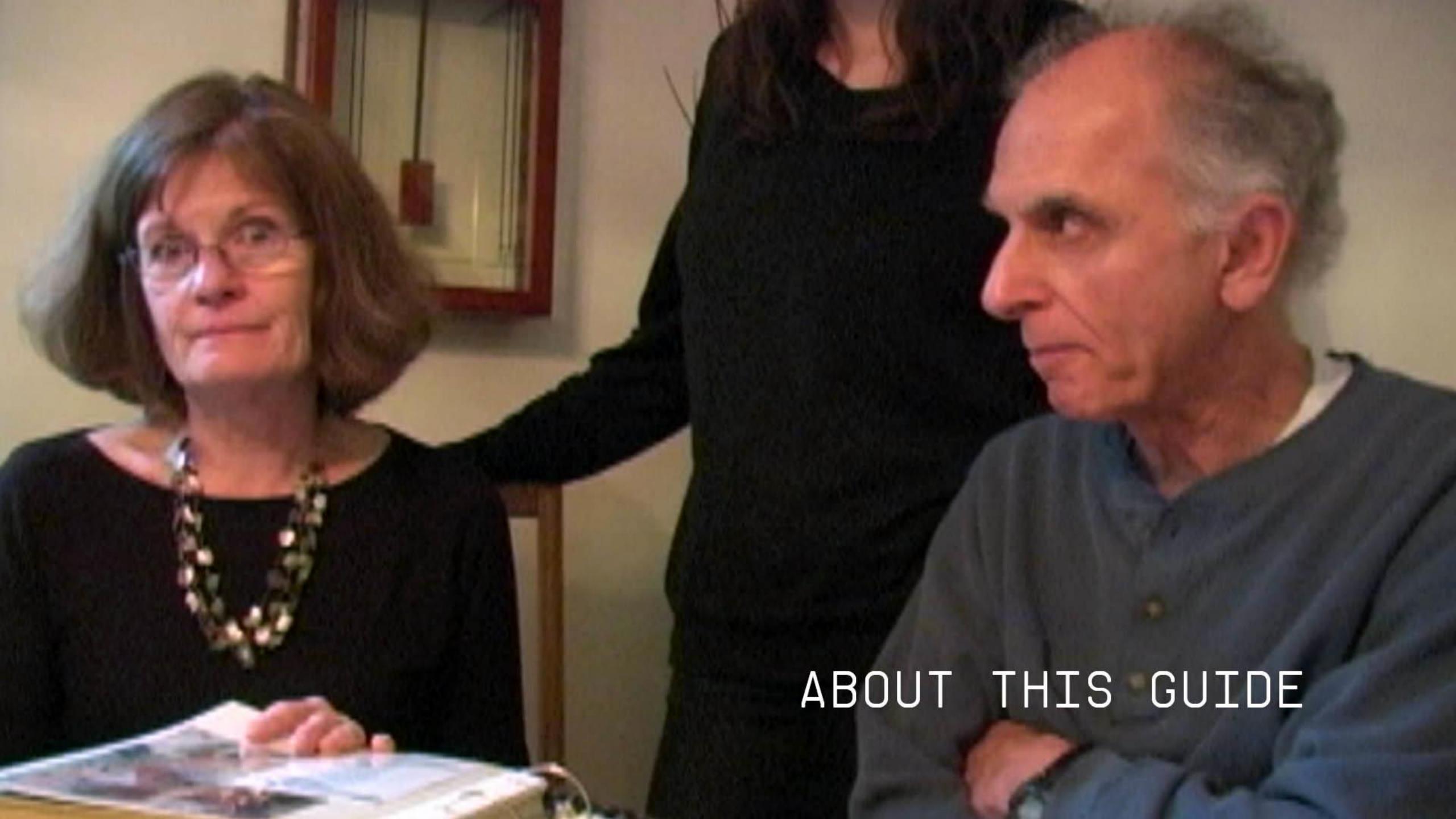


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"All sorrows can be borne if they can be put in a story." —Isak Dinesen



LETTER FROM THE FILMMAKER

We all deal with loss. We all understand how hard it can be to talk about death and to express grief. At a time when public grief rituals have largely fallen by the wayside, mourning can feel secretive and alienating. Our culture pressures us to overcome loss quickly and privately, so that anything but stoicism after a loss can feel isolating and indulgent.

I've learned - through making this film and talking to bereaved folks - that each loss can be as different from other losses as are the variety of human relationships we form with each other. Understanding a loss is understanding what was there - between you and the deceased person - before it was gone. There's infinite variety and this film presents just one case study, one family in the Midwest who faced a protracted tragic illness. My story, that of sibling loss, is one that's rarely discussed.

I hope this guide will be used as a conversation starter. Whether or not you stick to the questions here or go off book is really up to you. It's not meant as an academic treatise, but as a jumping off point. For me, until I spoke to my parents, sixteen years after my sister's death, I was unable to move forward through my grief. The conversations you see in *Peanut Gallery* - and many others - helped me be able to piece together a narrative of how my sister died and how it affected me. Of course this process had many bumps along the way, over the course of many years. I hope *Peanut Gallery* can also help lend a sense of humor to how difficult this work can be.

Mourning is not about moving through rigid and sequential phases and it's not about forgetting; it's about finding a way to still feel alive in an unfamiliar world. Grief takes a certain amount of creativity. Death is not logical. Death can seem ridiculous. Mourning is the process of rewriting our own life narratives and being open to what poetry we may find there.





SYNOPSIS

Molly Gandour, producer of Oscar®-nominated "Gasland," embarks on a mission to her family home, where her parents have agreed to participate, for the first time, in counseling over the death of her sister decades earlier. The family dinner table becomes a catalyst for raw examination of each other and their relationships. Molly finds humor and tenderness in all the imperfect ways we try to communicate with our family. She captures a personal catharsis that provokes viewers to break their own silences. An intimate, enthralling look at sibling relationships, grief and love.



SIBLING LOSS

Siblings are the forgotten mourners. Normally, sibling relationships are the longest of our lives—longer than those with our parents or with our children. Until the 1980s, the prevailing wisdom was Freud's notion that siblings could only be rivals. Since then, researchers have developed more complex views of sibling relationships, but information remains scant. Sibling relationships are often intimate, or nearly always start that way, and full of identification and competition, admiration and jealousy. Some researchers think we define ourselves in terms of our siblings; we fill the family roles they aren't filling.

1.8 million Americans have lost a sibling when they were under the age of 18. To this day, losing a sibling is often considered to be less painful than losing a parent or a child. Bereaved siblings are told, "This must be really hard for your parents." While hierarchizing pain is not generally useful, bereaved siblings suffer unnecessarily due to the ambiguity of their loss. Without recognizing that they have suffered a major blow, bereaved siblings often spend years in limbo, waiting for permission or validation to grieve.

Many bereaved siblings describe the feeling that they are "living for two." How does sibling loss affect someone's sense of identity? What are the developmental effects of losing a sibling during childhood or adolescence? How does sibling loss affect someone's experience of their own achievements, their close relationships, their children? Scientific literature has little to say on these topics. They are complicated research questions to scientifically investigate. Funding for research on siblings remains scant.

One in seven Americans lose a parent or sibling before age of 20. Losing a sibling in childhood probably introduces multiple complicating factors for the child's development. Little is known about the inner life of childhood grief. In fact, many adults buy into the myth that children cannot grieve. In truth, if a child is old enough to love then she is old enough to grieve. Even general research into childhood grief is scant. Most studies have relied on parent questionnaires and symptoms reported long after the fact.

How do you talk to children about grief? How and why do they react differently to loss than adults? How can we best help surviving siblings through the process of losing a brother or sister? How does such a loss impact their identity? Hopefully researchers of the future will help us parse and develop these questions.

CANCER FAMILY DYNAMICS

Each day 46 children in the U.S. are diagnosed with cancer and 35% of those will die. Cancer is the number one disease killer of children. This year 18,000 siblings will face a newly diagnosed brother or sister.

A cancer diagnosis throws a family system into crisis. Will she be okay? Who's going to be with her at the hospital? Who can help us with the other kids when we have to be at the hospital? How involved in the treatment should the siblings be? How are we going to understand everything that is going on? How much does our insurance pay of this treatment? Should we get a second opinion? Cancer families find themselves facing questions they never thought they'd have to ask.

Having a kid with cancer in the family raises tough and complex issues. How much should the ill child and her siblings know about the prognosis? How can we maintain some sense of normalcy for our family? Who are our most important supports? How can we cut our ill child some slack when necessary without letting things get out of control at home? How can we best nurture our other children during this process? How can we help each one of them understand what's going on? There are no easy answers.

In many cases, psychosocial support is not integrated into pediatric oncology care, and/or does not start with diagnosis. Support for siblings of cancer kids has grown tremendously in the past 20 years, but there are many hospitals and healthcare organizations that don't offer this support. Similarly, outreach and education for families about palliative care and end of life options are becoming more common but are certainly not the norm nor are they always covered by insurance.

1 in 3 Americans will get cancer. No one expects it before it happens. How can we help families who face this diagnosis feel less alone? We've included a partial list of resources at the end of this guide. How can we integrate psychosocial care for families into all cancer treatment at all healthcare organizations?

TALKING ABOUT DEATH

We all want to believe that eventually there will be a cure for every disease that could kill us. As we've become amazingly capable of extending life through medicine and technology, we've also become worse at facing the fact that death is the natural last event in any person's life.

Many families feel confused and intimidated about hospice and palliative care. Although the fields of medicine and psychology have developed practices aimed at coping with end-of-life issues, health insurance companies have made these practices difficult to implement. Misinformation abounds. National debates have complicated efforts to promote "the good death."

As Ira Byock says in *The Best Care Possible*, "Public policy discussions related to incurable illness, dying, death and grief are typically confined to either the costs of health care or the pros and cons of physician-assisted suicide. Neither are adequate proxies for the fundamental questions of how our society should respond to... ill members and the families who care for them." Consider this: "Although the evidence keeps building, it is still surprising to many people that hospice and palliative care help patients live longer."

Contemporary psychiatric discourse is making it easier to regard grief as an illness that can be treated with medication. Two prominent research groups recently proposed a diagnostic measure by which intense grief that lasts more than six months would be considered pathological, and the 2013 psychiatric diagnostic manual made it easier to prescribe antidepressants in the weeks immediately following a loss.

But more destructive than any trends in the insurance and psychiatric industries is the disappearance of public mourning rituals. For most of history, mourning rituals were public and communal, and lasted beyond the funeral. A hundred years ago, people would dress in mourning garb for sometimes years after the death of a close relative. Today we take a few days off from work and friends send awkwardly-phrased condolences via email.

Grief is not a disease. Mourning is not abnormal. Loss is not something we can avoid nor is it something we can just get over. We all struggle to find ways to talk about our loss. We need context and structure for these conversations. Our society is getting better at providing them as you can see from the partial list of resources that we provide at the end of this guide.



FOR INDIVIDUALS

- What are your immediate thoughts following the film? Which family member do you relate to most and why?
- What sorts of losses have you experienced in your life? These could be deaths or other types of losses, like loss of innocence, home, job, or even an object. How did you process this loss at the time it happened? How did you process it over time?
- How do your family dynamics compare to this family's dynamics? Do certain family members process grief and emotions differently than others? How does this affect how you treat big emotional issues together, as a whole?
- Do you have a sibling? If yes, what do you think was your sibling role in your family? Was your sister/brother older or younger, a mentor or a mentee? Were you the loud one, the quiet one, the artsy one, the one to follow in your parents' footsteps? If you're an only child, what role do you think you filled in your family?
- Does your family keep secrets? From each other and/or from the world at large? You don't have to share these secrets, but what was okay to talk about and what was not okay to talk about? What lines were drawn, where and why?
- We all go through an adjustment when we begin to see our parents as people vulnerable, struggling. Do you remember when you first saw your parents in this light? What emotions came up for you? How did those feelings affect your perceptions of them?
- What was your initial reaction to the death of someone you knew and loved? How have your feelings changed over time?
- What aspects of your childhood did you not understand or process at the time? When were you first able to look back and appreciate the larger context?
- What adults spoke to you about death when you were a kid? What did they say and how did you feel listening to them? What role or responsibility, if any, do you think adults have in speaking to children about death?

ACTIVITY: Write your own grief narrative. You can do this in prose, poetry, collage, music - however you feel most comfortable expressing yourself. Think about how you felt before the loss, as the loss happened, and afterwards. Try to stick to your own feelings.

FOR FAMILIES

- What are your immediate thoughts following the film? What stands out for you?
- Grief is different for each family member. How did you see Molly, Jack and Mary Jane in *Peanut Gallery* relate to their own grief? How did their grief needs and expressions sometimes help each other? How did they sometimes get in each other's ways? Do your family members have different or similar grief needs and styles? How do they play out in the dynamics of the family?
- Cancer changes a family. What sense did you get of changing family roles around Aimee's illness? How did your family dynamics change in the aftermath of a diagnosis or accident?
- As a sibling, do you feel pressure to hold up a certain role in your family? Do you let your brother or sister fulfill certain expectations, while you fulfill others?
- How do you feel about being the "well" sibling? And/or how do you feel about being the "ill" sibling?
- Many families struggle to talk about an impending death. What could be the benefits of such a conversation? What are your thoughts about the timing of such a conversation? What were your feelings about Molly's anger at not being directly told that her sister was going to die?
- Many people are unsure of how to speak with kids about death. What would be your approach to talking to death with toddlers, with school age children, with teenagers? This is a very complicated question.
- In the 1800s, 43% of the world's newborns died before their 5th Birthday. However, today childhood deaths are very rare. How do you think the rarity of child death in our culture has affected your situation if you are a surviving sibling?

ACTIVITY: What would talking about death look like in your family? For the parents? For the kids? What would it take to have this happen? Would you want such a conversation to happen or not? Who would be the family member most likely to start this talk? Would you want a helping professional with you? What would you hope to get out of such a conversation? What are the possible risks with such a conversation?

FOR MEDICAL PROFESSIONALS

- What are your immediate thoughts and impressions of the film? Describe any similar cases you've encountered in your practice.
- How do you and your staff deal with death when it occurs in your practice?
- Each family deals with illness differently. What sorts of dynamics have you witnessed? Does the family's communication style affect how you engage with them?
- In your experience, what support can be offered to the well siblings of ill children? Of course, physicians can only do so much. In your work with children, what programs or approaches seem helpful for the issues that might come up for well siblings?
- How do you view the role of the physician in relation to nurses, child life specialist, social worker, psychologist, hospice workers, palliative care specialist, etc. in speaking with patients and their families about the death process?
- Based upon her observations of leukemic children, ages three to nine in a hospital ward, Myra Bluebond-Langner states that terminally ill children understand their prognosis even if no one tells them. What do you think of this possibility?
- Keeping in mind that each case is unique and requires its own logic, how important do you think life extension is in relationship to quality of life? Are extreme life-saving measures appropriate to extend life for a number of months? Does this equation change for you when the patient is a child, or not?
- When you experience grief in the course of your work, how do you process it? If you wanted to express or share your grief over the death of a patient, who would be the most likely people you would seek out?
- How much education about dealing with death issues did you receive during each stage of your medical training (e.g medical school, residency, fellowship)? Are there issues related to this that you would like to see incorporated into the curriculum at any or all of these stages? What changes are you aware of in current training?

ACTIVITY - Gather resources and samples of end-of-life protocols. Investigate the places that seem to have a rationale and protocol that fit with the philosophy your practice would like to follow. Find family and sibling care protocols that are compatible and consistent with your desired approach.

FOR MENTAL HEALTH PROFESSIONALS

- What are your immediate thoughts, feelings and impressions in reaction to the film? How did it align with your expectations of what families go through? Did it shock or surprise you in any way? What are the disadvantages or perhaps advantages to this family finally doing this work together so many years later?
- Each family member had different grieving needs and strategies at different times. At times did you see the grief bringing the family together and at times did you see it drawing the family apart? Explore how the varied grieving strategies interacted.
- What different coping styles have you seen in grieving children? Have any of you had the opportunity to work with a grieving sibling over a significant span of time? What kinds of affects effect do you think sibling grief could have on a developing child/adolescent's personality development, friendships, romantic relationships, career choices, rituals in life? What are the variables in sibling relationships (e.g. age, age difference, personality, personality differences, degree of closeness, relationship at time of death) that you think could affect the surviving sibling's grief?
- Where do you think parental grief fits into how comfortable grieving siblings feel to express their emotions? What are your thoughts about a well-sibling who has lived for years with an ill-siblings chronic illness and then experiences a sibling death?
- What do you see as the difference between grief and depression? What has your training and experience taught you about the possibility that grief could become pathological at some point? How would you make that clinical judgment particularly with a young person? Could there be a developmental component to grief for some people who experienced a loss at a young age?
- How will you approach surviving siblings and grieving families any differently as a result of seeing this film? What would you like to add to its message from your own clinical or personal experience?

ACTIVITY - Think about what significance you place on a person's history as a bereaved sibling. How much time do you spend exploring it with him or her? Could psychological problems be occurring at a particular time because of an anniversary date, a particular life milestone that is approaching, etc.? The point here is not to become overly focused upon this possibly life defining loss, but also not to underestimate this potentially significant feature of a person's history. The literature would indicate it deserves some exploration.



READING LIST

Note from the filmmaker: Everyone processes grief differently. Some of us are more emotional and intuitive, while others are more analytical and intellectual. What I found most helpful were authors who were able to tell a story about their own loss and to explore that emotional space in depth. This list is by no means comprehensive. These are books that, personally, resonated with me and helped me learn how to tell my own story.

- 1. How We Die, by Sherwin Nuland
- 2. A Grief Observed, by C.S. Lewis
- 3. The New Black, by Darian Leader
- 4. The Empty Room, by Elizabeth DeVita-Raeburn
- 5. The Best Care Possible, by Ira Byock
- 6. Mourning Diary, by Roland Barthes
- 7. The Long Goodbye, by Meghan O'Rourke
- 8. Her, by Christa Parravani
- 9. Mortality, by Christopher Hitchens
- 10. On Grief and Grieving, by Elisabeth Kübler-Ross & David Kessler

FOR FAMILIES DEALING WITH CANCER

SUPPORT ORGANIZATIONS

NOTE: There are many more support organizations for a variety of diseases not listed here. Please ask your treatment team for suggestions and/or begin your own search for support organizations in your own town or a nearby city.

Friends of Karen - NYC/Tri-State area, provides support critically ill children and their siblings

Ulman Cancer Fund for Young Adults - community for cancer patients age 15-39

Cancer Support Community - support network with centers in 24 U.S. states

Leukemia & Lymphoma Society - provides information, resources and support to those affected by blood cancers

Stupid Cancer - addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health and social media

The Bone Marrow Foundation - offers financial assistance and free support services to bone marrow/stem cell transplant patients and their families

Childhood Leukemia Foundation - promotes patient education, advocacy, self-esteem and most of all - smiles. All programs are free of charge, and available to any pediatric cancer patient living in the continental United States

Leukemia Research Foundation - has a list of more great resources for families and young adults dealing with all cancers

American Childhood Cancer Organization (formerly Candlelighters) - offers free resources for kids, teens and families facing cancer, chapters in 26 states

Cancer Hope Network - matches cancer patients to volunteer cancer survivors for free one-on-one support, in U.S. & Canada

MacMillan Cancer Support - UK's cancer support network

American Cancer Society - provides resources and links on multiple aspects of living with cancer.

Cancer Hawk - connects patients and caregivers with services

Starlight Children's Foundation - provides virtual reality glasses, brave gowns, fun stations, celebrity visits and more in an effort to entertain, distract and create better health outcomes for ill children.

Ronald McDonald House Charities - provides housing and support for parents and families who need to be close to treatment facilities.

SUMMER CAMPS

Many summer camps are offered for cancer kids and their siblings. A comprehensive list can be found at: http://www.ped-onc.org/cfissues/camps.html

HOSPICE/PALLIATIVE CARE

NOTE: Pediatric palliative and hospice care are both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions, as well as their families. It is provided along with concurrent disease-modifying therapy when disease-modifying therapy is appropriate, or as the main focus of care when disease modifying therapies are no longer effective and comfort is of utmost importance. Your treatment team may be a resource for more information about considering this option.

National Hospice and Palliative Care Organization - offers extensive resources on choosing hospice or pediatric palliative care, as well as consultation for professionals/care providers

Compassion in Dying - UK organization for hospice education and outreach

FOR KIDS AND YOUNG ADULTS DEALING WITH CANCER

BOOKS

Many organizations provide lists of books that are appropriate for various age groups of children facing cancer, as well as for their caregivers. One such list can be found here: https://medicine.yale.edu/cancer/patient/specialty/pact/booklist.aspx

BLOG

Life, Interrupted - NY times blogger Suleika Jaouad writes about having cancer in her 20s.

ORGANIZATIONS

Stupid Cancer - addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health and social media

Ulman Cancer Fund for Young Adults - community for cancer patients age 15-39. Services of-fered in Mid-Atlantic and remotely.

Hello Grief - online grief community for grieving children and families, with great state by state resource links

First Descents - free outdoor adventure trips for young adult cancer fighters and survivors

FOR KIDS AND YOUNG ADULTS DEALING WITH LOSS

GRIEF ORGANIZATIONS

Dougy Center - activities, support, resources for grieving children. Based in Portland, OR, but includes links to local support across the US.

National Alliance on Grieving Children - extensive links to ideas, information and resources on how to support grieving children and families, including listings of local support throughout the US.

Fernlife - provides grief services to children and their families, based out of Cincinnati, OH but also offers phone consultations and community outreach

Actively Moving Forward - peer-led grief groups and community outreach on over 50 college campuses in the US & Canada.

Kids Connected - support for kids of a parent with cancer or who have lost a parent to cancer, based in Orange County, CA, mails support kits

Willow House - free services for grieving children, teens and families in the Chicago area

The Children's Room - free services for grieving children, teens and families in the Boston area

MISS Foundation - database of support groups and grief care providers

BOOKS

Love Letters to the Dead, by Ava Dellaira The Summer of Letting Go, by Gae Polisner

SUMMER CAMPS

NOTE: The National Alliance for Grieving Children keeps a list here: https://childrengrieve.org/camps. There are many new grief camps emerging.

Camp Erin - weekend camp for grieving kids (age 6-17), 45 locations

Comfort Zone Camp - free camp for grieving kids (age 7-17), currently in Virginia, Massachusetts, New Jersey and California

Camp Courage - for children (age 7-18)

Camp Live Laugh Love - free camp in Michigan

Camp Good Grief - grief camp on Staten Island

Camp Magic - one day grief retreats near St. Louis

Circle Camps for Grieving Children - free, week-long camp in Morgantown, WV for girls ages 8-16 who are grieving the loss of a parent

FOR BEREAVED SIBLINGS

BOOKS

The Empty Room, by Elizabeth DeVita-Raeburn
Love Letters to the Dead, by Ava Dellaira
Visions of Gerard, by Jack Kerouac
Shadows in the Sun, by Betty Davies
Sibling Loss, by Joanna Fanos
Franny & Zooey, by J.D. Salinger
Ambiguous Loss, by Pauline Boss
My Brother, by Jamaica Kincaid
Born to Rebel: Birth Order, Family Dynamics, and Creative Lives, by Frank Sulloway
Brothers and Sisters, by Judy Dunn
The Accidental Bond, by Susan Scarf Merrell
Sibling Relationships Across the Life Span, by Victor G. Cicirelli
Surviving the Death of a Sibling, by T.J. Wray
Grieving for the Sibling You Lost, by Erica Goldblatt Hyatt, DSW
Heart Work: A Family Pilgrimage Inspired by Sibling Grief, by Mary Jane Gandour

GRIEF GROUPS

Compassionate Friends - free support groups with nearly 700 chapters across all 50 US States, started for bereaved parents, some chapters have sibling groups & if they don't you can start one

Bereaved Parents of USA - free support groups for bereaved parents with many locations across the US, some chapters have sibling loss groups & if they don't you may be able to start one

COPE Foundation - support groups for parents, teens and siblings in New York

TAPS - Nationwide services for those who have lost a loved serving in our Armed Forces or as a result of his or her service.

FOR BEREAVED PARENTS

BOOKS

Heart Work: A Family Pilgrimage Inspired by Sibling Grief, by Mary Jane Gandour Grieving: How to Go on Living When Someone You Love Dies, by Therese Rando, PhD Parental Loss of a Child, edited by Therese Rando Healing Through the Dark Emotions, by Miriam Greenspan How We Grieve: Relearning the World, Revised Edition by Thomas Attig Ten Steps for Parenting Your Grieving Children, by Vicki Scalzitti

GRIEF GROUPS

See above, under Sibling Loss Grief Groups, all are applicable.

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MORE RESOURCES FOR BEREAVED ADULTS

BLOGS/MEDIA

Peanut Gallery blog - filmmaker Molly Gandour's thoughts on grief, sibling loss, and how grief changes over time

Open to Hope - website with inspirational stories of loss, also offers grief and loss interviews on radio and television show

What's Your Grief - website with many resources, created by two Baltimore-based mental health professionals with 20+ years of experience

Where's the Grief - podcast on grief by New York comedian Jordon Ferber

The Modern Loss - website with columns offering candid thoughts on grief

BOOKS

A Grief Observed, by C.S. Lewis
The Year of Magical Thinking, Joan Didion
Blue Nights, by Joan Didion
How We Grieve, Thomas Attig
The Hour of Our Death, by Philippe Ariès
On Death and Dying, by Elisabeth Kübler-Ross, M.D.
Bereavement: Studies of grief in adult life, by Colin Murray Parkes
Meaning Reconstruction & the Experience of Loss, Edited by
Robert A. Neimeyer
My Dakota, Rebecca Norris Webb

FOR ANYONE INTERESTED IN DEATH CULTURE

BOOKS

How We Die, by Sherwin Nuland
The New Black, by Darian Leader
American Afterlife, by Kate Sweeney
Stiff: The Curious Lives of Human Cadavers, by Mary Roach

GROUPS

Death Cafe - meet-up group with over 4,000 chapters in over 50 countries, where people talk about death, with a goal to increase awareness

Order of the Good Death - funeral industry professionals, academics, artists exploring ways to prepare a death phobic culture for their inevitable mortality

AfterTalk - website where you can write to loved ones, share with family and friends, also offers resources for grief therapists

FILMS

Consider the Conversation - Emmy-nominated series that intimately explores the American struggle with communication and preparation for end of life

FOR ANYONE INTERESTED IN PALLIATIVE CARE

BOOKS

The Best Care Possible, by Ira Byock

ORGANIZATIONS

Children's Hospice International - non-profit that promotes integrated hospice care in pediatrics from the time of diagnosis

Hospice Foundation of America - non-profit that provides professional development, public education and research on hospice and end-of-life care

Cicely Saunders International - non-profit dedicated to funding research and public education on best practices for palliative care

National Hospice and Palliative Care Organization - mobilizes social change for improved care at the end of life through advocacy, hospice reporting, resources

Center to Advance Palliative Care - national, member-based organization, that provides health care organizations with tools to implement and integrate palliative care

FOR ANYONE INTERESTED IN CANCER ACTIVISM

ORGANIZATIONS

Gabrielle's Angels Foundation for Cancer Research - funds research for blood cancers

Be The Match - the largest and most diverse bone marrow registry in the world, for those who need bone marrow transplants. Easy to join!

Light the Night Walk - series of fundraising campaigns benefiting The Leukemia & Lymphoma Society (LLS)

American Cancer Society (ACS) Cancer Action Network - volunteer action teams in over 400 communities across the nation fighting for legislation to help cancer patients and find a cure

Stand Up to Cancer - non-profit that funds cancer research

American Association for Cancer Research - non-profit that funds cancer research

Kids Without Cancer - raises funds for pediatric cancer research being done at Children's Hospital of Michigan, Wayne State University, and Karmanos Cancer Institute

