concerning the topics included. Families in the organization have also contributed specific situations that have been helpful in their own battle with Batten Disease. All material in this book is provided for information purposes only. Although Batten Disease Support and Research Association (BDSRA) has made every reasonable effort to assure the accuracy of the information contained in this book, BDSRA is not engaged in rendering medical or other professional services and advice. BDSRA does not guarantee or warrant that the information in the book is complete, correct, current, or applicable to every situation. BDSRA disclaims all warranties expressed or implied, concerning this book and the information herein. If medical or other expert assistance is required, the services of a competent professional should be attained.

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FORWARD

This publication was written to help parents explain the illness and grief surrounded by Batten Disease to the siblings of your affected child/ren. The resources listed in this document are only guidelines meant to help you better understand the grief and coping process in children, at many different ages. The resources listed include websites, articles, and books. They have been divided by age and topic to help you better navigate what may be useful for your family.

Remember, you know what is best for you and your family. If you suspect that your child may need professional help, please contact your doctor or a healthcare professional immediately. BDSRA is also available to help you find support groups in your area as well as talk with you about other sibling programs and services. We hope you find the following information helpful.

BDSRA
166 Humphries Drive
Reynoldsburg, OH 43068
(800) 448-4570 main toll-free
(888) 379-2546 Amy Lombardi
kirka@bdsra.org

Websites for Helping Your Unaffected Child

Helping Children who have siblings with serious illness/special needs

1. *Caring for siblings of seriously ill children*

http://kidshealth.org/parent/positive/talk/sibling_care.html

2. *Siblings of Kids with Special Needs*

<http://www.med.umich.edu/yourchild/topics/specneed.htm>

3. *When a Sibling is Seriously Ill (teens)*

<http://www.thechildrenshospital.org/wellness/info/teens/65884.aspx>

Helping YOUNGER CHILDREN cope with illness/death/grief

1. *Children and Grief*

http://www.aacap.org/cs/root/facts_for_families/children_and_grief

2. *Children and grief*

<http://www.hospicenet.org/html/children.html>

3. *Helping young surviving children*

<http://www.hospicenet.org/html/survive.html>

4. *Responding to Stressful Events: Helping Children Cope*

<http://www.phac-aspc.gc.ca/publicat/oes-bsu-02/child-eng.php>

Helping TEENAGERS cope with illness/death/grief

1. *Children's Comfort Care Resource page for Siblings*

<http://www.mattel.medsch.ucla.edu/pedspain/ccrp/sibling.php>

2. *Helping teenagers cope with grief*

<http://www.hospicenet.org/html/teenager.html>

3. *Responding to Stressful Events: Helping Teens Cope*

<http://www.phac-aspc.gc.ca/publicat/oes-bsu-02/teens-eng.php>

4. *When a sibling is seriously ill*

http://kidshealth.org/teen/your_mind/families/ill_sibling.html

Talking to your child about DEATH

1. *Helping children cope with the death of a loved one*

http://www.caringinfo.org/userfiles/file/child_cope_death.pdf

2. *Helping your child deal with death*

<http://kidshealth.org/parent/positive/talk/death.html#>

3. *Talking to your child about death*

<http://www.hospicenet.org/html/talking.html>

4. *The Child's Loss: Death, Grief, and Mourning*

http://teacher.scholastic.com/professional/bruceperry/child_loss.htm

5. *What children understand about death at different ages*

<http://www.hospicenet.org/html/understand.html>

6. *What do you tell children?*

<http://www.hospicenet.org/html/what-tell.html>

7. *Young Children and Grief – a website by children, for children*

<http://kidsaid.com/dougypage.html>

Sibling Grief and Loss

1. *Centering Corporation and Grief Digest Magazine*

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

2. *The Depressed Child*

http://www.aacap.org/cs/root/facts_for_families/the_depressed_child

--warning signs that your child may be depressed

3. *The Sibling Connection*

<http://www.counselingstlouis.net/index.html>

--website with many resources on child/teenager/sibling grief and loss

It is also important to know that many **hospitals** and **hospice organizations** offer **support groups to siblings** who are either going through or have gone through the death of a sibling. It is not necessary to have been part of a hospice program to receive the support services that may be available. Inquire with your local children's hospital or hospice organization for more information on what may be available in your area.

Books on Grief & Loss

Adeline Street Carol Lynch Williams Juvenile Fiction grades 4-6

This is a year in the life of 12-year-old Leah, in which she learns to move on after the death of her younger sister, Kelly, who died suddenly from an aneurysm.

Beat the Turtle Drum Constance C. Greene Juvenile Fiction grades 4-6

Thirteen-year-old Kate grows up quickly when her beloved younger sister, Joss, falls out of a tree and dies. She becomes acquainted with a wide range of feelings as she learns to cope with her loss.

A Birthday Present for Daniel : A Child's Story of Loss Juliet Rothman Juvenile Fiction grades 4-6

A little girl's brother has died and she tells the story of his loss and her feelings afterwards. This book addresses the issue of what to do about the birthday of the dead child.

Eighty-Eight Steps to September : A Novel Jan Marino Juvenile Fiction grades 4-6

Eleven-year-old Amy fights and plays with her 13-year-old brother Robbie like any sister. When he is hospitalized with leukemia, she stubbornly believes he will come home. Before he dies, she is able to fulfill his final wish.

Little Women Louisa May Alcott Juvenile Fiction grades 4-6

Also a film with the same name.

A story of four sisters Meg, Jo, Amy, and Beth. When Beth dies, Jo finds comfort in self-expression through writing. Semi-autobiographical.

Run, Run, As Fast As You Can Mary Pope Osborne Juvenile Fiction grades 4-6
Eleven-year-old Hallie has moved around a lot. But at least she always has her brother, Michael, to be her friend. When her family moves to Virginia, however, she is devastated by his death, made worse by her parents' hiding information.

The Soul of the Silver Dog Lynn Hall Juvenile Fiction grades 4-6
Feeling withdrawn and alienated after her younger sister's death from cystic fibrosis, teenaged Cory adopts a blind show dog and is determined to bring back some of his earlier glory.

Mourning Song Lurlene McDaniel Fiction YA
Dani's older sister Cassie has a brain tumor, and Dani is determined to fulfill her sister's last wish before she dies.

Phoenix Rising : Or How to Survive Your Life Cynthia D. Grant Juvenile Fiction grades 7-9
When her 18-year-old sister Helen dies of cancer, Jessie (Helen's younger sister) begins reading Helen's journal. As the story unfolds, moving between Helen's journal entries and Jessie's telling of the story, the reader is drawn into Helen's struggle with dying and Jessie's struggle with staying alive.

A Summer to Die Lois Lowry Juvenile Fiction grades 7-9
Thirteen-year-old Meg has a love/hate relationship with her older sister, Molly. When Molly dies, her earlier envy turns to feelings of guilt.

Children Are Not Paper Dolls Erin Linn Levy Non Fiction
This is a book of drawings and quotations from young bereaved siblings. They talk about their personal experiences of loss, hearing the news, what the funeral was like, how they reacted, how their families changed, their feelings of guilt and sorrow, and what helped them to heal. A good resource for bereaved siblings of all ages.

For Those Who Live : Helping Children Cope with the Death of a Brother or Sister by Kathy LaTour
This is not a long book, but its heartfelt compassion shines through every page. Only a bereaved sibling could have written it. The book talks about what happens when you lose a sibling-the grief that doesn't match what it "should," the change in family dynamics, the struggles and the hope. Using wisdom gathered from many sources, the author helps the reader face the reality of loss.

In the Shadow of Illness by Myra Bluebond-Langner
The author Myra Bluebond-Langner has written many articles about siblings who grow up with a brother or sister who has a chronic disease. Like the book, Sibling Loss, this book focuses on families with a child who has cystic fibrosis, but describes issues common to all families who have a child with a chronic or fatal illness.

Shadows in the Sun : The Experiences of Sibling Bereavement in Childhood

by Betty Davies Non Fiction

The grief of surviving siblings is an individual journey that does not fit well into the widely accepted descriptions of grief "stages."

"This book covers the immediate, short-term, and long-term responses to the death of a brother or sister in childhood and adolescence. It also describes the subsequent generational effects of sibling bereavement. Although the book is intended for professional caregivers, surviving siblings can learn much about themselves from a careful reading of this book. The final chapter brings together all that has gone before into a comprehensive model of sibling bereavement. Practical guidelines are offered for those who seek to help grieving siblings, children, and families." *from the book's cover*

Sibling Grief: Healing after the Death of a Sister or Brother by P. Gill White, Ph.D.

Sibling Grief is White's validation of the emotional significance of sibling loss. She draws on clinical experience, research, and wisdom from hundreds of bereaved siblings to explain the five healing tasks specific to sibling grief. White identifies the effects of this profound loss on daily actions and emotions and describes the dream patterns of bereaved siblings, showing how healing is reflected in the dream state. Throughout, she illustrates the long-lasting connection between siblings -- a connection that death itself cannot sever. Sibling Grief is a powerful mix of information, personal reflections, and poetry -- just what you need to begin your own healing journey.

Living With a Brother or Sister With Special Needs: A Book for Sibs by Donald Meyer and Patricia Vadasy

"Living with a Brother or Sister with Special Needs" focuses on the intensity of emotions that brothers and sisters experience when they have a sibling with special needs, and the hard questions they ask: What caused my sibling's disability? Could my own child have a disability as well? What will happen to my brother or sister if my parents die? Written for young readers, the book discusses specific disabilities in easy to understand terms. It talks about the good and not-so-good parts of having a brother or sister who has special needs, and offers suggestions for how to make life easier for everyone in the family. The book is a wonderful resource, not just for siblings and their parents but also for teachers and other professionals who work with children with special needs. This revised and updated edition includes new sections on attention deficit hyperactivity disorder, fetal alcohol syndrome, fragile X syndrome, traumatic brain injuries, ultrasound, speech therapy, recent legislation on disabilities, and an extensive bibliography.

Bobby's Books is a program that uses books to help children and adults deal with difficult issues. Using children's literature as a springboard for conversations will give kids the chance to express their feelings and tell their own stories. The website also offers information on Grief Camps for children, tools to help parents, and support programs that may be available in your area.

See the next page for a list of books about the illness or death of a sibling.

<http://www.bobbysbooks.org>

Helpful Articles

The articles included in the remaining pages of this book were pulled from different websites and newsletters. These articles were chosen because of their relevance to the topic, their insightful information, and specific examples. Each of these articles has been reprinted with permission. Their origins can be found below.

NICHCY News Digest – Children with Disabilities: Understanding Sibling Issues

National Information Center for Children and Youth with Disabilities

1825 Connecticut Ave NW, Suite 700

Washington, DC 20009

1-800-695-0285 (Voice/TTY)

<http://nichcy.org>

Responding to Stressful Events – Helping Children Cope

Published by the Public Health Agency of Canada

Ottawa, Ontario K1A 0K9

<http://www.publichealth.gc.ca>

Helping Children Cope with the Death of a Loved One

Caring Connections – a program of National Hospice & Palliative Care Organization

1731 King Street, Suite 100

Alexandria, Virginia 22314

703-837-1500 (Voice/TTY)

<http://www.nhpco.org>

Sibling Grief Through Childhood

Written by Betty Davies, PhD

The Forum – January/February/March 2006 edition

Association for Death Education and Counseling

111 Deer Lake Road, Suite 100

Deerfield, IL 60015 USA

847-509-0403 (Voice/TTY)

<http://www.adec.org>

Understanding Adolescent Sibling Bereavement

Written by Nancy Hogan, PhD, FAAN, CT

The Forum – January/February/March 2006 edition

Association for Death Education and Counseling

111 Deer Lake Road, Suite 100

Deerfield, IL 60015 USA

847-509-0403 (Voice/TTY)

<http://www.adec.org>