



Empowering kids touched by cancer

# Grief and Bereavement Tools For Childhood Cancer Families

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## Information for Bereaved Families

*Dear Parent:*

*Please accept my sincere condolences and deepest sympathy for the recent loss of your child. Please know that our commitment to support you and your family will continue as you begin this new phase in your journey, and that there are others within the kidsSTRONG community who are also walking this path and are prepared to extend their comfort and hope to you.*

*You are not alone.*

*I hope that the information in this grief and bereavement tool kit will be of help to you. Some of this information may be useful immediately, while some may not be needed until a later time or not at all. We developed this tool kit to try to assist you, newly bereaved parents, through a very difficult and painful time.*

*The list below is a brief look at the various experiences you may encounter as you begin the grief process. You are not going crazy, but are undergoing normal and natural responses to an incredibly profound loss. These reactions occur in no particular order, nor is there a right or wrong way to respond. Let this list be a guide to help you make sense of your initial responses to grief, and to empower you with the courage to move forward in the healing process. Healing is not forgetting; healing is remembering... and ultimately allowing the joy of your child's life to prevail over the pain of the loss.*

*I hope that the following resources provide information that is helpful to you. In addition on our kidsSTRONG community web pages you will also find:*

- *A Grief and Bereavement Resource list to help you in your search for information and support.*
- *Grief education opportunities in your local area and online.*
- *Honor Pages where a family can submit a written tribute and photo of their child.*

*Please feel free to post your experiences, comments and feedback. Again, we are truly sorry for your loss.*

*Sincerely,*

*Christine Falsetti, CEO and President, kidsSTRONG*



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## Helping Bereaved Parents (Simple Do's and Don'ts)

### Please Do...

- Do let your genuine concern and caring show.
- Do be available... to listen, to run errands, to help with the children or whatever else seems to be needed. Make specific offers for things you'd be able to do and continue to make them for several months.
- Do say you are sorry about what has happened to their child and about their pain.
- Do allow them to express as much grief as they are feeling at the moment and are willing to share.
- Do encourage them to be patient with themselves, not to expect too much and not to impose any "shoulds" on themselves.
- Do allow them to talk about the child they have lost as much and as often as they want to.
- Do talk about the special endearing qualities of the child that has died.
- Do give special attention to the child's siblings at the funeral home, during the funeral and in the months to come. They, too, are deeply hurt and in need of attention that their parents may not be able to give at this time or for quite some time.
- Do reassure them that they did everything they could, that the medical care received was the best, or whatever else you know to be true and positive about the care given to their child.

### Please Don't...

- Don't let your own sense of helplessness and fear keep you from reaching out to a bereaved parent.
- Don't avoid them because you are uncomfortable. Being avoided by friends and acquaintances adds pain to an already intolerably painful experience.
- Don't tell them what they "should" feel or do.
- Don't say, "You ought to be feeling better by now," or anything else which implies judgment about their feelings.
- Don't change the subject when they mention their dead child.
- Don't avoid mentioning the child's name out of fear of reminding them of their pain. They haven't forgotten it for one second.
- Don't point out that at least they have other children. Children are not interchangeable; they cannot replace the child who is gone. Don't say, "You can always have another child." Even if they want to and could, another child will not fill the void left by the child who died.



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- Don't suggest they should be grateful for their other children. Grief over the loss of one child does not discount parents' love and appreciation of their living children.
- Don't make any comments which in any way suggest the care given the child at home, in the emergency room, hospital or wherever was inadequate. Parents are plagued by feelings of doubt and guilt even without any "help" from their family and friends.
- Don't say, "I know how you feel" and "time heals all wounds" unless you do know how it feels.
- Don't pretend it never happened or the child never existed.

Remember that grieving is a personal experience. Although we cannot know how another individual will feel as they move through their grief, we can give our support by acknowledging the loss and reaching out to show we care.

The Do's and Don'ts were written by Lee Schmidt, Parent Bereavement Outreach, Santa Monica, CA 90402

## Myths of Grief

### Grief is orderly and predictable.

- Grief is chaotic.
- One does not know when the emotions of grief will hit.
- Emotions wax and wane when grieving.

### Everyone grieves the same.

- Grief is as individual as those who grieve.

### Grief is over after the funeral service.

- Many people believe that life should return to normal following the funeral service, however, the grieving process is barely starting as the shock and numbness give way to other emotions. Grief is a long process of adjustment.

### Ignore grief and it will go away.

- One must experience the pain of grief in order to heal. Ignoring grief prolongs grief.

### Staying busy is a good way to cope with grief.

- Staying busy may be helpful in short-term coping; however, it merely postpones one's grieving.

### If someone is not showing emotion, they are handling their grief.

- Expressing emotions is a healing agent in grief.



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### The goal of grief is to get over it.

- One does not get over the death of a loved one. People can learn to live with the reality of a loved one's death.

### Time heals grief.

- If one does not do the work of grief, time will not heal grief.

## Taking Care of Yourself

- Give yourself permission, time and space to grieve.
- Don't pretend that death doesn't hurt.
- Feel free to protest the "why" of the death.
- Don't judge your level of grief and healing by how others are grieving and healing, but by your own internal awareness.
- Understand and accept your limitations.
- Respect the grieving method and timetable of your spouse.
- Don't escape into loneliness.
- Get rid of imagined guilt and "if only."
- Laughter doesn't mean you are being disrespectful to your child's memory.
- Confront the fears of your death and the death of other loved ones.
- Cry.
- Eat nutritiously, and take a vitamin supplement containing 400 micrograms of folic acid every day.
- Honestly express your feelings about this death to people who will understand and not be judgmental, and who will not be hurt by our honest expression of feelings.
- Not crying doesn't mean you don't remember.
- It is fine to either enjoy being around other people's babies, or to be uncomfortable.
- Exercise to improve sleep.
- Set small goals.
- Accept others' verbal, nonverbal and physical expressions of caring for you.
- Postpone major decisions, such as selling your home or changing jobs.
- The decision to have or not have another child is yours alone.
- The question "How many children do you have?" is a difficult one, and you may find yourself answering it in the manner which best fits the situation and/or your own needs at that time.
- Consider participation in support groups; grief shared can be grief diminished.
- Avoid masking the pain with drugs or alcohol.
- Recognize that seeking professional counseling doesn't mean you are weak, inadequate or crazy.



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- Use religion, philosophy, poetry, music, art, gardening, tennis, walks at nature centers, reading, or volunteer work to gain relief and to understand.
- Talk about your experience to friends who were involved and to friends who were not involved with the death.
- Accept your friends with all their imperfections and occasional bad advice; you too have your moments of imperfection.
- Tell others what you want from them: help, emotional support, time-sharing.
- Recognize that you may not always want to talk about your baby; sometimes there is great relief being where no one knows you've lost a child.
- Realize that you cannot prevent, cure or skip the grief process; the only way OUT is THROUGH.

## Strategies to Help Survive Painful Times

Some strategies suggested here will be helpful; others may not. Try putting into practices some of the recommendations that you have not tried and find out what works for you. After a period of trial and error you will find out what helps you to survive and heal.

## Taking Good Care of Yourself

When we are overwhelmed by pain just making it through the day can be difficult. One thing that you do have control over is taking good care of yourself. We may forget about simple things that maintain our health and prevent illness; they are more important than ever now.

### Healthy Eating Habits

- Eat healthy meals regularly.
- Avoid skipping meals or overeating.
- Avoid excess sugar, caffeine, alcohol.
- Drink plenty of fluids.
- Take a multivitamin containing 400 micrograms of folic acid every day.

### Exercise/Physical Fitness

A consistent exercise/physical fitness regime can help you work out stress, deal with anger, improve sleep and physically feel better. (Consult with your doctor.)

- Take a brisk walk or bike ride.
- Work out regularly.



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## Relaxation Exercises

These are a variety of ways to relax your body and calm your mind. Taking slow, deep breaths is a simple way to calm yourself, and meditation tapes are available at libraries and bookstores.

## Dealing with Overwhelming Feelings

Feelings of sadness, anxiety, fear, anger, loneliness, and guilt can overwhelm us when we least expect it, leaving us feeling helpless and uncertain what to do.

- Talk it over with someone who will listen without judging or giving advice.
- Make a list of all the feelings you are experiencing now.
- Put your energy into an artistic endeavor about your loved one or your grief journey - paint, draw, write a poem.
- Time outdoors with nature can be healing.
- Music is soothing to some.
- Get involved in an intense physical activity: dance, walk fast, exercise, clean, garden.
- Start a journal to record your grief journey or to simply release the feelings you are experiencing (later it will help you see your progress).
- When you feel sad, make time to cry. Tears are healing.
- Learn about grief. Books on grief or stories of others' grief are reassuring.

## Coping With Intense Grief

There may be times the pain you feel is intense. You may need to stop what you are doing and focus on caring for yourself for a little while.

- Find a quiet place alone and do some slow, deep breathing.
- If taking it one day at a time seems overwhelming, just focus on getting through an hour at a time.
- Prioritize what really needs to be done. Grieving takes a lot of energy; you may not be able to accomplish what you are accustomed to for a while.
- Be gentle and patient with yourself. Grieving is hard work.

## Reaching Out to Others

Most of us have the need to share our pain and receive support from others. This is not always easy, as some people are unable to be with people in pain and unknowingly encourage you to deny or suppress feelings. You may need to ask for what you need instead of expecting others to know how to help you.

- Identify relatives, colleagues, and friends who are sensitive and supportive.





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- Seek out people who are helpful resources already in your community such as counselors, religious and community leaders.
- Consider joining a support group with others who have been through a similar experience.
- Seeing a therapist can be a real source of consistent support at this time.

### Don't Give Up Hope

When you are overwhelmed with pain, you may feel numb or feel that you'll never heal or be happy again. It takes time. If you make an effort to use these strategies on your own and to reach out to others, in time you will begin to feel the pain lessen.

- Remember that although you had no control over the loss you experienced, you do have control over your response to it.
- Although people who grieve experience many of the same feelings, everyone's journey through grief is unique. This journey is your own, and with some effort you will find what best helps you to survive and heal.

Written by: Annemarie M. Bezold, LCSW Caring for Surviving Children

## Caring for Surviving Children

Your child has feelings and symptoms of grief similar to those of an adult. He may also seem outwardly confused and defensive about death.

A surviving child is reacting to the loss of his sibling AND to the changed behavior of his parents and others. Reassure him that the depth of a parent's grief does not lessen the love felt for him.

Be aware of your child's level of understanding or misunderstanding: a child of two or younger has the concept of "here" and "not here," a child of 3-5 years sees death as temporary; at 6-10 years a child understands the reality of death and is curious about biological aspects of death and details of burial; from 11 on a child conceives of death in a manner similar to that of an adult.

Explain truthfully to your children, on a level they can understand, what caused the death of a sibling. Answer all questions simply and directly, giving answers to build on later, not ones that will have to be unlearned. Even a child of 2 or 3 can understand "his body could not work anymore." The more a child understands, the less fearful he will be.

Avoid euphemisms; they are easily misunderstood by children. Do NOT mix religious and medical causes. He was not taken because God wanted him in heaven. He died because his body could not work anymore. His body was buried



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in the ground. It might be that you may believe his spirit or all the things that made him special are with God.

Your surviving children had a close relationship with a dead sibling even if the relationship may not have been a loving one. Remember, grief will exaggerate the positive and negative feelings between your children; encourage them to discuss these feelings. Children often feel guilty and/or responsible for their sibling's death. Reassure them that fighting and negative feelings between brothers and sisters are common and do not cause death.

Do not be afraid to show emotion with your surviving children - a controlled silence from parents is much more difficult for children to cope with than open distress. It will also confirm the feelings he has.

By your example in facing your own grief, show your children it is okay to cry, to be sad, to be angry, to laugh, to use that child's belongings or to forget at times. Do NOT isolate your child physically OR emotionally.

Your child's silence does NOT mean there are no feelings or questions: the moment may not be right. Talk openly with him or read a book with him - it may encourage him to open up. Listen carefully to what he says, as well as what he does not say. It may be easier for your child to talk to a person outside the family.

It is often easier for children to "mourn at a distance" - show little emotion at a sibling's death but show tremendous empathy for characters in a book or overreact to a broken shoelace or lost toy.

Children, like adults, may temporarily regress emotionally and developmentally - tantrums, dependency, loss of manual skills, impaired learning ability, aggressive behavior. BE PATIENT AND LOVING. They may need more touching and holding.

Younger children may at first make jokes or continue normal play as a distraction; this is normal.

Children's temporarily assuming mannerisms or symptoms of a dead sibling or wearing his clothes are typical ways that children deal with death.

Share the belongings of your dead child. Perhaps each child would like something "for the moment" and something to carry into adulthood: a book, music, toy, clothes, photographs, and jewelry.

Give your child alternatives for using his grief positively - drawing, writing letters, poetry, stories, diary, hammering, gardening.

Allow your child (even the very young) to participate in family rituals if he'd like: visiting the cemetery, making arrangements for the grave, contributing to a memorial fund. Use HIS ideas of showing his love and his grief at anniversaries or special days.

There is a tendency to idealize the dead, and parents should take care not to make comparisons that could lead to feelings of unworthiness in remaining



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children. While it is difficult, parents should avoid being either overprotective or over-permissive.

Your child will continue to need information on his sibling's death at each new stage of growth. Be open to his questions. Respect his privacy.

The Compassionate Friends, Inc.

## Communicating with Grieving Children

**When my son Ben died, several of our friends and family members reached out to ask, “What can I do? What should I say?” Here is some of the questions we received along with advice and tips we received to help cope with the loss of our son. We found it helpful to publish this on our blog. You might want to do something similar. You can customize the answers for you and share with your friends.**

### **How do you tell a child, and how can you help that child cope?**

One of the parents or both parents together should tell the children about the loss of their sibling. Attention should be paid to the age or to the developmental stage of the child to know how to talk with them in simple language so they can understand. Often, the concept of death is not established in children who are younger than 6 years old.

### **What do you say to a child who has not yet developed a concept of death?**

A child who has not developed the concept of death should be given a more concrete interpretation of death. Often children have had pets that have died. So, one can talk about that or flowers that die. Explain death as part of life not something to be scared from. It is a part of the lifecycle. Many children have seen movies like, “The Lion King” in which the circle of life is a dominant theme.

### **Tell them that dying is part of living and a part of the lifecycle. Use simple words and just tell them that “Ben died.”**

Do not say the dead child is "sleeping" or "is on a journey" because you might have a child who will get scared to go to sleep. Do not say, "He was so nice that God called him home." You might have a child who starts behaving very badly to avoid dying.

Also in Ben’s case, please reassure your children that most people who get sick also get healthy. Ben had a very unusual disease, Burkitt’s Lymphoma. Reassure them that we do not expect this happen again. It is a good idea to use the name of the disease. This way you are able to contrast it with other diseases and different outcomes.

### **Should my child attend the funeral?**



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Helping the child go through the bereavement with the family as well as participating in funeral-related activities would help them understand and accept. Encourage the young child to go to the funeral but do not force them if they do not want to. If a child wants to go to the funeral, make sure there is a designated adult family friend who the child feels comfortable with to accompany the child as the parents are distraught with their grief and will not be able to help the younger siblings at this time.

## Children's Understanding of Death

This chart is to be used as a guideline. All children develop at different rates and it is important to remember that parents know their own child best.

### Newborn to Three Years

#### Child's Perception

An Infant/Toddler can sense when there is excitement, sadness and anxiety in the home, and can sense when a significant person is missing.

- No understanding of death
- Absorbs emotions of others around her/him
- May show signs of irritability; crying
- May exhibit changes in eating and in bowel and bladder movements
- Requires greater physical care, affection, reassurance

#### Providing Support:

- Keep normal routines and structure whenever possible
- Frequently give affection and reassurance
- Provide warm, loving caretaker when parent is not available
- Model healthy coping behaviors

### Three to Six Years

#### Child's Perception

A child of this age often thinks death is reversible or temporary, like going to sleep or when a parent goes to work; they often believe that people who die will come back.

- "Magical thinking" – the child may believe his or her thoughts, actions or words caused the death, or that the death is punishment for bad behavior
- Greatly impacted by parents' emotional states
- Has difficulty handling spiritual concepts
- May exhibit regressive behaviors; bed-wetting, return to using a security blanket or thumb sucking, etc.
- Difficulty talking about how they feel, therefore may act out in response to their feelings



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- Increased aggression - more irritable
- Will repeatedly ask the same questions in an effort to make sense of the loss
- Only capable of showing sadness for short periods of time; will escape into play

### Providing Support:

- Keep normal routines and structure whenever possible
- Provide opportunities to play, draw
- Read books on death and loss with child
- Help to provide words for the child's feelings and fears; gently discuss and seek to dispel "magical thinking"
- Be honest and tell a child if you do not have an answer
- Gently explain what has happened, and be specific and honest about the physical reality of death. Avoid saying things like, "your sister/brother has gone to sleep" or "went away" to avoid confusing your child about the nature of death.
- Make sure the child does not feel responsible for the death
- Be tolerant of regressive behaviors
- Model healthy coping behaviors
- Give affection and reassurance

## Six to Nine Years

### Child's Perception

#### Child begins somewhat to understand the finality of death

- Fear that death is contagious and other loved ones will "catch it" and also die
- Very curious about the body, and may worry if the deceased can eat or breathe in their current state
- Connects death with violence and may ask, "Who killed him?"
- Asks more detailed questions
- Irrational guilt - may possibly blame him- or herself for the death
- Continues to have difficulty expressing feelings, which may cause aggression
- Afraid to go to school or be away from the home, especially if living with a single parent
- Continues to have difficulty with spirituality

### Providing Support:

- Talk with the child and ask questions about how he or she feels
- Make sure child does not in any way feel responsible for the death
- Identify the child's specific fears; seek to have them share their bad dreams
- Provide opportunity for play, drawing, art
- Be honest and tell a child if you do not have an answer



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- Help them to recall positive memories of the deceased
- Model healthy coping behaviors
- Avoid saying things like, "Don't worry, things will be OK" or "You're such a strong boy/girl"
- Use honest words. Avoid saying things like, "Your brother went to sleep and is now in heaven" or "Only the good die young."

## Nine to Thirteen Years

### Child's Perception

Child's understanding is nearer to adult understanding of death; more aware of finality of death and impact the death has on them.

- Concerned with how their world will change with the loss of the relationship – "Am I still a big sister/brother?"
- Fewer questions and a fragile guise of independence
- May at first seem as if nothing has happened, then a grief reaction will surface
- Beginning to develop an interest in spirituality
- Disrupted relationships with peers; uncomfortable being at school
- Increased anger, guilt
- Self conscious about their fears (of their own death or of their parents')

### Providing Support:

- Encourage discussions, writing or drawing of their feelings
- Allow for regressive behaviors
- Be honest and tell a child when you do not have an answer
- Relieve child from attempts to take over adult responsibilities
- Model healthy coping behaviors
- Avoid saying things like, "You must be strong so I don't have to worry about you," or "Big boys don't cry."

## Thirteen to Eighteen Years

### Adolescent's Perception

Adolescents have a near-adult understanding of death.

- May engage in increased risk taking in an effort to reduce anxiety
- May act indifferent to the death of someone close as a protection against painful feelings
- May have a desire to share grief with his/her peers, not adults
- May need permission to grieve
- Feels anger, depression
- Escapes; drives fast, uses drugs or alcohol, sexually acts out
- Denial - tries not to think about it, doesn't want to talk about it
- Questions religious/spiritual beliefs



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### Providing Support:

- Don't assume they can handle themselves and their problems without help, support
- Be available, but don't push
- Help them find peers who will support their feelings, or find other trusted adults
- Give permission for regression
- Be honest and say when you do not have an answer
- Assist in relieving the adolescent of the burden of adult responsibilities
- Help with reckless behavior
- Discuss feelings of helplessness
- Model healthy coping behaviors
- Avoid saying, "You've got to be strong to help your mother" or "You seem to be taking this so well."

Sudden Infant Death Services of the Mid-Atlantic

## Grief of Grandparents

I am powerless, I am helpless, I am frustrated, I sit here and cry with her. She cries for her daughter and I cry for mine. I cannot help her. I can't reach inside and take her broken heart. I must watch her suffer day after day and see her desolation.

I listen to her tell me over and over how she misses Emily, how she wants her back. I can't bring Emily back for her. I can't buy her an even better Emily than she had like I bought her an even better toy when she was a child. I can't kiss the hurt and make it go away. I can't even kiss a small part of it away. There is no band-aid large enough to cover her bleeding heart.

I used to listen to her talk about a boyfriend and tell her it would be okay, and know in my heart that in two weeks she wouldn't even think of him. Can I tell her it'll be okay in two years when I know it will never be okay, that she will carry this pain of "what might have been" in her deepest heart for the rest of her life?

I see this young woman, my child, who was once carefree and fun-loving and bubbling with life, slumped in a chair with eyes full of agony. Where is my power now? Where is my mother's bag of tricks that will make it all better? Why can't I join her in the aloneness of her grief? As tight as my arms wrap around her, I can't reach that aloneness.

Where are the magic words that will give her comfort? What chapter in Dr. Spock tells me how to do this? He has told me everything else I needed to know. Where are the answers? I should have them. I'm a mother.

I know that someday she'll find happiness again, that her life will have meaning again. I can hold out hope for her someday, but what about now? This minute? This hour? This day?



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I can give her my love and my prayers and my care and my concern. I could give her my life. But even that won't help.

Written by Margaret Gerner, Bereaved Grandparent, St. Louis, MO Chapter, The Compassionate Friends

## When a Grandchild Dies

No one expects to outlive their own children, much less their grandchildren. It is so difficult to raise a family, see our children do the same, and see the cycle broken in this out-of-order way. No one is prepared for the grief that follows. As a grandparent you have a double grief. You grieve for you grandchild who has died as well as for your own child who is now a bereaved parent. You not only feel your own pain and sadness, but you also feel helpless and frustrated at not being able to help your bereaved child.

It helps to remember that there is no timetable for grief. Don't expect too much of your child, of his or her spouse, or of yourself. At first no one believes it. When the reality hits, everyone feels even more devastated. It is important to consider your needs as well as those of your bereaved child. Acknowledging and working on your grief will help you and, indirectly, your grieving child.

Don't be surprised if at first you can't reach out to your grieving child. Remember that you are grieving. Be patient with yourself. Eventually you may be able to talk, listen and help. If you find that you can't help specifically with the grief, you can send cards, tell them that you love them, etc. Explain that you wish that you could be of more help but that you don't know what to do.

### Suggestions for Helping Yourself and Your Grieving Child

- Read about grief. It is important to understand what you and your child are experiencing.
- It helps to be open and share your feelings. Your openness sets a good example for your child. Share the good memories and the good days as well as the pain of grief and the bad days.
- Talk about your dead grandchild. Mention his or her name.
- Find someone with whom you can talk freely - a friend, support group member, clergy, or counselor.
- Be available to LISTEN frequently to your child. Respect your child's way of handling the pain and expressing the grief. Don't tell your child how he or she should react.
- At special times (anniversary of death, birthdays, holidays) write and/or call your bereaved child (and his or her spouse). Mention that you realize what day it is. You are calling to say you love them and you wish that you could take some of their pain away.
- When adults are grieving, the child's siblings often feel neglected - plus they don't understand the grief that they themselves are experiencing. Try



- to spend extra time with your other bereaved grandchildren, offering to listen, and reminding them that they are very important and much loved.
- If possible, offer to take surviving grandchildren for an afternoon or a day; help with practical matters, such as preparing food, doing laundry, shopping; spend time alone with your child.
  - Most of us need hugs, even if we don't recognize that we do. It helps to hug and hold your child if you both are comfortable doing so.
  - Allow yourself and encourage your child to cry when needed. Crying offers relief.
  - Let the family know that you care; that you love them.
  - Hold on to the HOPE that eventually you/they will enjoy life again. Offer HOPE to your grieving child and family.

From Hope Bereaved Handbook, AGAST

## Subsequent Children

Moving on is always the hardest part of dealing with a death. Before our son Ben died, he asked us to have more children so his younger brother would not grow up alone. At first, we did not want to face the reality of Ben being gone, much less to consider having another child. Ben was our first, so when he died, the house was much quieter, as the laughter and noises from two children interacting were gone. It was my husband, John, our son, Jacob, and me. After a couple of months, we realized that Ben's request was wise beyond his years. So, we chose to honor his memory and request by adding more children to our family. Now, it was a matter of when and how.

As I look back on that time, I don't think you are ever really ready. You just decide you are going to try to have another child. Everyone around you will have an opinion, and most of them will volunteer their insight. Only YOU, the parents, will really know when you are ready. "Ready" is a strange term in itself for me. It had a bittersweet meaning as we looked to grow our family because of Ben but without his physical presence in our lives. It challenged me to work harder at developing a spiritual connection with him.

We started the process the way we had in the past, by trying to get pregnant. However, we quickly found that given my advanced age— 44 at the time—the probability of having a child without intervention was practically nil. I was lucky to have had Ben at 37 and Jacob at 39 evidently! After that report, we headed to the fertility clinic only to be told, "You have a 1% chance of getting pregnant with your eggs via in vitro, and a 2% chance of getting pregnant with donor eggs." Given the odds and my past pregnancy experiences (not fun ☹️) we decided on adoption as the best route to add to our family.



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We went to various adoptions agencies, public, private, local and international. We finally settled on public adoption after learning that there are over 80,000 children in the California foster care system alone!

As we prepared to welcome a new child in our home, I started on the emotional roller coaster ride again. To make room for another child in our lives meant having to deal with Ben's room, his clothes, toys and everything he touched. We sorted through the clothes, keeping some for us and Jacob, giving some to friends, and donating most of them to another boy Ben's age who had lost his home and all his belongings to hurricane Katrina. This was very hard, and I went through many boxes of Kleenex during this process. I went in the room for short periods of time to go through the things, and sometimes wondered if we were doing the right thing. I still missed Ben and was worried I wouldn't be able to attach to the next baby. I wondered if I should, because if he or she died, it would hurt more. I constantly reviewed everything I had and hadn't done during Ben's life as a parent and tried to convince myself that everything would be okay.

There is no right or wrong time to bring another child into your family. Some families never do. The one thing I have learned is that there is no right and wrong. You just have to do what works for you and your family. No matter what anyone else tells you, you are the only ones who can make those decisions.

By Christine Falsetti,  
Mother of Ben (4/18/1998 - 8/20/2005), Jacob, Michael and Katie

## After Childhood Cancer

### You Are Not Alone

You are among the mothers, fathers, families and friends of the nearly 4,000 children and teens who die each year from childhood cancer. You are not alone in feeling confused and very sad in trying to live without your child. Difficult days may rule your life for a long time, and many unanswered questions will remain.

- Why did my child die?
- What did I miss?
- Why do I keep saying, "If only I had..." if it is not my fault?
- Why didn't I take my child to the doctor for that cold or fever sooner?
- Why did I go back to work so soon?
- If no one can find a reason, isn't it my fault that my child died?
- I am angry, frightened, and exhausted - am I going crazy?
- There must be something that caused my child not to be cured. Why can't anyone tell me?

You try to piece together clues, signs, or reasons why your child died. You talk to other people about your child and about childhood cancer. You may find this hard and tiring.



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Losing track of time and being unable to perform simple activities are normal after a child dies. The daily routine changes in a lot of ways. Regular activities such as weekly grocery shopping or visits with friends or family become more difficult.

After a while, you will probably resume some of your usual activities. But you also may decide that some activities are too painful, such as visiting friends with children and seeing them at play. But these choices will be yours.

## Anniversaries, Holidays, and Special Events

Families observe cultural and religious traditions on occasions such as reunions, weddings, graduations, and anniversaries.

During the days and weeks after your child dies, there will be special events that will certainly be different without your child. You will face celebrations that focus on the joy of children such as Christmas, Mother's Day, Father's Day, and Halloween. Holiday reminders will be all around you in the stores, on television, and in newspapers and magazines.

Holidays and special events are reminders that life goes on around you. You will be torn between how holidays and festive occasions are normally celebrated and how you are going to celebrate them without your child. You may feel anxious, sad, and empty and may long to have your child be a part of the special times that usually involve the whole family.

Some people may not understand that you need to talk about and remember your child at these times because they want you to "get on with your life." You may want to talk about the loss of your child to childhood cancer for a long time. This does not mean that you are not recovering and coping with the death.

### What to Expect as You Face the Special Times

- The first year after your child's death will be the hardest, and your child's birthday and the anniversary of his or her death may be two very difficult times.
- Even if you seem better, the sadness and pain may return. It may be hard to be around other children. These are normal feelings.
- It is OK to celebrate and enjoy these times. It is OK to laugh and cry at the same time. Very quickly, you can go from laughing to crying.
- Other children in your family will need help during the holidays to celebrate as they have in the past or to understand why things are different.
- Some Parents...
  - Choose to celebrate and participate in these occasions as they always have in the past, but find it is a struggle. Sometimes they even avoid talking about the child who died.



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- Choose to do completely different things during the holidays and special events. They may not participate in any of the usual activities or traditions.
- Try to balance their participation in holiday activities and cope with the pain and sadness of missing their child.

### **These are difficult and personal choices. Remember...**

- What you and your family decide to do for anniversaries, during the holidays, or for special events is your choice.
- Your participation in these events may be very different during the first year or so. After a while, you may go back to normal activities or permanently change how you remember some holidays and special occasions.
- Celebrating holidays and special events will reflect your cultural background and traditions. It is important for you to value these traditions because they are part of your life during happy and sad times.

### **Family Gatherings**

Families gather for both sad and happy occasions. Happy times and sad times often bring families closer together.

Holidays, weddings, graduations, and reunions are times for celebration. Everyone is expected to be happy. Relatives and friends want you to join in as you have in the past.

Family and friends usually provide the most comfort and listen to you as you try to cope with your loss. But even the closest of relatives and friends cannot completely understand the hurt that you feel.

### **Friends and relatives want...**

To take your pain away... to offer you hope for better times... to see you "back to normal again"... to help you "forget about what happened."

### **But...**

No one can take your pain away... there will be happy times again, but they will be different without your child... you are now living a "new normal," one that is defined by your childhood cancer journey and the love you will always have for your child.

### **Talking About Childhood Cancer**

It is hard to understand how healthy children get cancer and die for no apparent reason. Explaining death and childhood cancer to others can be difficult. Sometimes it is helpful for a close friend or relative to provide information to others for you.

Sometimes people have wrong ideas about childhood cancer. They often wonder what could have been done to prevent your child from getting cancer. This is a



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common response because many adult cancers are associated with prevention. People may say things that are not true. Some people might give you information that has not been proven or compare the death of your child to another death they know about. They offer many types of information in the hope of helping you feel better.

Others may ask questions and make comments about your child. Sometimes their remarks will make you feel like you did something wrong or that you did not take proper care of your child.

### **Remember...**

You did not do anything wrong to cause your child to have cancer. You did all the right things. There was nothing you could have done.

### **Making Special Times Easier**

As you approach an anniversary, holiday or special event, do something to remember your child and to help ease your anxiety. Thinking about how you are going to handle such an occasion is often worse than the actual event. For example, having a memorial service or going to the cemetery before the occasion might comfort you.

- Realize that sadness and confusion may remain with you during these times. Feelings of anger, pain, and loss of control do not necessarily mean that you are not recovering from the loss.
- Make changes in the way you celebrate holidays and special events. These changes may be temporary or permanent.
- Take care to remember that other children and family members will want to continue to celebrate the occasion as usual.
- Start a new tradition in memory of your baby.
- Talk or write to other parents whose child has died. Find out how they have coped with the special occasions.

### **Memories**

The memories you have of anniversaries, holidays, and special events are of celebrations and family times together. Now you face these times feeling empty without your child. You have a different outlook about such occasions and may have images of how you would have shared the moments with your child.

While sadness will remain with you forever, the memories of your child are some of the most important keepsakes you will have. You can treasure them. You can share them with others.

Family and friends often feel they will cause you more pain by talking about your child. Let them know if you want to talk, and together you can build memories.

As time passes, happy memories of your child will gradually replace the sad ones, and you will be able to laugh again.



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"What we have once enjoyed and deeply loved, we can never lose, for all that we love deeply becomes a part of us."

Helen Keller

## Getting Through the Holidays

The whole world seems consumed with tinsel and glitter - but those who grieve are only aware of the terrible hole in their hearts. Here are some helpful thoughts which other bereaved parents have shared, with the hope of making your holidays easier.

Grieving persons have definite limitations: we do not function at normal capacity; therefore, we must reevaluate our priorities and decide what is really meaningful for our family and ourselves.

- We must decide what we can handle comfortably and let these needs be known to family, friends: whether to talk about our child openly; whether we can handle the responsibility of the family dinner, holiday parties, etc; whether we will stay around for the holidays, for example.
- Don't be afraid to make changes: have dinner at a different time, attend a different church, let children or friends take over the decorating or making cookies, etc.
- Our greatest comfort may come in doing something for others: giving a gift in memory of your baby, donating money we would have spent on our child's gift to a particular charity, adopting a needy family, inviting a guest to share our festivities, for example.
- Find a creative outlet. Write a memorial poem or story about your child and share it if you wish.
- Balance solitude with sociability. Solitude can renew strength, but being social can be equally important. Spend some time with close friends.
- Call other grieving parents who have experienced a holiday without their child and find out what they did to make things easier. There can be some relief just by knowing that you are not alone.

Adapted from SIDS Mid-Atlantic

## A Loving Good-bye

### Planning the Service

There are several options regarding a service for you child. The information gathered here is not meant to steer you toward one type of service or another, but rather to give you the information you need to make an informed decision.

When it comes to planning a service for you child, the only person whose opinion matters is you. The following is simply a brief explanation of the most common



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options and some practical tips for planning whichever type of service you choose.

## Types of Services

### *Graveside Service*

People often precede burial with some kind of graveside service usually conducted by a clergyman. These range from the very brief reading of some scripture and a prayer to longer services including songs, etc. Generally speaking, if there was an earlier funeral, the graveside service is fairly short.

In planning a graveside service, one should consider whether to have a tent erected in case of inclement weather. Some cemeteries and/or funeral homes provide tents and chairs free of charge; others do not. The longer the service, the more advisable it is to have a tent and chairs.

Also in planning a graveside service, one should consider whom to invite. Some people choose to have private family-only services; others are open to all who wish to pay their last respects.

### *Memorial Service*

Some people choose to have a private burial followed by a public memorial service. Or, in cases of cremation, memorial services are often held.

Memorial services can be held either in churches, homes, parks or funeral homes depending upon how many people are expected to attend, costs, and the family's own preferences. Some families do not want a service held in their church for fear that every time they go there they will be reminded of the loss of their child. Other families want the service held in their church because that is where they shared happy memories with their child.

Depending on one's general style, memorial services can range from the very formal to the very informal. Formal services can involve scripture readings, eulogies, special songs, and/or hymns, and are very similar to a funeral except that the deceased's body is not present. Informal services can involve all of the preceding as well as poetry readings and messages from friends and family members. One family even set up an open microphone for anyone who wanted to make a brief statement in memory of the child.

### *Funeral Service*

As opposed to memorial services that take place after burial or cremation, funeral services precede burial and involve the presence of the body.

Funerals usually take place at a church or a funeral home. These services, too, range from the formal to the informal.

One decision you must make is whether to have an open or closed casket at the service. Generally, three choices are available. Some people have a pre-funeral open casket viewing for those who wish to pay their last respects, and then have a



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closed casket service. Others have an open casket service followed by a brief period for people to pay their last respects before closing the casket. Finally, some people choose to have a closed casket service.

Another decision relevant to funerals involves whether to have pallbearers. Long ago pallbearers were needed to actually carry the casket from the church, load it into the hearse and unload it at the cemetery. These days, funeral homes have wheeled carts for transporting coffins, so the real need for pallbearers has been largely eliminated.

Many people, though, still choose to have pallbearers and can even request that a wheeled cart not be used. An infant's casket is very small and relatively light, so at most two pallbearers are actually needed for the task. Some people choose honorary pallbearers as a way of honoring special friends or family members who were close to the infant.

The following is a summary of just some of the most common arrangements regarding services:

- Graveside only (private or public)
- Private graveside, followed by public memorial service.
- Funeral, followed by graveside (private or public)
- Memorial service only (usually following cremation).

### General Tips

- Clear things in advance with your clergyman. It is not uncommon for people to choose a date and time for a funeral and expect a clergyman to perform it, only to learn that the church is unavailable at that time or that the clergyman has other plans.
- Ask whether people you want to participate in the service feel comfortable doing so. Often friends and family members are overwhelmed with grief as well and simply feel uneasy about participating in a certain capacity.
- Plan the service and share your plans with the clergyman or other leaders who will be presiding. While different religious persuasions have different types of services, almost all clergymen will work with you to make your service special. Remember, though, that some parents are so shocked by the death that they cannot plan a service. If that has happened to you, it is perfectly okay to ask friends or family members to plan the service.
- You may be asked whether you want flowers present at any service. People often send flowers to show their support for the family, and the presence of many beautiful flowers can be comforting. Other families choose to ask that, in lieu of flowers, donations be made in the child's name to a worthy charity.





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- Some people have bulletins printed and made available to those attending the service. Some funeral homes charge for this service. Some churches provide it free of charge.
- Some people like to incorporate framed pictures or multimedia of their child or other personal items into the service to make it more personal.

### **Always Remember**

Whatever arrangements you make, if they are what YOU want, they are good.

## **Choosing a Funeral Home**

### **Basic Points**

The decisions you are facing are ones that no parent imagined he or she would have to make for their child. While these decisions are painful, remember that this can be your way of honoring your child. This will be one way of giving your child a loving goodbye.

Making these final decisions about your child may take some time. Usually there is no rush. If you need more time to think, take the time.

Do what is right for you. Saying goodbye to your child is a very personal and private thing. Ask for what you need even if you think it won't make sense to others.

### **Choosing a Funeral Home**

Many people don't realize that they are not legally required to use a funeral home to plan and conduct a funeral. However, because they have little experience with the many details and legal requirements involved and may be emotionally distraught when it's time to make the plans, many people find the services of a professional funeral home to be a comfort.

If you have used a certain funeral home before and feel comfortable with them, feel free to use them. Your clergyman, hospice nurse, social worker or family may recommend a funeral home to you.

You may want to look around. If so, consider the following factors:

- Is the home locally owned and managed?
- Does the home have funeral directors on staff 24 hours a day?
- What are the charges for child services? Whichever funeral home you choose, call and make an appointment to meet with a funeral director.



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### Items to Take With You

Take an outfit of clothes for your child to wear, including a diaper for a baby if you wish. The clothes need not be fancy. What is important is that you are comfortable with the clothes.

You may choose to bring a cap, hat, or favorite blanket, which can be arranged around your child’s head, if necessary. If an autopsy was performed, it generally involves making incisions on the back on the head, and these are sometimes visible.

If you would like your child buried with a favorite toy, stuffed animal or some other special items, take them along as well.

### Meeting with the Director

Your meeting with the funeral director will involve three parts: gathering statistical information; planning the service, if any; and discussing financial arrangements, all of which are discussed below.

### Financial Arrangements

Funeral Directors are required by federal law to frankly discuss with you the costs of their services and to obtain your signature that they have done so.

When comparing prices, be sure to consider the total cost of all the items together, in addition to the costs of single items. Every funeral home should have price lists that include all the items essential for the different types of arrangements it offers. Many funeral homes offer package funerals that may cost less than purchasing individual items or services. Offering package funerals is permitted by law, as long as an itemized price list also is provided. But only by using the price lists can you accurately compare total costs.

### Comparing Funeral, Burial & Cremation Options

This table can be used as a guide to help organize information when comparing costs at several funeral homes or exploring burial options. Keep it with you when you are asking questions on the phone or visiting. Be sure to have extra paper (a notebook) to jot down additional information.

<b>Name of Funeral Home/Other Option</b>		
<b>"Simple" disposition of the remains:</b>		
Immediate burial		
Immediate cremation		
If the cremation process is extra, how much is it?		
Donation of the body to a medical school or hospital		



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<b>"Traditional," full-service burial or cremation:</b>		
Basic services fee for the funeral director and staff		
Pickup of body		
Embalming		
Other preparation of body		
Least expensive casket		
Description, including model #		
Outer Burial Container (vault)		
Description		
Visitation/viewing – staff and facilities		
Funeral or memorial service – staff and facilities		
Graveside service, including staff and equipment		
Hearse		
Other vehicles		
Total		
<b>Other Services:</b>		
Forwarding body to another funeral home		
Receiving body from another funeral home		
<b>Cemetery/Mausoleum Costs:</b>		
Cost of lot or crypt (if you don't already own one)		
Perpetual care		
Opening and closing the grave or crypt		
Grave liner, if required		
Marker/monument (including setup)		
Total Cost of Option		



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## Statistical Information

The director will need certain statistical information for a death certificate. This information will include your child's name, date and place of birth, date of death, parent's names, and other such information.

You will receive one free copy of the death certificate but must pay for any additional copies. If you had life insurance on your child, you will need copies of a death certificate for the insurance company and should order extra copies at this time.

It is at this point that the director will also ask you whether you are going to want an obituary printed in the paper. This is entirely up to you. Obituaries vary from simple statements of the child's name, dates of birth and death and listings of surviving relatives such as the parents, siblings and grandparents, to poems or passages or scripture. Some people even print pictures of their children. There is no right or wrong where obituaries are concerned. The choice is entirely your own. Ask your Funeral Director for the cost for the printing.

## Burial or Cremation

The choice between burial and cremation is entirely up to you. Both options cost approximately the same amount of money, so your choice should depend solely on your own preferences.

### Burial

If you choose burial, you will need to choose a casket at the funeral home. The selection of infant and young child caskets is limited. The main consideration for you is whether you will ever want to move your child's body to another cemetery, which often happens if people move out of state, or if they bury their child in a children's section of a cemetery and later want him/her moved to be beside them.

If you think you will ever want to move your child's body, you will need to tell the funeral director that and choose a casket with a "vault." Vaults protect the casket from the elements and make it possible to later move it. Also, if you're planning on burying any toys or stuffed animals with your baby, be sure and let the funeral director know this so that he can help you select the right size casket.

If you choose burial, you must also decide whether to have your child embalmed. Most people choose embalming. Some state laws require that children be embalmed if not buried within 24 hours of their time of death or the funeral home may insist on embalming. It is important to realize that the delicate nature of children's bodies may create disappointment at the final appearance of the body when compared to what you are used to seeing in embalming procedures on adults.

### Cremation



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With cremation, your options are numerous. The body is cremated shortly after death, without embalming. The cremated remains are placed in an urn, monument, or various other containers. You may choose to have some of the ashes turned into precious gemstones such as diamonds and jewelry.

No viewing or visitation is involved, although a memorial service may be held, with or without the cremated remains present. Some or all remains can be kept in the home, buried or placed in a crypt or niche in a cemetery, or buried or scattered in a favorite spot. It is always advisable to check for local regulations regarding scattering in a public place.

Direct cremation usually costs less than the traditional full-service funeral. Costs include the funeral home's basic services fee, as well as transportation and care of the body. A crematory fee may be included or, if the funeral home does not own the crematory, the fee may be added on. There also will be a charge for an urn or other container. The cost of a cemetery plot or crypt is included only if the remains are buried or entombed.

Cremation is just one step in the commemorative process-- the preparation of the human remains for memorialization. Today, there are many different types of memorial options from which to choose. Memorialization is a time-honored tradition that has been practiced for centuries. A memorial serves as a tribute to a life lived and provides a focal point for remembrance, as well as a record for future generations. The type of memorial you choose is a personal decision. The limit is set only by your imagination.

### **Making Your Own Good-bye**

There are so many ways you can make your good-bye to your child special. Following are things some parents have done or wish they could have done.

- Keeping a lock of your child's hair. Simply ask the funeral director to do this for you.
- Making a footprint or handprint.
- Placing a toy, a blanket, or something special to you in the casket with your child.
- Placing a picture of you in the casket.

This information is adapted from the Oklahoma SIDS Alliance "A Loving Good-bye" packet as well as the US Federal Trade Commission, "Consumers Guide to Funerals"

### **Choosing a Cemetery**

The decisions you are facing are ones that no parent imagined he or she would have to make for his or her child. While these decisions are painful, remember that this can be your way of honoring your child. This will be one way of giving your child a loving goodbye.



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Making these final decisions about your child may take some time. Usually there is no rush. If you need more time to think, take the time.

Do what is right for you. Saying good-bye to your child is a very personal and private thing.

### **Child vs. Adult Sections**

Many cemeteries have special sections reserved for children. In some, these areas are landscaped to make them even more comforting. Usually child plots are significantly less expensive than adult ones. Also, many parents take comfort in burying their child among other children.

On the other hand, some parents want their child buried beside other family members or will want the child beside them when they eventually die. In either case, the child must be buried in the regular or "adult" section of the cemetery or be moved at a later date. Please note that if you plan on moving your child at a later date, you must choose a casket with a "vault". Vaults protect caskets from the elements and make it possible to move them later.

### **Monument Restrictions**

It is important when choosing a cemetery to inquire about any monument restrictions they may have. Some cemeteries allow only flat markers because raised monuments impede mowing. Others strive for "garden" atmosphere and allow only flat markers with vases. A few are actually so restrictive as to require that monuments be of a certain type and size and purchased from them.

Sometimes the rules differ between adult and child sections at the same cemetery. Also, some cemeteries require that one purchase two or three adult plots together and that they be completely paid for before any monument may be placed.

Whatever the restrictions may be, it is important to take the time to choose a monument you will be comfortable with.

### **Costs**

In addition to charges for actual plots, cemeteries may also charge fees for opening a grave and for setting monuments. Additional fees may be charged if a tent is used during a graveside service. Sometimes people have donated back to a cemetery their unused plots for use by families in need. Sometimes cemeteries will reduce their prices or waive them altogether.

## Helping Children through the Funeral Process

### Deciding Whether or Not Children Should Attend the Visitation and Funeral

The purpose of a funeral service is to pay tribute to a life that has been lived - regardless of how short that life has been. A memorial service of some kind is important because it provides a formal, public opportunity for the beginning of healing. Taking part in a visitation for the dead sibling at the funeral home can help brothers and sisters start to understand the difference between being alive and being dead. It can also give them a chance to say good-bye in their own special way.

- Someone close to the child should explain what the visitation, funeral, burial, or other rituals will be like in order to help the child decide whether or not to attend.
- Children understand a lot more at younger ages than adults sometimes think they do, and probably more than adults understood at their age.
- It may help to think of how old you were when you attended your first funeral, and what your own reactions were.
- Funerals serve the purpose of allowing adults and children alike to share their grief, express their feelings, and begin to understand that death has occurred. The attempt to protect children by keeping them away from the funeral may instead make them feel left out of an important family activity at a time when they are in special need of feeling loved and included.
- However, forcing a child to attend the funeral or to view the child's body is counterproductive. But if they can at least attend the funeral, it may help them cope more effectively with later losses in the family. Let them move at their own pace.
- Try to give children opportunities to talk about what is on their minds. They may have their own reasons for not wanting to take part in a funeral or other memorial activity. Adults can make an effort to try to understand a child's reasons and responses, and can discuss them with the child.
- If it is decided that the children will attend the funeral, parents, grandparents, or another close adult should explain in more detail what they can expect, i.e., what will happen, how or in what order things will take place, what the funeral home will be like, who else will be there, how others are likely to act, and how the children will be expected to act.
- The family and the funeral director should set aside a quiet, private time, for just the family to say good-bye, hold their child, and to give children an opportunity to ask their questions. No one outside the immediate family should be present at this time, because the child gathers strength from the family and may be intimidated by strangers.
- During public activities, children should not be left to "fend for themselves." Ask someone with whom the children are close to stay with them. This

should be a person who can be trusted to answer their questions in ways which will reinforce the beliefs of the parents and family. This will also ensure that someone will be available to take the children home early, if necessary.

- It is very important when a child is about to view the body of his or her brother or sister for the first time that someone close to them should hold his or her hand. This allows that child to gain support from that individual and have someone to look to as a model to imitate during this traumatic time.
- If a surviving sibling is very young, and attending the visitation or funeral does not seem appropriate, other options might be considered. A close family member or friend could bring the child for a very brief time and then stay with the child at home until the rest of the family returns. In instances when attendance may be considered inappropriate, very small children could be included in a private family time before or after the funeral.

### Preparing Children for the Funeral

- Tell children in advance what to expect from other people. People may appear to be "just chatting." Some people may laugh, while others may cry; both reactions are equally OK. Let children know that however they feel is also OK.
- Some children may have a need to touch or kiss the child's body. Explain what that may be like.
- It is especially important to use the words "dead" or "death" in explaining what has happened to the deceased. This will help to prevent confusion and begin to teach the child that death is a natural part of life. Phrases such as "he went away" or "she went to sleep" often cause misunderstanding and unnecessary fear. Sometimes it may be necessary to explain other terms that children may hear people use to describe death, i.e., "passed away," "kicked the bucket," etc.
- If children are familiar with their religious beliefs, death can be explained within their own religious context. However, it is important not to use statements that may confuse children, such as "God wanted the baby," which may lead children to believe that God may want them next.
- Adults who can openly display their own natural grief will help children to learn appropriate mourning behavior.

### Preparing for Questions Children May Ask

- Start by asking children what they have already heard or may be thinking about the death. Ask them what questions they have. Tell them what happened as soon and as honestly as possible. Debunk rumors, and correct misinformation.
- Reassure them that cancer is not contagious; they cannot catch it from the deceased child.



- Sometimes siblings feel that they are responsible for the death because they may at times have wished that their sibling would just "go away." Reassure children that no one is to blame for their sibling's death -- including them.
- Reassure them also that they are not going to lose mom and dad.
- Address the issue of the child being taken to the hospital by the ambulance, if this was the case, and not coming back. Some children have had a hard time not believing that their sister or brother is still just at the hospital.
- If resuscitation was attempted in the surviving child's presence, explain that you, hospital personnel, and/or the paramedics did everything possible to try to keep the child from dying. Some children can become confused and may believe that the CPR was the cause of the child's death.
- Children often need reassurance that their own life, schedule, and activities will stay the same - as much as that is possible.
- Always encourage children to continue to ask their questions and to express their feelings.
- Remember that their questions and reactions are likely to reflect their own level of development, life experiences and individual personalities. Younger children may ask more concrete questions ("Is it cold in the coffin?"); older children may have more technical questions ("What does embalming mean?").
- There is no more important consideration than dealing with each situation in the context of the child's own cultural, ethnic, and religious beliefs. Tell people who want to help that they can do this best by reinforcing what the parents and family are telling their children.
- Expect occasionally to encounter some resistance from people who disagree with these parental messages. Explain to such people that their concerns are appreciated, but that at this difficult time one must do what the parents and family feel is right for them and for their children.

### **Include Children in Rituals and Memorials**

- Children need to be involved in family activities in appropriate ways. Some may take part in specific funeral arrangements; others can be involved in related activities, such as choosing flowers (or a flower) from them for the deceased brother or sister, or picking out a song to play at the service. A particular child might decide whether or not to put a flower in the casket. Sometimes including children in selecting clothing helps them feel a part of the process. Seeing their brother or sister's body in familiar clothing may help with their acceptance and relieve anxiety.
- Depending on the age of the child, a sibling may want to choose a special toy or picture to put in the casket. Younger children could color a picture and put it with their brother or sister; older children may want to write a letter about how they feel.



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- Surviving children may like to have some remembrance of their brother or sister to keep, such as an article of clothing, toy, or picture.
- Children can also be encouraged to remember their brother or sister in different ways in the years following the death. Keeping pictures around or revisiting an album of photographs can be ways to encourage conversations about the deceased child.

## Keep in Mind

The information listed above focuses on how to help children through the funeral process. It is important to remember that each child, family, and situation is unique. This information is to be used only as a guide. Feel free to adapt what fits for you and the children you are helping.

## Books on Grief

Below is a brief list of books we found useful when our son Ben passed away from cancer in 2005. We welcome your comments and suggestions on what has been useful to you. Thank you.

[\*We Were Gonna Have A Baby, But We Had An Angel Instead\*](#) By Pat Schwiebert. Illustrated by Taylor Bills, Copyright 2003 Grief Watch

[\*Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing With Loss \(Elf-Help Books for Kids\)\*](#) by Michaelene Mundy and R. W. Alley (Paperback - Sep 1998)

[\*Tear Soup: A Recipe for Healing After Loss\*](#) By Pat Schwiebert and Chuck DeKlyen. Illustrated by Taylor Bills, Copyright 1999 Grief Watch

[\*A Birthday Present for Daniel: A Child's Story of Loss\*](#) (Young Readers) (Paperback) by Juliet Cassuto Rothman, Illustrated by Louise Gish, Copyright 1996

[\*No Matter What\*](#) (Hardcover and Paperback) by Debi Gliori, Illustrated by Debi Gliori, Copyright 1999

[\*Always and Forever\*](#) (Hardcover and Paperback) by Alan Durant, Illustrated by Debi Gliori, Copyright 2004

## Glossary of Terms

Courtesy of the California Department of Consumer Affairs, Cemetery and Funeral Bureau

**Alternative Container:** An unfinished wood box or other non-metal receptacle without ornamentation, often made of fiberboard, pressed wood or composition materials, and generally lower in cost than caskets.

**Casket/Coffin:** A box or chest for burying remains.



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**Cemetery Property:** A grave, crypt or niche.

**Cemetery Services:** Opening and closing graves, crypts or niches; setting grave liners and vaults; setting markers; and long-term maintenance of cemetery grounds and facilities.

**Columbarium:** A structure with niches (small spaces) for placing cremated remains in urns or other approved containers. It may be outdoors or part of a mausoleum.

**Cremation:** Exposing remains and the container encasing them to extreme heat and flame and processing the resulting bone fragments to a uniform size and consistency.

**Crypt:** A space in a mausoleum or other building to hold cremated or whole remains.

**Disposition:** The placement of cremated or whole remains in their final resting place.

**Endowment Care Fund:** Money collected from cemetery property purchasers and placed in trust for the maintenance and upkeep of the cemetery.

**Entombment:** Burial in a mausoleum.

**Funeral Ceremony:** A service commemorating the deceased, with the body present.

**Funeral Services:** Services provided by a funeral director and staff, which may include consulting with the family on funeral planning; transportation, shelter, refrigeration and embalming of remains; preparing and filing notices; obtaining authorizations and permits; and coordinating with the cemetery, crematory or other third parties.

**Funeral Planning Society:** See Memorial Society.

**Grave:** A space in the ground in a cemetery for the burial of remains.

**Grave Liner:** A concrete cover that fits over a casket in a grave. Some liners cover tops and sides of the casket. Others, referred to as vaults, completely enclose the casket. Grave liners minimize ground settling.

**Graveside Service:** A service to commemorate the deceased held at the cemetery before burial.

**Interment:** Burial in the ground, inurnment or entombment.

**Inurnment:** The placing of cremated remains in an urn.

**Mausoleum:** A building in which remains are buried or entombed.

**Memorial Service:** A ceremony commemorating the deceased, without the body present.



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**Memorial Society:** An organization that provides information about funerals and disposition, but is not part of the state-regulated funeral industry.

**Niche:** A space in a columbarium, mausoleum or niche wall to hold an urn.

**Urn:** A container to hold cremated remains. It can be placed in a columbarium or mausoleum, or buried in the ground.

**Vault:** A grave liner that completely encloses a casket.