

Guide For Parents and Caregivers



MY LiFE BY ME A KID'S FOREVER BOOK

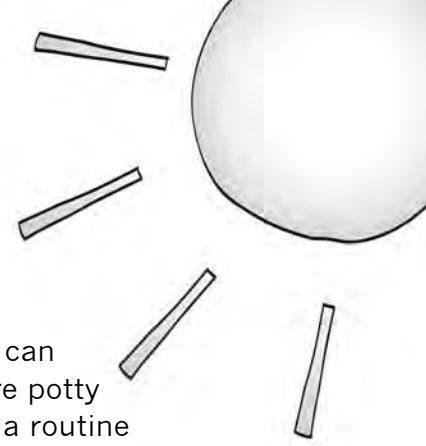
by Beth Barber, PsyD

No one ever imagines that their child's life may be cut short. *My Life By Me* is meant to serve as a guide for you and for your child's clinicians and caretakers. It is intended to ease your discussions of the past, present, and potential effects of your child's illness, and help your child resolve any unfinished business. There is not one way to use this autobiographical scrapbook, as it is up to you and, most importantly, your child to decide which pages to complete and the order and speed in which to proceed. There are no right or wrong answers, because the scrapbook will reflect reality as your child is seeing and experiencing it.

People of all ages give meaning to their lives through the stories they tell about themselves. A life story becomes a way for children to inform themselves and others about their lives; it also serves as a way of forming an identity. Life storybooks are beneficial in helping children comprehend their world and understand where they fit in relation to their family, their illness, and the hospital and medical personnel.

By creating a life storybook, your child can express and document his or her feelings nonverbally, and securely retain them to be used over and over again when your child decides that they are ready to talk about them further. Stories can reflect your child's inner fears and fantasies, offering a significant degree of resolution and comfort. Scrapbooks can also serve as a ventilator mechanism for ill children, allowing you and hospital staff a view of your child's perceptions and adjustments to his or her illness. Pictures provide a space for children to uninhibitedly express thoughts and feelings, reducing the pressure to talk directly about themselves. The scrapbook allows for great flexibility, as the only limits are the creativity of you and your child. By using art as a coping mechanism, your child has the opportunity to creatively express emotions. He or she will be making choices, as well, which can provide a sense of mastery and control in a sometimes out-of-control situation. Ultimately, art serves as a visible legacy of your child's life. This scrapbook provides permanent proof of your child's existence, leaving behind a lasting mark on the world.

Children's Development



Children naturally progress through certain development stages. However, when faced with a terminal illness, their progression is often altered. Understanding the ways terminal illness can affect your child's development may help you understand your child and his or her experiences.

The Effects of Traumatic Stress on Childhood Development

Terminal illness alters a child's progression through natural development stages, and your child may rapidly mature, regress, or both. For example, a ten-year-old child may mentally mature, knowing more about his or her illness and treatment than any adult, but behaviorally regress, resorting back to thumb-sucking and acting out. Even though terminally ill children advance cognitively, they may regress behaviorally. This, combined with being unable to do "normal" childhood activities (school, sports) and being physically incapable of doing certain things for themselves (dressing, bathing), often fosters low self-esteem, a sense of helplessness, and a lack of control.

Validating your child's fears and providing him or her with as much control as possible at any age is crucial in reducing feelings of shame and isolation. Below, you will find a list of typical physical, cognitive, social, and behavioral development milestones in children's lives, as well as information on how having a serious illness may impact their growth. Remember that each child grows and matures at different speeds and ages.

Regardless of your child's chronological age or development stage, it is important he or she has permission to express experiences in a manner that removes shame and promotes unconditional love and acceptance.



Ages Six and Younger:

Children younger than six can typically talk and write, are potty trained, and can sleep on a routine schedule. These physical milestones may be altered by traumatic stress: Children younger than six may regress to younger behaviors, like baby talk or bedwetting. They may want to be held more than expected, and they can experience sleep problems, muscle weakness or tension, stomachaches, and a decreased appetite.

Cognitively, children at this age can understand that something exists even when it is out of sight, they are beginning to solve problems and cooperate with peers, and they exhibit impulse control. Children experiencing traumatic stress, on the other hand, may be impulsive and fidgety, and may not engage in problem-solving or independent decision-making.

Social milestones for children six and under are about attachment and independence. Children begin to feel attachment, trust, and security when their basic needs are met, and they are increasingly independent and want to explore. A terminally ill child may instead seem helpless and agitated, might be overly dependent on others, and may be fearful of strangers and new experiences.

Finally, children six years old and younger are developing behaviorally. They generally experience the occasional tantrum or outburst, but they are also beginning to play side by side with other children, are learning to share, and initiate play with peers. Traumatic stress can alter this development, and children may cling to their caregivers; have more verbal, emotional, and physical tantrums than expected; and may not engage in cooperative play.

Ages 7–11: Physically, children in this age range typically experience growth spurts, show increased muscle coordination, and average 10 hours of sleep each night. Children who have experienced traumatic stress may see these developmental milestones altered. They might have nightmares or other problems sleeping, and may under- or overeat, or experience pain, headaches, stomachaches, rapid heartbeat, muscle weakness or tension, dizziness, and shortness of breath.

Typical cognitive milestones at these ages include the ability to concentrate for increased periods of time, stronger reading and writing abilities, and an understanding of cause and effect. Children with terminal illness may instead have trouble with concentration and focus, might misperceive information or motives, and can seem preoccupied with death.

By the ages of 7–11, children tend to have stronger impulse control. Socially, children this age are typically developing a sense of self and beginning to show responsibility. They may spend more time with friends than family, and begin to bond with adults besides their parents. When these milestones are altered by traumatic stress, children may blame themselves for their illness, fear that more bad things will happen to themselves or to loved ones, and might find it hard to think about anything except their illness. They may also be irritable or suffer rapid and intense mood swings.

Children ages 7–11 also tend to experience significant behavioral advances: they are generally able to participate in established routines without many reminders, and they become increasingly curious and ask many questions of adults. Children experiencing traumatic stress, on the other hand, may seem paranoid, aggressive, withdrawn, or disorganized. They may participate in repetitive and focused play that is based

on their illness, and might revert to earlier childhood behaviors like thumb-sucking or bedwetting.

Ages 12 and Older: Older children go through puberty, which involves many physical developmental milestones. Children going through puberty generally have an increased need to sleep and tend to need to eat more. Older children who are experiencing traumatic stress might have problems with sleeping or eating. They might experience pain, like headaches or stomachaches, or muscle weakness, tension, dizziness, and shortness of breath. They may also be less interested in personal hygiene than would be expected.

On the cognitive track, older children exhibit an increased ability to think abstractly, solve problems, see other people's points of view, and test their own individual thoughts. When those milestones are altered by traumatic stress, an older child might seem distractible or have learning impairments. These children might be absent-minded and have difficulty problem-solving, planning, and rationalizing. They can feel helpless, out of control, and even ugly or just different from their peers. Like children ages 7–11, children ages 12 and older may also be preoccupied with death.

Older children also typically experience many social changes as they develop. They begin to form individual identities and have their own beliefs and morals. They tend to show a greater need for independence and privacy, and they begin to separate from their parents and their friends become increasingly important. They generally begin to be interested in romance, and tend to enjoy social activities. However, older children who have experienced traumatic stress might withdraw from family



or peers, and can experience loneliness and isolation. Older children with terminal illness may feel guilt or blame themselves for their illness, and might be embarrassed by their physical symptoms.

Older children can take on more responsibilities at home and in school, but behavioral development for older children can also include mood swings and challenges to parental authority. Children whose development is altered due to traumatic stress may also experience mood swings and irritability, although they may be more extreme. They also tend to challenge parental authority, but may do so by engaging in dangerous and rebellious behaviors like drug and alcohol abuse, sexual promiscuity, or self-harm. Older children who are experiencing traumatic stress may also withdraw from family, peer, and social activities.

Children's Understanding of Death in General

You may be wondering what and how much your child understands about death. Your child may have gone through the death of a family member or pet in the past, or this may be your child's first encounter with the topic. Many circumstances (e.g., age, life experiences, or culture) shape your child's comprehension of death. Below, you will find common ways that children think about and experience death according to children's chronological age.

Ages 3–6: At this age children see death as similar to sleep, believing that the person is alive, but in some limited way. The child is not able to completely separate death from life. Children may believe that the dead continue to live on. For example, they may believe that a deceased person is alive in the ground where he or she was buried. Very

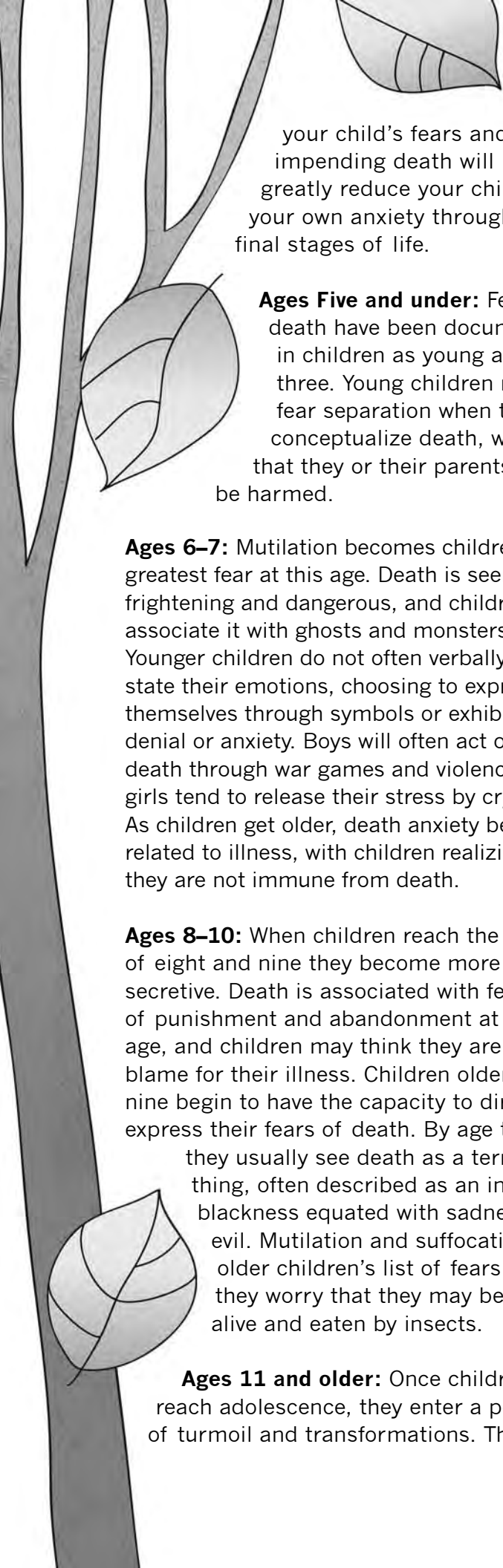
young children frequently ask questions about the deceased person like how he or she is eating, going to the toilet, breathing, or playing. Similar to a game of peek-a-boo, death is viewed as reversible, rather than final. Magical thinking is often involved in their perception of death. Children may believe that they have done or thought something bad to become ill or to cause the death of a loved one.

Ages 6–9: Children this age become very curious about death, asking specific questions about what happens to one's body when life stops. "Death" is often seen as a separate person or spirit such as a skeleton, ghost, angel of death, or bogey man. Death is typically perceived as final and frightening. Children this age begin to recognize that death is real, but they perceive it as mostly happening to the elderly (not to themselves).

Ages Nine and older: By the time a child is nine years old, death is understood as unavoidable, final, and universal. Older children often talk to those around them, especially their peers, as a way of receiving answers to unanswerable questions. For example, a child may ask, "Now that Grandpa died, when is Grandma going to die?" This is often a way of seeking control and confirming the story of the death.

Children's Fears of Death

Regardless of your child's age, one of the keys to managing your child's fear requires that you know how to tolerate it, face it head on, and discover correct actions. Fear lets you and your child know that something is not right and needs immediate attention. Rather than telling your child not to be afraid, you may find it beneficial to help your child describe what he or she is afraid of. The act of description may help to reduce the fear. Acknowledging



your child's fears and impending death will likely greatly reduce your child's and your own anxiety throughout the final stages of life.

Ages Five and under: Fears of death have been documented in children as young as three. Young children mostly fear separation when they conceptualize death, worrying that they or their parents may be harmed.

Ages 6–7: Mutilation becomes children's greatest fear at this age. Death is seen as frightening and dangerous, and children associate it with ghosts and monsters. Younger children do not often verbally state their emotions, choosing to express themselves through symbols or exhibiting denial or anxiety. Boys will often act out death through war games and violence, while girls tend to release their stress by crying. As children get older, death anxiety becomes related to illness, with children realizing that they are not immune from death.

Ages 8–10: When children reach the ages of eight and nine they become more secretive. Death is associated with fears of punishment and abandonment at this age, and children may think they are to blame for their illness. Children older than nine begin to have the capacity to directly express their fears of death. By age ten, they usually see death as a terrible thing, often described as an incredible blackness equated with sadness and evil. Mutilation and suffocation tops older children's list of fears and they worry that they may be buried alive and eaten by insects.

Ages 11 and older: Once children reach adolescence, they enter a period of turmoil and transformations. Their

two main fears are typically related to their physical development and the future. Adolescents desperately seek some control over their bodies, health, and their individual futures. Death poses the ultimate challenge to their locus of control, resulting in denial and defiance of death. Some adolescents need to cling to their belief of personal immortality in order to get by day to day.

Spirituality

Regardless of age, those who are dying naturally seek out meaning and purpose. Your child may benefit from empathic listening, prayer, music, touch, and performing religious rituals to ease his or her physical and emotional pain. Many children believe that God has an appointed time for life and that he has reasons for allowing death.

During an illness, your child's spirituality may be challenged, leading to feelings of isolation, abandonment, and uncertainty about the meaning of life. Your child may ask, "How could God let this happen?" "Is God punishing me?" or "Why has God abandoned me?" Your child may be comforted by believing in some form of life after death. Those who hold on to the idea of life after death have been found to be better equipped to cope with their impending separation from loved ones while simultaneously maintaining hope and love. Prayer has also been found to be helpful for terminally ill children, as it can potentially increase feelings of safety while decreasing children's sense of loneliness.

Children often express their religious views through symbolism, such as dreams, art, or poetry. Terminally ill children's drawings commonly display a wide array of religious and mythological death imagery, demonstrating a sense of power over dying through themes of death and

rebirth. You can take advantage of your child's imagination, encouraging him or her to take a ride on a "magic carpet" for imagined trips to heaven or a land that is devoid of pain in order to encourage relaxation and coping. You can also make a "prayer pillow," which provides your child opportunities for creativity and communication while simultaneously leaving him or her with a physical object to be used in prayer or meditation. If your child is older, he or she may appreciate techniques such as spiritual reviews of life that cover relationships, achievements, and regrets.

Ages Six and Younger: Faith reflects hope and trust. Children this age have vivid imaginations involving magical thinking. Their image of God often reflects powerful male figures in their lives. Their spirituality can play a large role in developing their knowledge that they are loved and valued, providing them with courage.

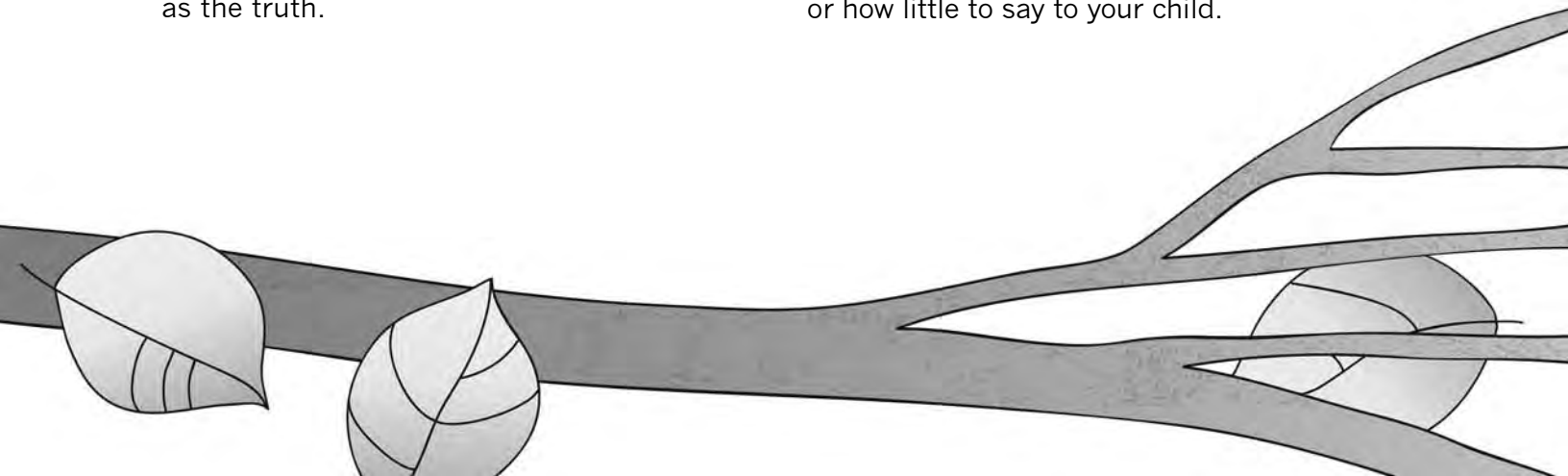
Ages 7–11: Faith is often about being right or wrong. Worry can play a role, and children this age may fear punishment for their sins or God's wrath. Their views and beliefs typically resemble those of their parents, and they accept external interpretations as the truth.

Ages 12 and Older: Older children increasingly search for meaning, purpose, hope, and value in life. They begin to form their own thoughts and beliefs regarding their faith, accepting internal interpretations as the truth.

Children's Understanding of Their Own Death

Children typically value the opportunity to spend their last days with loved ones, even though their behavior may tend toward isolation. Terminally ill children often experience great conflict as they are simultaneously attracted to and appalled by life due to the immediate physical and mental suffering that they experience as a result of their disease. Children's understanding that they are dying has been documented in children as young as three. You have likely noticed that your child understands the magnitude and effects of his or her illness better than most adults. Your child may conceal the fact that they know they are dying from you in order to protect you from even greater emotional pain. Children often carry a great deal of guilt about their illness, seeing themselves as a burden to their families.

Denying the reality of the situation in no way alleviates your child's concerns as he or she gains an advanced understanding of death. When you fail to acknowledge the severity of your child's condition, he or she may not want to communicate fears, worries, or questions. Withholding information from your child is not only unhelpful, but may be emotionally, mentally, and physically damaging. The loneliest children are those who know of their fate but are unable to communicate it. Deciding how much to say and when should depend on your child and your situation. You should ultimately focus on being open and honest rather than worrying about how much or how little to say to your child.



Communicating About Death

As a parent or caregiver, you might feel unable to cope with or talk about your child's illness. It's common for parents to avoid the topic of illness and death with their child; you might fear that you won't be able to control your sadness, or that you may add to your child's pain. But by expressing your own emotions, you inform your child that it is OK to grieve and voice concerns. Here are some other things to keep in mind as you broach this difficult subject with your child.

The book is designed for, although not limited to, children ages 7 to 11. By this age, most children have a basic understanding of death. Children who are faced with a chronic illness demonstrate an even more accurate comprehension of death at an earlier age. Without being directly told, ill children pick up on cues and pieces of information, knowing better than many adults the severity and details of their illness. However, this does not mean that your child does not desire answers or reassurance. Your child's questions about life and death are likely very similar to those of adults, and may include:

1. What did I do to deserve this?
2. Will death be painful?
3. Where will I go?
4. Will I be forgotten?
5. What will happen to my family, friends, or possessions?
6. How do others see me?
7. Who am I?
8. Will I be alone?

While some children will use words to voice their experience and what they are feeling, the majority will choose other forms of communication, such as drawing and symbolism. Children's drawings serve as a transitional space in which internalized feelings can be projected into a concrete

form. Art for children is often relaxing, reducing their defenses and increasing communication. There are four main ways that art has been found to be beneficial for hospitalized children: (a) it serves as another problem-solving approach; (b) it provides a safe means of expressing feelings and desires that the child may perceive as unacceptable; (c) it grants children a less stressful means of communication; and, (d) it provides a glimpse into children's internal worlds. It is often most helpful to allow your child to choose the form, color, and design of his or her artwork. Instead of pushing your child to discuss his or her drawings or making assumptions about your child's drawings, you may find it more beneficial to allow your child to be the informant on the drawing. In a child's drawings, what he or she chooses to leave out is often more important or just as important as what is included. For example, children who leave themselves out of a family portrait may be feeling isolated or unimportant.

Rather than discussing fears and concerns with words, your child may have an easier time communicating through artwork. There are several pages in this scrapbook where your child can express who he or she is and what he or she needs by drawing or cutting out pictures. By using photographs, your child may identify as an individual rather than a patient. You can also remind your child that he or she is not alone, while emphasizing family unity and strengthening family bonds, by looking at photographs.

Your child does not always need you or the doctors to have all the answers. Rather, most ill children desire open and honest communication. Most importantly, any terminally ill child needs to know that he or she matters, will be cared for, and will not be alone.

When you're speaking with your child about death, avoid clichés and euphemisms such as “passed on,” “were lost,” or “went to sleep,” as your child may take these literally, leading to great uncertainty and fear. Depending on your child's level of comprehension, try to speak of death matter-of-factly, focusing on the permanence and universality of death. When talking with your child about death you should proceed slowly, allowing the child to ask questions, conveying hope, and establishing love and security based on trust.

Remembering the “6 E's” may be helpful when talking to your child about death.¹

1. **Establish** a pact between yourself and your child from the start, making open communication the norm.
2. **Engage** your child in conversation at proper times, using changes in his or her condition as an open door.

3. **Explore** what your child already understands about the illness and what he or she wants or does not want to know, dispelling any misconceptions.
4. **Explain** the illness in a way that is age appropriate. Children often want to know what is occurring and what is to come.
5. **Empathize**, validate, and clarify your child's emotional reactions.
6. **Encourage** your child by confirming that you will be there to discuss any questions or concerns. Not making any guarantees, but confirming that life's tasks will continue, ensures some form of stability.

¹ Beale, E., Baile, W., & Aaron, J. (2005). Silence is not golden: Communicating with children dying from cancer. *Journal of Clinical Oncology*, 23, 3629-3631.

Additional Resources for Parents and Caregivers

Bereaved Children and Teens

By: Earl A. Grollman, A supportive guide for parents and professionals. Beacon Press, 1995.

Beyond the Innocence of Childhood

By: David Adams & Eleanor Deveau, Helping children and adolescents cope with life threatening illness and dying. Baywood Publishing Co., 1995.

Children and Death

By: Danai Papadatou & Costas Papadatos, Guide for coping with and caring for dying children. Hemisphere Publishing Corporation, 1991.

Talking About Death

By: Earl A. Grollman, Practical guidebook for caregivers who are faced with explain death to a child while struggling with their own feelings about death. Beacon Press, 1990.

When Bad Things Happen to Good People

By: Harold S. Kushner, Written by a father who tries to make sense of the death of his 3-year-old son. Avon, 1983.

Comfort: A Journey Through Grief

By: Ann Hood, A mother's memoir chronicling the death of her 5-year-old daughter and its soul-searching aftermath. W.W. Norton, 2008.

A Grief Observed

By: C.S. Lewis, Honest record of searching for meaning following the death of a loved one. HarperOne, 2001.

Our Greatest Gift: A Meditation on Dying and Caring

By: Henri J. Nouwen, Discusses the realities involved in caring for those who are dying and facing death ourselves. HarperOne, 1995.

Resources for Children and Adolescents

If I Die and When I Die

By: Franki and Barbara Sternberg,
Exploring death with young people – Poems
and pictures by children. Prentice-Hall,
Inc., 1980.

Lifetimes

By: Bryan Mellonie & Robert Ingpen, A
picture book explaining death to children.
Bantam, 1983.

There is a Rainbow Behind Every Dark Cloud

By: Gerald G. Jampolsky, Written by 11
children facing life-threatening illnesses.
Celestial Arts, 1979.

Black Jack Jetty: A Boy's Journey Through Grief

By: Michael A. Carestio, Fictional story of a
boy's journey through grief, anger, anxiety,
and guilt. Magination Press, 2010.

Samantha Jane's Missing Smile: A Story About Coping with the Loss of a Parent

By: Julie Kaplow & Donna Pincus, Fictional
story that provides tools for overcoming grief.
Magination Press, 2007.

Gentle Willow: A Story for Children About Dying, Second Edition

By: Joyce C. Mills, Helps ill children address
feelings of disbelief, anger, and sadness,
along with love and compassion. Magination
Press, 2004.

Little Tree: A Story for Children With Serious Medical Problems, Second Edition

By: Joyce C. Mills, Helps children who have
experienced life-challenging illnesses or
accidents. Magination Press, 2003.

When Someone Has a Very Serious Illness; When Someone Very Special Dies

By: Marge Heegaard, Activities and
information to help children cope with
loss, grief, and change. Woodland Press,
1992/1988.

Sad Isn't Bad

By: Michaelene Mundy, This guide tells
children what they need to know when
dealing with grief. Abbey Press, 1998.

Kathy's Hats: A Story of Hope

By: Trudy Krisher, A biographical sketch
of a girl's experience with cancer and
chemotherapy. Albert Whitman & Company,
1992.

Resources for Siblings

Jenny: Coming to Terms with the Death of a Sibling

By: Stephanie Jeffs, A storybook written for
K - 4th grade, providing a gentle explanation
of loss and death. Abingdon Press, 2006.

Last Week My Brother Anthony Died

By: M.W. Hickman, A touching story told
through the eyes of a girl whose infant
brother died. Abingdon Press, 1984.

What About Me?:

When Brothers and Sisters get Sick

By: Allan Peterkin, Discusses conflicting
emotions when a sibling becomes seriously
ill. Magination Press, 1992.

I Know I Made It Happen: Children and Guilt

By: Lynn Blackburn, Gives support and
understanding during crises, Centering
Corporation, 1990.

When Dinosaurs Die: A Guide to Understanding Death

By: Laurie Krasny Brown, Explanation of death
and its aftermath for young children, Little,
Brown Books for Young Readers, 1998.

The Next Place

By: Warren Hanson, A story of light and
hope to a place where earthly hurts are left
behind, Waldman House, 1997.

Tear Soup

By: Pat Schweibert and Chuck DeKlyen, A
recipe for healing after loss, Grief Watch, 2005.

