



A JOURNEY TO HEALING

SCNJ Parent Resource and Support Guide



Statewide Hotline 1(800) 545-7437

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I'M SO GLAD YOU CAME

Anonymous

I'm so glad you came for I will always know your light in my hands.

Always.

The power of your leaving was exquisite, a kind of profound silence.

I will always be able to recall it in a moment.

Always.

But I am so glad you came.

So incredibly honored to have known you at all.

I will always know your light in my hands, and in a blink, I will see it.

Always.

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INTRODUCTION

What is the SIDS Center of New Jersey (SCNJ)?

The Sudden Infant Death Syndrome (SIDS) Center of New Jersey (SCNJ) was established in 1988 under the auspices of the New Jersey Department of Health. The program is mandated to serve three missions: (1) bereavement support for New Jersey's families whose infants and toddlers have died suddenly and unexpectedly; (2) research into efforts to identify underlying causes; (3) public health education to help reduce the risk of such deaths. The program is based at Robert Wood Johnson Medical School, a part of Rutgers, The State University of New Jersey, and the Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center. It is supported by a grant from the New Jersey Department of Health to Rutgers Robert Wood Johnson Medical School in New Brunswick, NJ and by a grant from the CJ Foundation for SIDS to the Joseph M. Sanzari Children's Hospital, Hackensack, NJ. This resource booklet will provide you with information about the bereavement support mission of the SCNJ and the services we provide without cost.

What bereavement services does the SCNJ provide?

All referred families receive bereavement support through their first year of bereavement. No fee is charged. The SCNJ also provides families with programs for continued support beyond that time. Support is offered through the following services

- Telephone outreach
- Home visits in person or virtually through Skype, etc.
- Support groups with other bereaved parents: both online and in-person
- 24-hour hotline support: 1-800 545-7437
- Clergy support
- Referral to local mental health services as needed.
- Peer contact - pairing a newly bereaved family with a family who has experienced the devastation of losing an infant or toddler to sudden and unexplained death more than a year ago.
- Speakers' bureau: Coordinating parent presenters for community education and awareness events to share their personal experience.
- Annual state-wide memorial services: we hold a memorial service in the summer, usually in July, and in the winter, usually in December. The services may include all members of the family including surviving and subsequent children.
- Newsletter
- Help in understanding a diagnosis.

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INTRODUCTION (cont'd)

Who receives these services?

Families are referred to the SIDS Center of New Jersey if they have experienced the sudden and unexpected death of their infant or toddler. They are referred so that they may be offered the support just described.

What are Sudden Unexpected Infant Deaths?

Following a detailed evaluation by a medical examiner, most Sudden Unexpected Infant Deaths will receive one of three diagnoses: Sudden Infant Death Syndrome (SIDS), Ill-defined and Unspecified Causes (Undetermined) or Accidental Suffocation and Strangulation in Bed. In addition, a small number of cases will turn out to be due to a previously undiagnosed medical condition and will receive a medical diagnosis related to the condition identified.

The majority of Sudden Unexpected Infant Deaths will be classified as Sudden Infant Death Syndrome (SIDS) by the Medical Examiner.

"SIDS is the sudden death of an infant which remains unexplained even after a thorough investigation involving a complete autopsy, an examination of the death scene and a review of the medical history." (*Willinger M. et al. Pediatric Pathology, 1991*) It is a diagnosis pertaining to the first twelve months of life and commonly occurs during sleep in a seemingly healthy infant. It is called a diagnosis of exclusion because all known causes that might explain the death have been ruled out. In short, the diagnosis means that no specific answer can be found to explain why this death has occurred. The absence of answers makes the grief from SIDS uniquely painful and makes the provision of medically and scientifically accurate information a core component of bereavement support. Research into SIDS is aimed at uncovering the medical conditions that might explain such deaths and risk factors that can increase its likelihood. But it is important to know that it has been fully established that SIDS is not contagious, that it is not caused by vaccines, that it is not caused by abuse or neglect, and that it is not caused by suffocation, choking or smothering. Although the number of infants diagnosed with SIDS has declined, following risk reduction campaigns, it still remains one of the leading causes of infant mortality. In 2013, 1,561 infants in the United States died of SIDS.

Ill-defined and Unspecified Causes of Mortality may be used as a diagnosis if the medical examiner cannot conclude that all possible causes of a sudden infant death have, in fact, been ruled out. The terms used by medical examiners vary in this diagnosis wherein some may use the term undetermined or similar language. In 2013, 1042 infants received this diagnosis.

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What are Sudden Unexpected Infant Deaths? (cont'd)

Accidental Suffocation and Strangulation in Bed is a diagnosis given when the death scene investigation has identified a physical condition that has caused such an event. An example would be an infant found sleeping face down on a pillow with a heavy blanket covering his head. It should be emphasized that in providing this diagnosis, the medical examiner has determined that the death was accidental. In 2013, 818 infants in the United States received a diagnosis of Accidental Suffocation and Strangulation in Bed.

What are Sudden Unexplained Death in Childhood?

Sudden Unexplained Death in Childhood (SUDC) is the sudden and unexpected death of a child over the age of 12 months, which remains unexplained after a thorough case investigation is conducted." (Krous et al. 2005). Here at the SIDS Center of New Jersey we support families whose toddler passed away aged 3 and under suddenly and unexpectedly.

Regardless of the final cause, the sudden death of an infant or toddler is a devastating event that affects not only the bereaved parents, but also grandparents, siblings, aunts and uncles, cousins, friends, neighbors, and colleagues at work. It is a death like no other, and no one should have to go through such a loss without close and caring support. Our program is here to provide that support for you.

MATERIAL IN THIS RESOURCE PACKET

The SIDS Center of New Jersey has prepared this resource packet to support grieving families as they travel on their unique journey. Information on the needs of surviving brothers and sisters is also addressed. Although some of this may be difficult to read now, please know this can be a useful resource in the future. **You can always contact us on our 24-hour hotline at 1-800-545-7437. The hotline is direct access to a clinician 24 hours a day, 365 days a year who can provide support, answer questions, or provide referrals.**

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ONE MOMENT AT A TIME

Lisa Capizzi, MSW, LCSW

With the turn of each calendar page, the world is “moving along”. Many parents, grandparents, children, and other family members impacted by their grief will be experiencing pain and sorrow. In my role as a licensed clinical social worker who works with bereaved families since 1995, I have found that a vital key to coping is a philosophy I call: *One Moment at a Time*.

One Moment at a Time is a mindset for bereaved family members. It allows you to grieve at your own pace despite what you perceive society and others may be encouraging you to do. It is the ability to spend parts of your day remembering, crying, laughing, going to work, or carrying on your day without the fear of judgment from others. It is a tool to create a personal journey towards healing. Many family members who cultivate a personal grief process through *One Moment at a Time* report feeling relieved that they do not have to follow a set timetable for grief. They also have reported feeling close to their child/grandchild/ sibling and better able to manage day-to-day grief.

For *One Moment at a Time* to work, the bereaved need to seek out and surround themselves with compassionate and loving people who can support and empower them during their personal bereavement process. These personal connections — whether they involve a family member, a professional, or a friend — can lighten their daily struggles with pain and suffering. But what if the individual’s pace of grieving does not match that of the spouse, family member, or friend — the very person that may provide the most support? One of the best ways to navigate this situation is open communication between both people.

Opening the lines of communication between grieving people is not always easy. Grief will magnify the challenges that a relationship already faces and this conflict may affect one’s ability to grieve *One Moment at a Time* successfully. A therapist or member of the clergy can be very helpful to families during these times. A therapist is trained to help families with a variety of therapeutic techniques that can teach communication, empowerment, compassion and empathy.

Movies, books and resources can also assist families in grieving *One Moment at a Time*.

Rabbit Hole is a good example. Released in 2011, it starred Nicole Kidman for which she received an Oscar nomination for best actress. The plot deals with a couple, and their families, struggling to survive after the sudden death of their young son and how grief intersects with their lives as individuals, a couple, and as family members. The movie is a wonderful tool which eloquently portrays the effort, compassion, and compromise that relationships can endure after experiencing the unthinkable. Comfort can also be found in many excellent books. Access to resources is also a vital tool in the healing process.

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ONE MOMENT AT A TIME (cont'd)

Lisa Capizzi, MSW, LCSW

To help those in grieving *One Moment at a Time*, here are some strategies from people who have successfully developed their own personal grief journeys. Thank you to those family members who have shared so willingly!

- Journal feelings, scrapbook memories, or blog, etc. As time passes, many parents have expressed their fear of others, or even themselves, not remembering their child's memory. This is a way to remember and decrease that fear.
- Create a lasting memorial for your child, such as setting up a scholarship, planting a tree, starting a garden, or designing a website.
- Seek professional support, either individually or through groups.
- Encourage a new hobby.
- Use the child's name and speak about them as often as they like.
- Celebrate the child's birthday in a special and meaningful way to that family.
- Exercise. It is a stress reducer, energy enhancer and also releases endorphin chemicals which can combat depression.
- Encourage yoga. It is a way to calm the mind, find a focus, strengthen and stretch tense muscles. Yoga can help promote an overall sense of wellbeing.
- Get enough sleep- it will help restore the body and mind.

Not all of these strategies will work for every individual. Perhaps none of the above will be helpful to you. Help each other to brainstorm to discover activities that may be a match for you. Taking grief *One Moment at a Time* brings comfort and helps the bereaved to create their unique successful grief journey.

Bereavement, Grief and Mourning

After losing a loved one, we often hear the words "grief," "bereavement," and "mourning" used interchangeably. While these terms are similar, they in fact mean different things. **Grief** refers to the reaction we have after a great loss. Grief includes all the feelings, physical symptoms, and social reactions we have to this loss. Everyone experiences grief differently. Anger, guilt, anxiety, and sadness are all normal grief emotions. **Bereavement** is the period after a loss during which we experience grief. Much like how everyone experiences grief differently, everyone has a different length of bereavement. Some may be in bereavement longer than others. **Mourning** is the outward expression of grief specific to the individual, including certain rituals and ceremonies. Mourning typically involves the longer process of adjusting to the world without our loved one.

Source: <https://www.alzinfo.org/articles/bereavement-and-grief/>,
<http://www.griefcounselor.org/articles/grief-article-mourning-grief.html>,
<http://www.webmd.com/cancer/tc/grief-bereavement-and-coping-with-loss-pdq-supportive-care---health-professional-information-nci-definitions-of-terms>

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WHAT IS GRIEF?

No matter what the autopsy reads, your grief is all consuming. Grief is a natural process of emotions that occurs when someone dies. Grief integrates into normal routines at variable timeframes for each person. It is an intense, lonely, and personal experience. No two people will experience the death of an infant/child the same way. A sudden, unexpected death of an infant/child is different from any other death because our children are "not supposed to die." The death is incomprehensible. There is no right or wrong way to grieve. When your infant/child dies not only does the death destroy the dreams and hope you had as parents but it also forces your family to face an event for which you are not prepared. Many parents wonder if they will be able to tolerate the pain, to survive it and be able to feel that life has meaning again. Grief can have its ups and downs. Intense reactions may return on specific dates (birthdays, holidays, anniversaries, etc.), or in connection with milestone events (moving from the home where the infant/child died, the growth of a subsequent sibling beyond the age of the infant/child that died, etc.). As times moves on, the pain from grief becomes less sharp and more integrated into your life. Happiness does return, very, very slowly at first. At some point you begin to laugh and to appreciate life again. You are a changed person and will never be the same. Family, friends, and your community at large will help you to slowly start your journey to healing.

PARENTS AND THE GRIEVING PROCESS

Initial grief reactions: Shock, Disbelief, Denial or Numbness.

These reactions are normal. Others, who are not familiar with the grieving process, may incorrectly assume that you are strong and holding up well. Some people may also wrongly assume you are insensitive and incapable of experiencing the loss. What they do not understand is that shock, disbelief, denial and numbness allow you to begin to face the tragedy without losing control. These reactions may last from minutes to weeks.

When your infant/child's death becomes a reality.

Crying, weeping, incessant talking are all normal reactions. You may feel very alone. Your spouse, children, family and friends will all express grief differently. Some may have trouble sharing feelings, be uncomfortable talking about death or unable to meet your need for comfort and support. Help may be obtained from your religious affiliations, counselors or other bereaved parents.

Some of the emotions you may experience.

There is no "correct time" to express emotions. It is important for you to allow yourself full expression of the emotions that you feel when you feel them. Well-meaning family, friends, and even strangers, will offer you advice on how you should be grieving. Parents often tell us this is so difficult to deal with.

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PARENTS AND THE GRIEVING PROCESS (cont'd)

Guilt: You blame yourself or each other for something you did or did not do in the past or present. “If only” becomes a familiar saying or thought. Many times you feel guilty thinking of all the things that you wish you had done with your infant/child. The “what ifs” take over your brain for quite some time. With the help of your support network, the “what ifs” take over less space in your brain as time goes on. They never completely leave your thoughts, but it does become easier as you process your feelings.

Anger: You can feel angry with yourself, your spouse, the doctor, even the infant/child for having died. You may be angry with a higher power who allows infants/children to die. These thoughts may cause great anxiety, even though they are normal. It is important to express your anger in healthy ways. Meditation, therapy, exercise, yoga, prayer, going out with friends, even screaming in private are all possible tools to help you process your anger.

Fear: After the death of your infant/child you may experience an overall sense of fear that something else horrible is going to happen. You may become extremely protective of your other children. At the same time, you may fear your adult responsibilities. Fear is a natural emotion that occurs after the unexpected death of your child. Ways to help manage your fear include: meditation, therapy, exercise, yoga, prayer, going out with friends, and talking with loved ones.

Difficulty concentrating: Your mind may wander, making it difficult to read, write and make decisions. Sleep may be disrupted, leaving you edgy and overtired. Even with sleep, you may feel exhausted. You may feel as if you are “going crazy”. This is part of the grief experience that does get better with time and healing.

INTENSITY AND DURATION OF GRIEF

It is important to remember that the pain of intense grief doesn't last forever. As parents, you will always remember your infant/child and grieve. Often it feels like the pain will never soften. Time makes the pain less sharp. It does not disappear, it becomes less consuming over time. The timeframe is so variable. That is not to say that we will get over the grief, but it can soften so that memories that once caused so much pain can become memories that are comforting. Look forward to that time. The pain becomes less sharp as time moves forward.

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THE TASKS OF GRIEVING

There are many different theories about grief. You may be familiar with grief described as a series of five phases as described by Dr. Elisabeth Kubler-Ross during the late 1960's. Another theory that was developed by Dr. J.W. Worden in the early 1980's identifies grief not as a succession of phases through which a person passes and over which s/he has little or no control, but as a series of four tasks, which a person must work hard to complete: Below is the series of four tasks.

Acknowledge the Reality of the Loss: After any death, grieving family members and friends usually express disbelief -- "I can't believe this is happening to us," or "How could my infant/child be dead? He was fine when I put him down for his nap just 20 minutes before." Grieving family members often experience strong feelings of wanting their infant/child back at all costs or wanting to know, or assign, a certain cause to (or blame for) their infant/child's death. Their first task is to acknowledge that their infant/child has died. Ultimately, our hope is that they accept that there was no way to know their infant/child was going to die and that they will not ever have their infant/child back.

Experiencing the Pain of Grief: While grieving family members begin feeling the pain of grief from the moment they discover their infant/child has died, the full extent of their pain may initially be "numbed" by the shock or disbelief surrounding the death. Many family members experience their most intense pain (both physical and emotional) after they have acknowledged their loss and are trying to resume "normal living." Unfortunately, it is also generally at this time that the family ceases to receive comforting calls and notes from friends. They are expected to return to their usual productivity at work or home. Such sudden absence of attention and increased (often-unrealistic) expectations from others leads family members to feel isolated and may cause them to suppress their pain. By allowing themselves to express and release their pain, family members are better able to move forward through grief.

Adjusting to a Life without your Infant/Child: As the pain of grief is released, family members begin finding ways to accommodate the changes in their lives brought on by the infant/child's absence. They begin to weigh the options related to issues such as what to do with the infant/child's room or things; or returning to (or taking on new projects at) work; or how to answer the question "how many children do you have?" They once again turn their full attention to parenting their surviving children or may start planning to become pregnant. Such adjustments may be difficult because they require the family members to develop a degree of detachment from their child. Many families may take some time to make these adjustments and may struggle with their issues for a while before they make decisions.

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THE TASKS OF GRIEVING (cont'd)

Healing: As you begin to heal and make new decisions, family members will eventually begin enjoying the people and activities that brought them pleasure before the infant/child died. However, your new sense of happiness may be interspersed with periods of guilt or regret because you fear that by enjoying yourself you are *forgetting* the presence and devastating loss of your infant/child. Many grieving family members will describe moving forward as a process, rather than a decision. It may take months, sometimes years, to acknowledge the changes. One indication that they have incorporated the grief into their lives may be demonstrated through their realization that "There are other people in the world who want and need my love -- and loving them does not mean I love my child any less." As time passes, the painful days become less frequent. There is no set time in which healing takes place after your child dies. The pain of your child's death becomes less intense, but not forgotten. Birthdays, holidays, and the anniversary of your child's death can trigger periods of intense pain and suffering. You need to take care of yourself physically, emotionally, and spiritually. Physical intimacy with each other and sex are both important parts of a relationship, but may be difficult at this time. It's important to remember that sexual expression does not have to lead to intercourse nor to pregnancy. Some parents believe that having another baby will ease their pain, but it may make your grief more difficult to handle. Talk to each other and your doctor.

IS THIS NORMAL?

Anna Irizarry-Wood MSW, LCSW

Many parents, caregivers, family members, and friends ask, "I'm scared to ask but is this normal?" The following is a short list of their experiences:

1. I hear my baby/child crying. I can still smell my baby/child.
2. I have a hard time getting out of bed.
3. I can't stop thinking about my baby and how my baby died.
4. I don't want to talk to anyone because feel numb and disconnected.
5. I keep thinking that something horrible is going to again happen to my family.
6. I feel like this never happened and find myself looking for my baby.
7. I can't stop thinking about bad things that happened to me before I had the baby.
8. I have nightmares and don't want to tell anyone about the details.
9. I sleep two or three hours a night.
10. I haven't been able to get back to work a year after the baby died.

An unexpected death of a baby/child takes a significant toll on a family member's body, mind, and spirit. Some may have challenges with sleeping, digestion problems, chest pain, frequent urination, muscle pain, headaches and many other physical symptoms. Emotionally, some may feel disconnected, angry, shock, frustration, denial and many other feelings. Some family members may begin to question their spiritual beliefs, seek more spiritual guidance, or disconnect from their spiritual beliefs.

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IS THIS NORMAL? (Cont'd)
Anna Irizarry-Wood MSW, LCSW

Everyone's grief is different although many share similar responses. There are times when the debilitating feelings of grief take longer to subside and when the death of the baby/child can cause someone to feel like they are constantly in danger. Some family members may begin to feel numb, shut down, experience nightmares, loss or increase in appetite, and have severe depression and anxiety. Please contact our staff if you are experiencing any of these symptoms on our 24 hotline at 1-800 -545-7437. The SIDS Center of New Jersey, recognizes that many families experience these responses. We are always here for you and your family.

TEN SUGGESTIONS FOR COPING WITH YOUR GRIEF

1. Whatever you are feeling, it is normal. There is no right or wrong way to grieve.
2. Your body requires food and fluid even if you do not want it. It is important to eat small nutritious snacks and meals at regular times and drink plenty of fluids.
3. Sleeping is often difficult. If you cannot sleep, it is important to rest throughout the day. However, try to maintain normal sleep patterns by sleeping longest at night.
4. Your energy level will probably be low. Give yourself permission to rest.
5. Seek out supportive family and friends who will listen to you talk about your infant/child.
6. Be patient with yourself. It is o.k. to say no to things that are overwhelming. When you are stronger, then you can say yes.
7. You will not forget your infant/child. Your infant/child will always be part of your life. Choose personal ways to memorialize your infant/child.
8. Keep a journal to write how you are feeling and what you are doing. Write as often as you need.
9. If you feel that you cannot cope on your own, consider a professional counselor who can give you support and insight.
10. Find the support of other bereaved parents through local support groups.

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**A JOURNEY TO HEALING
GRIEVING DURING THE HOLIDAYS**

Whatever your age, whatever the cause of death, holidays lived in the absence of your infant/child can be an extremely difficult time. Customary routines are ended, never to be repeated in quite the same way. Easy-going laughter, once flowing so naturally, may become awkward or even altogether missing. Gift-giving, once so filled with fun, may seem somehow empty and so sad. Familiar songs, once so comforting, may catch in your throat or bring tears to your eyes.

All this happens against a backdrop of significant questions you may find yourself asking: What exactly is happening to me? Can I possibly survive this, and do I even want to? How long will this turmoil last? Is what I am feeling normal? Am I losing touch with my sanity?

The holiday period in itself adds its own share of questions: How can I make it through all the events of the holidays while missing so desperately my infant/child. Would I be better off to ignore the holidays this year? Should I act as if everything were normal? Should I make major changes in my holiday rituals?

Most likely there will be many questions. It's important for you to know at the outset there are few universal "right" and "wrong" answers. There may be various answers, depending upon the unique factors of your situation: who you are as a person, what your family is like, how much time has passed since your infant/ child has died. It's also important to remember that not all your questions will have ready answers. Sometimes you must learn by doing, and then learn even better by trying it another way.

Keeping in mind there has never been a loss precisely like yours, there are still some general guidelines bereaved people have found helpful through the years. We hope you will treat them as suggestions rather than as prescriptions. Use them as ideas you can expand upon. Shape them to fit your distinct circumstances and to serve your personal needs. Above all else, remember that others, *many* others, have faced something similar to what you're facing right now. They have learned what it is like to endure and to survive and often even to grow through their experience. What they have learned is what you can learn, too. The ways they have persevered are ways you can adopt as well.

Most of all, we hope you'll choose to believe this: your holidays can still be a significant time for you. They will be different, but they can still be meaningful. They may hurt, but they can also hold hope -- even great hope. Below are some tips to help you navigate.

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GRIEVING DURING THE HOLIDAYS (cont'd)

Accept the likelihood of your pain.

1. When you're facing your first holiday without the one who has been so close to you, a good starting point is with this awareness: chances are it will be a painful time. While it may have its difficult moments, the approaching holiday time does not have to be an absolute catastrophe. More often than not, people report that the experience itself did not turn out to be as trying as they feared. Chances are good that can be your experience, too. Yes, you will probably feel pain. Yes, you may wish this year's calendar would skip over November and December. But, no, it does not have to be awful. There are things you can do to help.
2. Feel whatever it is you feel. You may be learning what many others have learned: some people will try to hurry you through your grief. Some may insist on continually cheering you up. Others may give you advice about what you should and shouldn't do or how you should and shouldn't feel. Whatever else you do this holiday time, do your best to claim your own feelings. As much as you are able, own up to the fact that something has happened in your life, that this naturally causes a reaction within you. You're not a robot -- you're a responsive human being who is capable of all sorts of emotions. Whatever it is you're feeling these days, remind yourself that feelings are normal, whatever they happen to be. They're a sign that you're human, that you care deeply, and that whatever you feel today, you can feel differently tomorrow. Your feelings seldom lead you astray. They usually lead you to yourself.
3. Take charge where you can. So much of your life is not under your control. The loss you've experienced and the resulting inescapable changes have robbed you of a power you may have taken for granted. Yet there are some actions you can take and some decisions you can make that are within your authority. Begin to take control of your life in specific ways, even if those ways seem small. This may be a good time to evaluate the holiday traditions you've established through the years. Which ones are meaningful, ones you want to keep? Which ones have outgrown their usefulness? Which ones might you forego for a year or two, and which ones are so important to you that you *must* perform them, even if it's hard to do? Which ones can you adapt to fit this year's circumstances?

Some examples are:

- Consider designing new rituals -- ones that will include opportunities to remember the past while acknowledging that the present has changed.
- Change your holiday meal routine, by dining out at a restaurant rather than at home, or by having the main meal in another's home.
- Changes might be made in how holiday decorations are done.
- Changes in how gifts are given out, or when, or where.

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- In general, choose life in all the ways you can. Be among people who offer you vitality. Practice those disciplines that bring you energy. Do those things that give you satisfaction. Take charge in little ways and you'll find they're not so little -- they're important.

Adapted with permission from: *Grieving during the Holidays*

PROFESSIONAL COUNSELING MAY BE HELPFUL FOR YOU

Complicated grief occurs when the initial grief emotions continue and significantly impact functioning over the long term. Professional support should be sought around the six month mark if symptoms of complicated grief are present.

The American Academy of Bereavement reports that intense grieving lasts 3 months to 1 year. Some people continue to experience profound grief for up to 2 years. Signs that counseling would be helpful include:

- Chronic Depression
- Desire to die and talk of suicide
- Frequent talk of reunion with the deceased infant/child
- Inability to eat or excessive eating
- Inability to sleep or excessive sleeping
- Increased use of alcohol, recreational or prescription drugs
- Numbness, flatness or “no feeling at all”
- Isolation from family and friends
- Hopelessness and helplessness or the inability to “see the light at the end of the tunnel”

Everyone who has experienced the death of an infant/child has one, some or all of these feelings at some time during the grief process. Determining when to seek professional help is a very personal issue. Many couples find that they are understood for the first time in the presence of an unbiased, trained counselor. Certainly when grief becomes overwhelming and no longer manageable, professional counseling should be sought. Help can be found in your community through mental health agencies, churches and hospitals. With the assistance of a professional, your grief can become more manageable.

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WHEN TO SEEK IMMEDIATE ASSISTANCE

Be aware that during this process it is normal to **occasionally** express thoughts that may initially feel/ sound alarming, such as "I just want to be with my child "or "Life's not worth living anymore now that my child is gone." This is part of normal grief. **If you expresses any of the below, immediately notify a family member and go to your local emergency room. You can also call 911.**

- 1. You want to die and you have a plan.**
- 2. You want to hurt your spouse/child or someone else.**

You are not alone.

“There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief, of deep contrition and of unspeakable love.”

...Washington Irving

MOTHER’S GRIEF

The instant you find out that you are going to become a mother you imagine a future life with your child. What they will look like, what they will grow up and become, holding them in your arms, and many other beautiful moments in life. A perfect world is envisioned as mother and child. When death occurs, your perfect world is shattered. We are not meant to bury our children, it is not the circle of life. Hopes, dreams, the future, all gone. Broken promises of sharing maternal love forever. Now you are in a dark place wishing, begging, and hoping for some light. The people who celebrated your pregnancy, and birth, are now giving condolences. This is not how you imagined your life. Family, friends, and your community are ways to help you navigate and travel this unwanted journey. The SCNJ is here to provide you support, guidance, and to connect you to other grieving mothers.

Below is an excerpt from one of our newsletters written by our Program Director, Dr. Barbara Ostfeld. Her words have brought many families comfort and hope. We end this section with a poem that was written by a bereaved mother.

Excerpt from Healing Times Spring Summer 2012

Barbara Ostfeld, PhD Program Director SCNJ

For many years a dear friend of mine feared that the memory of her son would fade from family history. Then, one Mother's Day her fears evaporated. Her youngest child, who was born long after her son had died, presented her with a family portrait, one she drew in crayon, the preferred tool of five-year-olds. My friend saw four stick figures. There were two big ones, one with a skirt, and she realized that they represented her and her husband. The two little ones she understood were the "artist" and her older sister. But the drawing also contained an object that looked like an egg with four legs. "What's that?" she asked. Somewhat exasperated at having to explain what she was sure was quite apparent, the little girl said, "*That* is our baby brother in his

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carriage. You can't see him, but I know he's in there." Not just mother, but now daughter too, saw herself as part of a family of five.

As I have written to you before, over three decades have passed since I have been able to celebrate Mother's Day with my son Daniel. On that first Mother's Day, two months after his death, I felt grateful that I could hold and draw comfort from my other young children, but the pain of fresh loss overwhelmed us. Although those feelings were with me every day, Mother's Day was a harder day, especially in the beginning. I wondered, "How could I get through this every year?"

As you and I have all learned, grief takes us on a journey. It exposes us to many feelings over the years and can even surprise us along the way, strange as that may seem. I have survived over 35 Mother's Days without my Daniel in the room. Yet, I remain his mother, and he, my son. He never leaves my heart, and so, he is present at all occasions, even Mother's Day. In my journey, Mother's Day has become something I could not have imagined in the beginning, a day of peace. A grandson was born on Daniel's birthday, a miracle, I thought, and one that would bring new joy to that date. My youngest son, the baby's father, put it this way as he spoke to family and friends who gathered to celebrate the new baby. "Since my own birthday fell close to my son's due date, I thought that it would be nice if my child turned out to share that date with me, but God had a much better plan." His words filled the hearts of everyone in the room. These were the people who held us up and helped us endure the early days. We were now taking a moment to appreciate something of great comfort. Daniel remains part of our lives. On Mother's Day, we will gather with our children and grandchildren. He is still thought of and loved by his siblings. One became a physician, motivated as he told me one long-ago day when he was just eight, by the desire to, "help make everybody better." In the young faces of my grandchildren I see features of their uncle. They have his photo. They will know his story. I am grateful.

At each step you take along your journey, please know that the members of the SIDS Center of New Jersey are here for you.

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**A PAIR OF SHOES
Anonymous**

I am wearing a pair of shoes.

They are ugly shoes.

Uncomfortable shoes.

I hate my shoes.

Each day I wear them, and each day I wish I had another pair.

Some days my shoes hurt so bad that I do not think I can take another step.

Yet, I continue to wear them.

I get funny looks wearing these shoes. They are looks of sympathy.

I can tell in others eyes that they are glad they are my shoes and not theirs.

They never talk about my shoes.

To learn how awful my shoes are might make them uncomfortable.

To truly understand these shoes you must walk in them.

But, once you put them on, you can never take them off.

I now realize that I am not the only one who wears these shoes.

There are many pairs in this world.

Some women are like me and ache daily as they try and walk in them.

Some have learned how to walk in them so they don't hurt quite as much.

Some have worn the shoes so long that days will go by before they think about how much they hurt.

No woman deserves to wear these shoes.

Yet, because of these shoes I am a stronger woman.

These shoes have given me the strength to face anything.

They have made me who I am.

I will forever walk in the shoes of a woman who has lost a child.

A JOURNEY TO HEALING

FATHER'S GRIEF

There are many gender based myths discussing how people grieve differently. Generally speaking all people grieve differently, it is not always specific to your gender. There may be traits that are sometimes associated with gender, but both parents are broken hearted regardless. Parents may be on the same page or not, but they share in the devastation. Grief is not linear. Because such unrecognized differences exist in the way men and women grieve, neither parent is able to fully comfort or support the other. Apart from feeling "empty" themselves, they do not understand the way each needs to grieve. Both may become angry and frustrated with the other, putting strain on the relationship during this traumatic period.

One way we can be supportive is to encourage the man to grieve in a way that is comfortable for him. Our understanding and listening to him and his needs can be a healthy way to process your child's death together.

Below is an adapted version from "*Grief- A Man's View*", Peter Dunn, counselor, SIDRF, Melbourne, Australia, that describes possible roles that may describe men in their grief.

STRONG MAN ROLE- At an early age men are given the message that they are to be emotionless. Society has helped to reinforce these ideas in adolescence and adulthood. Men are "permitted" to cry at the time of death and at the funeral, but not long afterwards.

PROTECTOR ROLE- Society has also given men the "protector" role. When a man's child dies he may feel like a "failure" as he could not save his child. He may also experience a sense of failure when he can't protect the rest of his family from the pain of grief nor shield them from the effects of his own grief.

SELF-SUFFICIENT MAN ROLE- Man has been brought up to be self-sufficient and often resists seeking professional help. Men are often reluctant to come to meetings with other bereaved fathers where feelings may be shared. They are therefore often left to struggle through their own feelings and emotions, and how to express them. Often community members, family, and friends focus on the mother and her loss and don't even ask how the father is doing.

PROVIDER ROLE- After the death of a child, unfortunately the father often returns to work sooner than he may be ready. He may find his co-workers treat him differently and are unsure how to respond to him. The father may feel isolated. He may throw himself into his work to avoid returning home where there is the reality of death and grief. Avoiding home may only distance you more from your support systems and your need to grieve. Open displays of grief may be helpful and necessary for some people. To expect such behavior of all or even some men may be counter-productive to their own way of grieving.

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10 WAYS FAMILY AND FRIENDS CAN HELP FATHERS GRIEVE

By Lisa Capizzi Marain, MSW, LCSW

1. Encourage open discussion
2. Let fathers speak about their pain
3. Remind fathers they are not alone
4. Just listen, do not try to solve their problems
5. Encourage fathers to reach out to other grieving fathers
6. Allow fathers the time to process what has happened to them
7. Allow fathers to turn to or away from their faith as needed
8. Let fathers cry
9. Let fathers know you are there for them always
10. Allow them time to be alone with their pain.

Not all of these strategies will work for every individual. Perhaps none of the above will be helpful to a certain individual you know. Help them brainstorm to discover activities that may be a match for them. Grief is such a personal and unique journey. Often times, just letting them know you care can make a difference. The Grieving Dad's project is a resources specific for fathers. <http://www.grievingdads.com/home-page/> this webpage is a place where grieving dads can connect to each other. It is run by a bereaved father. There are blogs, stories, and resources. Below is a poem that he shared on his webpage through his relationship with Grief Haven.

DEAR MR. HALLMARK ONE MORE TIME

Hello there Mr. Hallmark man,
I wrote to you in May
To ask that words of love be shared
With my mom on Mother's Day.
Just as there is no card for Mom
To let her know I care,
There is no card for my dad, too,
And I have so much to share.
It's very hard for my loving dad
To know that I'm okay.
To protect me was his job, he feels,
So he thinks he failed some way.
Although I had to leave this world,
While still considered young,

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There is no way he ever failed—
There's no more he could have done.
My dad he tends to question
Those things he cannot see.
I always send him little signs
To say, "Hey, Dad, it's me!"
I hear him crying in the car,
The shower hides his tears.
He feels he has to be so strong
For those he holds so dear.
My dad he often gets so mad
At what became of me.
He wants so much to understand,
He says, "How could this be?"
I somehow need to let him know,
Though impossible it seems—
For him to live and laugh again
Will fulfill so many dreams.
The card I need to send right now
To a dad as great as mine,
Will thank him for the love he gave
Throughout my brief lifetime.
He's still the one that I call Dad,
Our bond's forever strong,
'Cuz even though he can't see me,
Our love lives on and on.
Please help me find a way
To tell my dad that when
It comes his time to leave the earth
I'll be waiting there for him.
And also, Mr. Hallmark man,
Please help him to believe,
That nothing will ever change the fact
That my dad he'll always be.

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GRIEVING ALONE: A SINGLE PARENT'S EXPERIENCE

Adapted from Kelly Osmont. The Compassionate Friends.

When a single parent experiences grief over the death of an infant/child, there may be several issues and dilemmas encountered that are different from those faced by the bereaved parent who has an involved partner. This article addresses some of those challenges.

A Strong Sense Isolation -When your infant/child dies the world may seem to tumble around you. It may feel particularly frightening to a single parent, for there is no partner to reach out and bridge the gap of isolation. Often the isolation becomes real, after a few weeks of bereavement. Friends who have been supportive may drift away, assuming someone else is checking on your well-being. Having a "parent contact" available by phone and willing to talk or listen can be a lifesaver.

Inconsistency -Every hour of every day may seem like a challenge to "get through," and the only person you know you can depend on is you! Those who have understanding relatives nearby can look to them for stability during the early months of grief. With family you can often "just be." Close friends can be asked to fill this important role, too.

Sharing Emotions- Much of the stress from the loss of a loved one can be relieved by simply sharing with another person your thoughts, feelings, and ideas. Sometimes we do not have the emotional strength to dial the phone. We may dread finding that all our friends are busy or not home, knowing we may end up feeling more rejected than when we began. Someone can help you look at the situation from a different angle. We need others and people who will listen.

Going Back to Work Sooner Than You May Be Ready -A single parent who has other children at home often has additional responsibilities. Not only is the parent grieving over the loss of an infant/child, he or she may also have to go back to work for a living. That parent may also have to try to maintain stability at home for remaining children, and handle the normal, everyday household problems. Additionally, if there are other children, that parent must devote attention to them. Special support systems can be very helpful. For example, friends might volunteer to come in or take the children out, bring dinner, do the laundry, etc.

Sharing The Special Memories- As a single parent, you may not have anyone who remembers your infant/child as you do. If you have other children, you will be able to talk with them and share your memories.

Support from the Opposite Sex- getting emotional support from a non-bereaved person may be difficult. Dating and seeking emotional support from another may be stressful. Explain what you are going through to others, so they can have a better understanding of what you are going through. In facing the pain of grief, you may not have much energy left for building a new relationship during the first year after your infant/child dies.

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GRIEVING ALONE: A SINGLE PARENT'S EXPERIENCE (cont'd)

Adapted from Kelly Osmont. The Compassionate Friends.

Making Decisions and Facing Major Events Alone- After the memorial service, you are left with many decisions. Sorting through all of your infant/child's possessions, each article of clothing, letters, and papers, such tasks can be grueling to face alone. Each time milestone events such as birthdays or holidays arrive, you may want to thumb through your address book and find someone whom you could talk to and help you handle those difficult times.

The Need for Touch -Often people who have lost a loved one have a strong need for touching and hugging. The contact not only feels good, but also can have a healing quality. Being single may mean there is no one nearby to provide that gentle touch on the back or that consoling hug when the pain erupts. When you are single, it may be helpful to find other sources like friends and relatives who know how to hug and do for you. Reach out to them as often as you need. If you have surviving children, hug them often. You will all benefit from it.

TEEN PARENT GRIEF

Adapted from Shattered Dreams- A Time for Precious Memories, Susan Ellison, RNC and Intensive Caring Unlimited Newsletter

Single teenage parents who infant/ child has died often find themselves in the role of a child again. Well-meaning grandparents may often take over decision-making, wanting you to return to school and return to being just a teen. You may feel you have no one to talk to or understand what you are going through. Trust yourself and what you need during this difficult time. If you take the steps to take care of yourself you will move through the process of grief at exactly the right pace for you. You will survive, but it will take some work to get through this. Remember, you don't have to do it alone. Sometimes the act of blaming is a natural and necessary part of the grief process. You may hear yourself say, "If only I had..." or "Why did this happen?" Be gentle with yourself and others while you go through this process of healing.

When your baby dies, this can be the deepest loss you go through in life. The weeks and months ahead may be the hardest time in your life. People go through this pain in their own way and in their own time. Getting through this pain is called grieving. This is what we know about grief:

- Grieving is a very personal thing and is a natural reaction to loss.
- Grieving is normal and healthy.
- Each person grieves in his or her own way.

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- Grieving is painful.
- Grieving has no time limit.
- Physical reactions such as pain in the stomach, tightness in the chest or throat are normal, as well as having trouble eating and sleeping.
- Feelings of guilt and anger are normal.
- The pain of grief will ease.
- Grief provides us with an opportunity to heal and grow.

Adapted from Shattered Dreams- A Time for Precious Memories, Susan Ellison, RNC and Intensive Caring Unlimited Newsletter

Here are some suggestions that may help you:

- Share your feelings with friends and family who are supportive and take the time to listen to you.
- Know you will survive.
- Get help from someone you trust like your parents or school nurse, a teacher or counselor.
- Stay away from drugs and alcohol, especially when you are grieving, as they will not help make the pain go away, but only make it last longer.
- Avoid blaming yourself.
- Talk about your baby when you need to.
- Try to eat small meals or healthy snacks throughout the day. It's very important to also drink lots of fluids when you are grieving.
- Try only to nap for short periods of time during the day. This will help you get a restful night's sleep.
- Allow yourself to have fun.
- Consider whatever you do to be normal for you. Don't be afraid if you imagine you hear your baby crying or feel like your arms are aching. This is part of normal grief.

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FOR GRANDPARENTS...A “DOUBLE” GRIEF

From the moment you became a parent yourself, you have sought to protect your child from the pain and sorrows in life. Mostly, you have been successful, you've had the ability to solve problems, and the power to lessen hurts.

Suddenly, your adult child is facing a pain far deeper than any other pain in life. It may be deeper than anything that you have ever experienced, or perhaps you can understand this sorrow because you, too, have lost a child.

Either way, you are now experiencing a variety of emotions: helplessness, frustration, grief, guilt, and anger. You are suffering a “double grief”. You are grieving for your grandchild; all your hopes and dreams have been shattered. You had wondered if he or she would “favor” your side of the family, wondered what she/he would “become”, and had perhaps even bought gifts for “later on” (like that first tricycle or that special doll). Your grief may not even be recognized. You had a special relationship with your grandchild—one of unconditional love.

You may feel frustrated and helpless because this is one pain that you can't “just kiss away”. All the little ways that you had to coax a smile from your child are useless now; all the magic words that used to solve the problems are empty. You can only sit by, offer support, and watch your child learn to live with the terrible loss.

Grandparents often think that “they should cope better, have all the answers, control the situation and be an example. When all that they have offered: advice, financial aid, babysitting, experience, and help, is not accepted, asked for, or is even rejected, they often feel guilt, frustration and anger.”

Guilt and anger. Often, the two are intermingled. It can be difficult to determine where one begins and the other ends. Grandparents sometimes experience “survival guilt”...it seems unnatural that a grandparent live longer than a grandchild; grandparents often express the wish that they “could change places” with the beloved grandchild. You may be feeling guilty for things that you didn't do (Why didn't I baby-sit every time I was asked? Why didn't I spend more time with this grandchild?). Perhaps you aren't well, or for some other reason, you were unable to see your grandchild as often as you might have wished.

You may be very angry. Angry at God for “taking” this grandchild, angry at the doctors, nurses or paramedics for being unable to save your grandchild's life, angry at your other grown-up children whose families are intact (though a common reaction, grandparents feel a great deal of guilt because of this anger.). You might even find yourself angry at your own child wondering if there was anything they could have done or should have seen. Finally, you might be angry at yourself as you wonder if your genes or chromosomes were “responsible” for your grandchild's death.

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FOR GRANDPARENTS...A “DOUBLE” GRIEF (cont’d)

Please know that grief is a highly individual process. People do not need to be urged to grieve in some predetermined way. There are tremendous cultural differences in how people will grieve— even a husband and wife will seldom grieve in the same way. As parents move along in their grief, there will always be setbacks, some triggered by specific events related to the child (birthdays, anniversaries, etc.) and some seemingly unrelated. An unexpected death is uniquely difficult because of its very nature. Its suddenness and the lack of answers to important questions intensify the grief reactions.

You can't make the pain go away, you can't bring your grandchild back, but you can help make your child's adjustment to the loss much easier. By grieving together, you reaffirm that grief is normal and that life will go on. Someday there will be peace again.

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The Compassionate Friends, a support groups for parents and grandparents who have lost children of all ages to all causes, devised a list of “DO’s and DON’Ts” for the families and friends of bereaved parents. Their suggestions along with a few of our own include:

DO...

- Let your genuine concern and caring show.
- Be available...to run errands, to listen, to help with the other grandchildren, to do whatever else needs to be done at the time.
- Allow them to express as much grief as they are feeling at the moment and are willing to share.
- Say that you are sorry about what happened and about their pain.
- Encourage them to be patient with themselves, not to expect too much of themselves and not to impose any “shoulds” on themselves.
- Allow them to talk as much and as often as they wish about their child.

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- Reassure them that they did everything they could, that there was nothing that they missed and that there was nothing else ANY ONE could have done to save their child's life.
- Help them let go of the questions and the guilt.
- Remember your grandchild's birthday and anniversaries with the parents.
- Do give special attention to your grandchild's brothers and sisters (they are hurt and confused, too, and in need of attention which their parents may not be able to give at this time).

DON'T...

- Let your own sense of helplessness keep you from reaching out.
- Say you know how they feel unless you have also lost a child.
- Say "you ought to be feeling better by now" or anything else which implies a judgment of their feelings.
- Change the subject when they mention their child.
- Remove pictures of your grandchild from your own home (they need their child remembered).
- Avoid mentioning your grandchild out of fear that you will remind them of their pain (they haven't forgotten it!).
- Point out that at least they have their other children (children are not interchangeable).
- Say that they can always have another child (even if they want to, or can, another child will not replace the child that died).
- Make any comments that suggest that the care given their child at home, in the emergency room etc., was inadequate.

RESOURCES FOR GRIEVING GRANDPARENTS

ORGANIZATIONS

The MISS Foundation's Alliance of Grandparents, A Support in Tragedy The MISS Foundation that provides resources for bereaved grandparents. <http://grandbrigade.org/>
1-888- 455-MISS

The Compassionate Friends – provides support to parents, grandparents, and siblings
<http://www.compassionatefriends.org/home.aspx> Phone: 1-877-969-0010

Grandparent Grief- provides online support and resources for grandparents
<http://www.healingheart.net/grandparents.html>

AARP Grief and Loss Programs- provides grief programs and online support
<http://www.aarp.org/griefandloss/> Phone: 1-888-687-2277

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Bereaved Parents of the USA –support for parents, siblings, and grandparents

<http://www.bereavedparentsusa.org/> Phone: 1 - 708 -748-7866

BOOKS

Grandma's Tears - Comfort for Grieving Grandparents by June Cerza Kolf

When a Grandchild Dies - What to Do, What to Say, How to Cope by Nadine Galinsky

Grandmother's Gift - A Memory Book for My Grandchild - Peg Streep & Claudia Karabaic Sargent (Illustrators)

Grandparents Cry Twice: Help for Bereaved Grandparents - by Mary Lou Reed

Grandparent's Sorrow – by Pat Schweibert, RN

When a Grandchild Dies – by N. Galinsky

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FAMILY, FRIENDS, CO-WORKERS, AND THE COMMUNITY

Often times you will be faced with well-meaning people who want to support you, but ultimately their words may be so hurtful. “They are in a better place.” “You are young and can have more children”, “Is this your first pregnancy?”, “You have other children”, “They were young, you hardly knew them.”, “It’s God’s will”, “You should....”

Unless you have experienced the death of your child, it is impossible to understand what you are going through. In these situations parents often respond differently depending on what is going on in the moment. Some parents choose to have a “teaching moment”, others choose to just ignore the person and their comments. Below are resources to help you in this part of your journey.

PLEASE SEE ME THROUGH MY TEARS

By Kelly Osmont

You asked, "How are you doing?"... As I told you, tears came to my eyes...you immediately began to talk again, your eyes looked away from me, your speech picked up, and all the attention you had given me went away...

How am I doing? I do better when people will listen to my response, even though I may shed a tear or two...for I so want their attention; but to be ignored because I have pain which is indescribable to anyone who has not been there...I hurt and feel angry. So when you look away, I am again alone with it.

Really, tears are not a bad sign, you know! They're Nature's way of helping me to heal... They relieve some of the stress of sadness. I know you fear that asking how I'm doing brought this sadness to me. No, you're wrong....the memory of my son's death will always be with me, Only a thought away. It's just that my tears make my pain more visible to you...but you did not give me the pain...it's just there.

When I cry, could it be that you feel helpless? You're not, you know.

When I feel your permission to allow my tears to flow, you've helped me more than you can know.

You need not verbalize your support of my tears. Your silence as I cry is my key...do not fear. Your listening with your heart to "How are you doing?" helps relieve the pain, because once I allow the tears to come and go! I feel lighter. Talking to you releases things I've been wanting to say aloud, and then there's space for a touch of joy in my life.

Honest...when I tear up and cry, that doesn't mean I'll cry forever---maybe just a minute or two-then I wipe the tears away, and sometimes you'll even find I'm laughing at something funny ten minutes later.

When I hold back my tears, my throat grows tight, My chest aches and my stomach begins to knot up... Because I'm trying to protect you from my tears... Then we both hurt...

Me, because I've kept the pain inside and it's a shield against our closeness, and, then you hurt because suddenly, we're distant.

Please take my hand...and I promise not to cry forever... (It's physically impossible, you know.)

When you see me through my tears, then we can be close again.

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WHAT SHOULD AND SHOULDN'T I SAY.

Adapted from suggestions by The Compassionate Friends Network

DO's

DO remember that you can't take away their pain, but you can share it and help them feel less alone.

DO let your genuine concern and care show.

DO treat the parents equally. Fathers need as much support as mothers.

DO be available...to listen, to run errands, to drive, help with the other children, or whatever else seems needed at the time.

DO say you are sorry about what happened to their child and about their pain.

DO accept their moods whatever they may be, you are not there to judge. Be sensitive to shifting moods.

DO allow talk about the special, endearing qualities of the child that died.

DO give special attention to surviving siblings-at the funeral and in the months to come (they too are hurt and confused and in need of attention which their parents may not be able to give).

DO reassure the parents they did everything they could, that the care the child received was the best possible.

DO put on your calendar the birth and death of the child and remember the family the following year(s).

DO extend invitations to the family. But understand if they decline or change their minds at the last minute. Above all continue to call and visit.

DO send a personal note or letter or make a contribution to a charity meaningful to the family.

DO get literature about the condition and grief process to help you understand.

DON'T's

DON'T think the age of the child determines how painful his loss is to his family.

DON'T be afraid to offer a hug, it can often be more comforting than words.

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DON'T avoid the family because you feel helpless, uncomfortable, or don't know what to say.

DON'T change the subject when someone mentions the child that died.

DON'T push the parents through the grieving process. It takes a long time to heal and everyone heals at their own pace.

DON'T encourage the use of drugs or alcohol.

DON'T tell a grieving family what they should feel or do.

DON'T try to find something positive in the child's death.

DON'T point out to grieving parents that at least they have their other children.

DON'T say they can always have another child.

DON'T suggest they should be grateful for the time they had together.

DON'T tell parents you know how they should feel, even if you also lost a child.

DON'T think death puts a ban on laughter. There can be much enjoyment in memories.

DON'T forget to "find the time" to call and keep in touch, especially on holidays and anniversaries.

DON'T use clichés and sayings that are often used to try to make sense of this tragedy. These statements often hurt more than help. A simple hug or an honest "I don't know what to say" is often the best way to show you care.

HELPING YOUR LOVED ONE....

Jennifer McConville and Pam McElgunn- parents whose babies died of SIDS

During this time of disbelief, the families affected by the sudden and unexpected loss of their child need the companionship and support of their friends and family members. Immediately we wish to provide comfort in a manner as to make the pain diminish for a while. But there are other ways in which we can help our loved one. The following are some suggestions in how you can lend a hand during this difficult and emotional period.

- Child Care- babysit the older children for a few hours, parents might want to attend a support group.
- Play Date- take the children somewhere fun (park, playground, library) as a special outing, it will give the parents quiet time.
- Car-Pool- drop-off / pick-up older siblings from school or other scheduled activities.

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- Housekeeping-daily chores will begin to pile up, offers to do the laundry, ironing, tacking clothes to dry cleaners, and vacuuming will be needed.
- Prepare Meals-vary the menu or order the meal and have it delivered. It's best that the meals be small in amounts and can be easily heated or frozen.
- Groceries / Miscellaneous-shop for the essential food items, bread, milk, etc. and help open mail, organize bills, and discard junk mail.
- Thank You Notes-help write and mail cards for funeral/ flowers, etc.
- Belongings-offer to help parents (when they are ready) to go into baby's room and put clothes and belongings away.
- Holiday Season- help shop for gifts for other siblings, help decorate,
- Photographs/Videos-ask other friends / family members to make copies of any photos they may have with the baby...create a photo album for the parents to treasure.

Remember... each family will react differently and will want different amounts of help from family and friends. Respect their wishes, but let them know that you are there for them. Continue to talk about the baby using his/her name. Remember that they may be gone in the physical sense, but they are never forgotten!

SUGGESTED READINGS FOR ADULTS

Empty Cradle, Broken Heart By Deborah Davis

Not Just Another Day: Families, Grief and Special Days. By ML Throckmorton

Creating a New Normal...After the Death of a Child By Fox S. Bloomington

Tearsoup By *Pat Schweiber and Chuch DeKlyn*

On Earth as it is in Heaven by *N.A, Noel*

What Do They Do All Day in Heaven by *Staci Thomas*

A Time to Grieve: Meditations for Healing After the Death of a Loved One by *Carol Stuardacher*

Healing a Parent's Grieving Heart-100 Practical Ideas After a Child Dies by *Alan Wolfett*

How Can I Help: Twelve Things to Do When Someone You Know Suffers a Loss and What Will Help Me: Twelve Things to Remember When You Have Suffered a Loss by *James E Miller*

How to Survive the Loss of a Love by *Peter McWilliams, Harold Bloomfield and Melba Colgrave.*

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I Wasn't Ready to Say Goodbye: Surviving, Coping and Healing After the Sudden Loss of a Loved One *by Brook Noel and Pamela D. Blair*

Mommy, Please Don't Cry; Tender Words For Broken Hearts *by Linda DeYmaz*

Recovering After Loss *by Bob Deits*

Remembering with Love: Messages of Hope for the First Year of Grieving and Beyond *by Elizabeth Levang and Sherokee Isle*

The Mourning Handbook: The Most Comprehensive Resource Offering Practical and Compassionate Advice on Coping with All Aspects of Death and Dying *by Helen Fitzgerald*

The SIDS Survival Guide Information and Comfort for Grieving Family and Friends and Professionals Who Seek to Help Them *by Joani Nelson Horchler and Robin Rice*

When Goodbye is Forever-Learning to Live Again After the Loss of a Child *by John Bramblett*

When Life Takes What Matters Most: Devotions to Comfort You through Crisis and Change *by Susan Lenzkes*

When the Bough Breaks, Forever After the Death of a Son or Daughter *by Judith Bernstein*

Growing Up In Heaven *by James Van Praagh*

The Angel with the Golden Glow: A Family's Journey through Loss and Healing.
By Al-Chokhachy, E.

A Guide to Understanding Guilt during Bereavement
By Baugher, R.

The Death of a Child: Reflections for Grieving Parents
Behme, T.J.; Pierce, G.F.A., ed(s).

Recovering from the Loss of a Child
Donnelly, K.F.

Then an Angel Came.
Gino, C. This book relates how SIDS affects the whole family.

SIDS and Infant Death Survival Guide: Information and Comfort for Grieving Family and Friends and Professionals Who Seek to Help Them.

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Third Edition. Cheverly, MD: SIDS Educational Services. 2003.320 p.
This book, written by and for SIDS and infant death survivors.

When Bad Things Happen To Good People

Kushner, Harold S.

A Guide for Fathers: When a Baby Dies

Nelson, T.

I Wish I Could Hold Your Hand: A Child's Guide to Grief and loss.

Palmer, P.; O'Quinn Burke, D.

Heart Works: A Father's Grief

Peterson, J.

**How Do We Tell the Children? A Step-by Step Guide for Helping Children Two to Teen
Cope when someone Dies**

Schaefer, D.; Lyons, C.

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CHILDREN AND GRIEF

Grief in a family affects the family life and the child/ren feel these changes. Children report feeling very much alone following a death in the family, despite the efforts of their parents to tend to the children's needs. Children tell us how helpful it is to "talk about it" over and over again. "Talking helps get the sadness out" and "The guilt and hurt would have been even worse if we did not talk." But children do not usually start the conversation because they often want to protect the parent from any additional pain. It is never too late to "talk about it." Our own ability to discuss and accept the death changes with time, just as it does for our children.

We can be most helpful to children by being open to talking about death. There are many excellent children's books, which address the subject sensitively and openly. Parents should speak with the teachers of the surviving siblings. The teachers of the surviving siblings should be notified of the death of the infant/child and the impact of this loss should be discussed. Parents and teachers can then initiate open discussions with the siblings. These discussions are important, as children are unlikely to bring up the subject. Below are resources and ages and stages of grief.

AGES AND STAGES

Age 2-4

Developmental Stage/Task - Egocentric. Believe world centers around them. Narcissistic. Lack cognitive understanding of death and related concepts. Limited language skills.

Concept of Death - Death seen as reversible, as abandonment, not permanent. Common statements: "Did you know my sister died? When will she be home?"

Grief Response - Intensive response but brief. Very present oriented. Most aware of changes in patterns of care. Asking questions repeatedly.

Signs of Distress - Regression: changes in eating and sleeping patterns, bed wetting, general irritability and confusion.

Possible Interventions - Short, honest answers, frequent repetition, lots of reassurance and nurturing. Consistent routine. Play is their outlet for grief.

Age 4-7

Developmental State/Task - Gaining a sense of autonomy. Exploring the world outside of self. Gaining language. Fantasy wishing and thinking. Initiative phase seeing self as the initiator. Concerns of guilt.

Concept of Death - Death still seen as reversible. Personification of death. Feeling of responsibility because of wishes and thoughts. Common statements: "It's my fault. I was mad and wished she'd die."

Grief Response - More verbalization. Great concern with process. How? Why? Repetitive questioning. May act as though nothing has happened. General distress and confusion. **Signs of Distress** - Regression: nightmares, sleeping and eating disturbed. Possible violent play. Attempts to take on role of person who died.

Possible Interventions - Symbolic play using drawings and stories. Allow and encourage expression of energy and feelings through physical outlets. Talk about it.

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Age 7-11

Developmental Stage/ Task-Concrete thinking. Self-confidence develops. Beginning of socialization. Development of cognitive ability. Beginning of logical thinking.

Concept of Death-Death seen as punishment. Fear of bodily harm and mutilation. This is a difficult transition period, still wanting to see death as reversible but beginning to see it as final.

Grief Response-Specific questions. Desire for complete detail. Concerned with how others are responding. What is the right way to respond? Starting to have ability to mourn and understand mourning.

Signs of Distress-Regression: school problems, withdrawal from friends. Acting out. Sleeping and eating disturbed. Overwhelming concern with body. Death thoughts (desire to join one who died). Role confusion.

Possible Interventions-Answer questions. Encourage expression of range of feelings. Explain options and allow for choices. Be available but allow alone time. Symbolic plays. Allow for physical outlets. Listen and allow for talk about the death.

Age 11-18

Developmental Stage/Task -Formal operational problem solving. Abstract thinking. Integration of one's own personality.

Concept of Death-A more "ADULT" approach. Ability to abstract. Beginning to conceptualize death. Work at making sense of teachings.

Grief Response-Extreme sadness. Denial. Regression. More often willing to talk to people outside of family and peer support. Risk taking .Traditional mourning.

Signs of Distress-Depression. Anger often towards parents. Suicidal thoughts. Non- compliance. Rejection of former teaching. Role confusion. Acting out.

Possible Interventions- Encourage verbalization. Allow for choices. Encourage self- motivation. Listen. Be available. Do not attempt to take grief away.

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HELPFUL GUIDELINES IN TALKING TO CHILDREN ABOUT DEATH

Many parents have reported that one of the most daunting tasks is to inform the surviving children that their sibling, cousin, friend, or schoolmate has died. Our hope is to provide you with guidelines to help families find the most effective way that feels right for your situation. Typically children will have varied responses regardless of what their age /developmental ranges are. If the child is not your own, it can be very beneficial to coordinate with their parents and share this information. **Most importantly, if a child says that they want to kill themselves immediately take them to your local emergency room where a professional can assess their mental health. If you are unable, call 911 or your local police department immediately for assistance.**

1. Be honest, open and clear. Whenever possible, adults should give children the facts regarding the death. Tell them immediately. While there is no need to describe great lingering detail, the important details should be given. These may be horrifying, but it is always important to give factual developmentally appropriate information to the child. The imagination of a child will "fill in" the details if they are not given. Too often, these imagined details are distorted, inaccurate, and more horrifying than the actual details, and can ultimately interfere with the long-term healing process. Avoid euphemisms such as, "passed on," "gone away," "departed". In and of itself, the concept of death is difficult enough for a child to understand; using euphemisms will only add to the difficulty. Discuss the funeral with the child. Do **NOT** force him or her to go. Decide what is right for your family based on the child's development and personality. If you decide they will go, explain in detail what they will see, hear and your expectation of them. Most of all be honest with the child about the depth of the pain he or she will feel. "You may say, 'this is the most awful thing could happen to you.' Contrary to popular belief, minimizing the grief does not help. *All of the above is general guidelines depending on your child's personality, development, and family values. You know your children best.*

2. Do not avoid the topic when the child brings it up. Let the child see you grieve; it gives them permission to grieve on their own. "It will help the child to see the remaining parent, friends and relatives grieve. Grief shared is grief diminished...if everyone acts stoically around the child, he or she will be confused by the incongruity. If children get verbal or nonverbal cues that mourning is unacceptable, they cannot address the mourning task." Similar to other trauma, the adults around the child need to be available when the child wants to talk, but should avoid probing when the child does not want to talk. This may mean answering one question, or struggling with a very difficult question. "Does it hurt when you burn to death?" Don't be surprised if in the middle of your struggle for the "right" answer, the child returns to play and acts disinterested. The child has been unable to tolerate the level of emotional intensity and are coping with it by avoiding it at that point.

Children will sense if the topic is emotionally difficult for adults around them. A child will try to please adults by either avoiding emotional topics or persisting with topics that they sense are more pleasant. Try to gauge your own sense of discomfort and directly address this with the child. It is reassuring to children that they are not alone in some of their emotional upset.

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HELPFUL GUIDELINES IN TALKING TO CHILDREN ABOUT DEATH (cont'd)

Children look to adults to understand and interpret their own inner states. Younger children will even mirror the nature and intensity of an adult's emotions. So if you feel you will be unable to control your emotions when you are trying to help the child, you will need to use some coping strategies yourself. Take a few moments, collect yourself and then try to help the child. It is only human to lose control and be very emotional in these moments. After you feel more composed, you can help the child understand how you were overcome with emotion, "Just like you feel sometimes." Explain that you struggle to understand too — that "We need to help each other when we are sad."

3. Be prepared to discuss the same details again and again. Expect to hear things from the child that seem as if they didn't "hear" you when you told them the first time. The powerful, pervasive implications of death for the child can be overwhelming indeed. The child's responses to death of a parent, sibling, or other loved one will be similar to the child's responses to other traumatic events. This will include emotional numbing, avoidance, sadness, and regression, episodic manifestations of anger, frustration, and fear of the unknown (e.g., the future), helplessness, and confusion.

The child will have recurring and emotionally recollections of the loved one, and about the death of the loved one. If there is no clear image of the death, the child will imagine various scenarios. These images will return over and over again. As they do, the child (if she feels safe and supported by the adults around her) will ask about death, the specifics of the death, and the loved one. Patiently, repeat clear, honest facts for the child. If you don't know something — or if you also have wondered about the nature of death or a detail in this specific loss — tell the child. Help the child explore possible explanations, and help the child understand that you and others can and do live with many unknowns. In this process, let the child know, however, that there are things we do know — things we can understand. Bring positive memories, images and recollections of the loved one into the conversation.

4. Be available, nurturing, reassuring, and predictable. All of these things make the child's grief easier. They feel safe and cared for. The loss of parents, siblings and other loved ones is extremely traumatic, and will forever change these children's lives. The child has, in some sense, a lifelong task of working, re-working — experiencing and re-experiencing the loss of these loved ones. Each holiday, each family occasion, will bring the loss and the death of the loved one to this child. Available, nurturing, and caring caregivers, teachers, therapists, and adults will all make this journey easier. Stay close to the child, giving them physical affection. Keep other stressing situations, such as moving or changing schools to a minimum; after the ceremonies, continue child's regular routines.

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HELPFUL GUIDELINES IN TALKING TO CHILDREN ABOUT DEATH (cont'd)

5. Understand that surviving children often feel guilty. A child surviving when family members die may often feel guilty. This can be a very destructive and pervasive belief. The guilt children feel is related to the false assumptions they make about the event. An important principle in this process is that children do not know how to verbalize or express guilt in the same fashion as adults. Guilt, as expressed by children, may often be best observed in behaviors and emotions that are related to self-hatred and self-destruction. The child will not likely be able to articulate that survivor guilt is intimately related to their sense of worthlessness or self-abusive/destructive behaviors.

The children surviving a sibling's sudden death will have great survivor guilt. "Was there something wrong or bad about me? I could have been there — I should have been there." These thoughts will recur in any variety of permutations. And most of the time, the outcome of these thoughts will be guilt. If these children's caregivers, teachers, and therapists can minimize these potentially escalating and destructive ideas, the child's recovery will be eased.

6. Take advantage of other resources. There are many other well-trained professionals willing to help you and the child in your care with these problems. Take advantage of them. Always remember that the loss does not go away, but the way children experience loss will change with time, hopefully maturing in ways that make it easier to bear. The traumatic loss of a parent, a sibling, and a peer will always be with these children. With time, love, and understanding, however, children can learn to carry the burdens of traumatic loss in ways that will not interfere with their healthy development.

SIBLING GRIEF

Alissa K. Sandler, MSW, LCSW, Section Chief SCNJ

The sibling relationship is unique. The death of a sibling therefore, presents a unique experience that has been left virtually unexplored in the literature. While parents are grieving the death of their child they may not be available to attend to the grief of their living children. This can lead to a feeling of isolation, leaving a brother or sister to work through their grief alone.

More recently, parents of grieving siblings and grief counselors have begun to address this issue. The impact is immense. The legacy that a grieving sibling carries forward is immeasurable. If allowed to be explored, it may provide insight for future generations about family grieving. The living sibling also plays a role in educating society about the conditions that a brother or sister succumbed to.

Most of the information that is available regarding sibling bereavement is anecdotal. Parental attitude determines how a deceased sibling is incorporated into the family. As parents and families have been allowed to openly grieve so to have siblings.

It is important to recognize that children grieve. The way they grieve is determined by their age. However, children, even infants and toddlers experience sadness especially if their caretaker is sad,

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distant or distraught. Therefore acknowledging siblings' feelings is vital. Allowing them to express an array of emotions will help them cope during a very stressful time. It is difficult to accept the expression of feelings such as crying, stubbornness, playfulness, and periods of withdrawal. However, like adults, it is unavoidable. Encouraging siblings to talk about their brother or sister, draw pictures, write poetry, attend memorial services is helpful. This process helps a child work through their grief and decreases isolation. Siblings want to be part of the grieving family.

Allowing children to talk and ask questions can be painful for adults. However, children learn and obtain control through this process. When children ask about what happened to a brother or sister:

- Let the child direct the questions
- Keep it simple
- Explore and remove any issues of blame
- Listen
- Be honest

Help children honor their sibling:

- Create a memory book
- Plant a tree
- Light a candle
- Release a balloon
- Write a poem
- Draw a picture
- Acknowledge anniversaries of the siblings birth and death

The bereavement community is beginning to see the results of a decade of "open grieving" related to infant and child death. Sisters and brothers, including the subsequent sibling, seem to be well adjusted and consequently comfortable with issues of death and dying. They are loving and compassionate people. Parents and their children can grieve together and receive comfort and support from one another. A sibling allowed to integrate a deceased brother or sister into their lives seems to feel more complete. After all, the sibling relationship is unique and needs to be nurtured in life and death.

RESOURCES FOR CHILDREN AND THEIR FAMILIES

Hello Grief: <http://www.hellogrief.org/resources/new-jersey/>

Hello Grief provides New Jersey grief resources.

National Alliance for Grieving Children – Family Programs in New Jersey:

<https://childrengrieve.org/index.php?q=programs-new-jersey> The National Alliance for Grieving Children (NAGC) provides a network for resources for families across America.

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Good Grief: <http://www.good-grief.org/for-families/about-our-program> 908-522-1999 Good Grief provides free peer support programs in New Jersey to children, teens, young adults and families after the death of a mother, father, sister or brother.

Comfort Zone Camp: www.comfortzonecamp.org

Comfort Zone offers free grief resources, resilience training and ongoing support to children who have suffered the loss of a parent, sibling or primary caregiver. Our programs focus on the strengths of each child, empowering them to grieve, heal and grow in healthy ways.

Imagine: <http://imagineNJ.org/> 908-264-3100 Located in Westfield, NJ

Imagine is a free year-round children's grief support center that serves NJ children age 3-18 and young adults 18-30 who are grieving the death of a parent or sibling, or who are living with a parent or sibling with a life-altering illness. Concurrent support groups are provided for the parents or guardians of the children.

The Alcove Center for Grieving Children and Families : www.thealcove.org 609-484-1133 Located in Northfield, NJ The Alcove's mission is to provide a safe place where New Jersey children and their families can receive comfort and support in healing.

Children's Art Therapy Program at Riverview Medical Center: 732- 530-2382

<http://www.riverviewmedicalcenter.com/RMC/forpatientsandfamilies/patientandvisitorguide/SupportServices.cfm>

Located in Red Bank, NJ

Hearts & Crafts Grief Counseling : <http://www.heartsandcraftscounseling.org> (201) 818-9399 Located in Ramsey, NJ. Since 1994, Hearts & Crafts Counseling has provided families in New Jersey individual and group counseling services. We help children, teens, and adults learn to cope, survive and ultimately thrive after suffering the loss of a loved one or experiencing any other life-altering situation. Hearts & Crafts is a non-profit organization supported largely by our modest fees and private donations.

My Sister's Kids: <http://www.mysisterskids.org/> (856) 357-2321

Serving Gloucester, Cumberland and Salem County areas. Peer support for Children, Teens & Families.

Joseph T. Quinlan Bereavement Center <http://www.karenannquinlanhospice.org/bereavement/> 973-940-0413 Located in Newton, NJ

Samaritan Center for Grief Support (800) 596-8550 <https://www.samaritannj.org/support-groups> - Located in Marlton, NJ.

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RESOURCES FOR SIBLINGS (cont'd)

Sudden Unexplained Death in Childhood Program – International Grief Program for families (800) 620-7832 www.sudc.org SUDC serves families across the USA and beyond.

Journeys Program: Valley Home Care: (201) 291-6000 x 7133
http://www.valleyhealth.com/Valley_HomeCare.aspx?id=46 **Located in Paramus, NJ**
Journeys serves children 3 thru teens coping with the life threatening illness or death of a family member. We offer individual, family and group therapy.

Common Ground Grief Center : 732-606-7477 <http://www.commongroundgriefcenter.org>
Located in Manasquan, NJ

Dougy Center: The National Center for Grieving Children and Families
Toll Free: 866-775-5683 Email: help@dougy.org www.dougy.org
The National Center for Grieving Children & Families has provided support and training locally, nationally and internationally to individuals and organizations seeking to assist children in grief. The website offers resources for adults and kids and they have Spanish support groups and resources as well. Their site also offers workbooks and pamphlets on grief.

Fernside: A Center for Grieving Children
513-246-9140 www.fernside.org The website exists to reach out to the community with support and advocacy for grieving children and their families. The website includes information for siblings as well and support information for parents.

Solace House
1-816-363-2600 www.solacehouse.org. The website has a resource link to other grief support services. Their belief is that “no child should grieve alone”

The Sibling Connection
www.counselingstlouis.net. This site has been created as a resource for: anyone who has experienced the death of a brother or sister.

The Compassionate Friends: Sibling Resources
www.compassionatefriends.org The Compassionate Friends is a national nonprofit, self-help support organization that offers friendship, understanding, and hope to bereaved parents, grandparents and siblings.

KidsAid
www.kidsaid.com- An online resource to give kids their own place to deal with their feelings with other kids who have suffered major losses. Kids can often help kids better than adults can, because they understand a lot of things that adults might not.

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RESOURCES FOR SIBLINGS (cont'd)**

Coalition to Support Grieving Students - 877-53-NCSCB (877-536-2722) or
info@grievingstudents.org or <http://grievingstudents.scholastic.com/>

The Coalition to Support Grieving Students is a unique collaboration of the leading professional organizations representing classroom educators (including teachers, paraprofessionals, and other instructional staff), principals, assistant principals, superintendents, school board members, and central office staff, student support personnel (including school counselors, school nurses, school psychologists, school social workers, and other student support personnel), and other school professionals who have come together with a common conviction: grieving students need the support and care of the school community.

BOOKS FOR CHILDREN AND TEENS

Isabelle's Dream: A Story and Activity book for a Child's Grief Journey by Betsy Bottino Arenella The book has 24 pages of narrative and illustrations which tell the story of Sophia who returns to her sister in a dream, reminding her that her spirit will always remain through the beauties of nature.

What Do They Do All Day in Heaven? By Staci Thomas - Parents and the children can discuss death of a sibling and heaven

When My Brother/Sister Died – Dorothy Gehres Fraembs
Stories told from the children's perspective about feelings of loss resulting from the death of a sibling.

Where's Jess? – Joy & Marv Johnson (*Ages 3-8*)
Story about how the brother and his family grieve after their baby, Jess, dies.

The Fall of Freddy the Leaf - by Leo Buscaglia (*Ages 4-8*)
This is a warm, wonderfully wise and strikingly simple story of Freddy the Leaf-how Freddy and his companion leaves change with the seasons, finally falling to the ground with the winter's snow. This is a classic and wonderful for explaining death to a child.

Sad Isn't Bad - A Good Grief Guidebook for Kids Dealing with Loss - by Michaelene Mandy and RW Alley (*Ages 4-8*)
This book is loaded with positive, life affirming advice for coping with loss as a child. This guide tells kids what they need to know: the world is still safe, life is good and hurting hearts do mend.

The Badger's Parting Gifts - by Susan Varley (*Ages 4-8*)
All the animals loved badger and when he dies they are overwhelmed by their loss. Then, they begin to remember and through their memories the animals find strength to face the future with hope.

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BOOKS FOR CHILDREN AND TEENS (cont'd)

Libby Died. - *By Jack and Annette Simon (Ages 4 –8)*

Children ask many questions about death and this book explores some of the common ones.

Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies - by Janis Silverman (Ages 5–teen)

An art therapy and activity book for children coping with the death of someone they love. Sensitive exercises address all the questions that children may have during this emotional and troubling crisis. Children are encouraged to express in pictures what they are often incapable of expressing in words.

When Someone VERY Special Dies: Children Can Learn to Cope with Grief – written by Marge Heegaard (to be illustrated by children) (ages 6-12)

This book was designed to teach children death education, to recognize and express feelings of grief, encourage open communication and help adults discover unhealthy misconceptions the child may have.

Losing Someone You Love – Elizabeth Richter (*Ages 7 and up*)

Fifteen young people tell about the death of their brother or sister. They tell about their feelings, sorrows, fear, loneliness and anger and their difficulties both at home and at school.

Children Facing Grief – Jan Rodmond (*Ages 8-16*)

A collection of letters written by children ages 6 to 15 who tell about their feelings and experiences after the death of a brother or sister. They tell what hurt and what helped very openly and honestly.

Children Are Not Paper Dolls – written by Erin Linn (Ages 9-15)

Six bereaved siblings ages 10 to 13 write and draw pictures about funerals, family, friends, school, feelings, holidays, etc. They tell it like it is.

I Wish I Could Hold Your Hand - by Pat Palmer and Dianne O'Quinne Burke (Ages 9 –12)

This warm and comforting book gently helps grieving children identify their feelings and learn to accept and deal with them.

To Healing Your Grieving Heart: 100 Practical Ideas For Kids - by Alan Wolfet (*Ages 9-12*)

A clear concise book with sensitivity and insight that offers suggestions for healing activities. It acknowledges that death is a painful part of life. It offers ideas and activities aimed at reducing confusion, anxiety and the huge personal void so that the living can begin their lives again.

Today My Sister Died – Ronee Christy Domske (Ages 10 and up)

A book written from the point of view of a 5th grader, discussing death and a family's reaction.

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BOOKS FOR CHILDREN AND TEENS (cont'd)

My Brother Joey Died Today – McLendon & Messner

The young girl in this story feels angry and guilty after her brother dies suddenly. She feels better after talking with other kids in a support group. (Ages 10-14)

Healing Grieving Hearts for Teens - by Alan Wolfelt (*Ages: Young Adult*)

A book written in clear, user-friendly prose. Each page presents a different idea designed to help teens recognize mourning as a natural process connected with loss, reassuring them that they should not be afraid of deep sometimes uncontrollable emotions and showing them how to release grief in healthy positive ways.

Fire in My Heart, Ice in My Veins-A Journal for Teenagers Experiencing a Loss - by Enid Samuel Traisman (*Ages: Young Adult*)

The journal encourages teens to work through grief in creative and healthy ways. It allows them to keep permanent memories of the person who died.

Dancing on the Moon - by Janice Roper and Lauren Grimm (*Ages infant to Pre School*)

This book is designed to help families coping with a SIDS loss. Written by a parent whose 3-month-old son died of SIDS.

The Tenth Best Thing about Barney - by Judith Viorst and Erik Blegvard (*Ages 4-8*)

In simple phrases narrated by a child whose cat, Barney has died. The author honestly and simply handles the emotions of losing a beloved pet and the questions about the finality of death.

I'll Always Love You- by Hans Wilhelm (*Ages 4-8*)

This story is about Elfie, a dachshund, and her special boy who go through life together. One day Elfie doesn't wake up. The family grieves and buries her. Very sweet and tender.

What's Heaven By Maria Shriver - Religious connotation around a grandparent who died, good explanation of the concept of heaven

I Miss You: A First Look at Death By Pat Thomas Explains to children the concept of death

What on Earth to Do When Someone Dies by Trevor Romain Ages 9 - 12

This simple, insightful, straight-from-the-heart, this book is for any child who has lost a loved one. The author talks directly to kids about what death means and how to cope.

All God's Creatures Go To Heaven by Amy Nolfo-Wheeler. All ages.

"The angel paintings of artist, Nancy Nolfo, beautifully portray the story of Jacob, a child angel on a journey of discovery. It is an inspiring message of joy and hope. This is a story about baby angels who are in heaven and they take care of God's animals. A new little boy goes to heaven and receives a pet to love and take care of.

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

WAYS TO REMEMBER

- Create a memory book or photo album
- Write a poem, story or song
- Go to the cemetery and visit
- Add their name to holiday cards
- Plant a tree
- Do something special on the anniversary or birthday day
- Volunteer for SIDS Center of New Jersey
- Participate in SIDS Center of New Jersey events
- Give a gift to a hospital for children and say it is in memory of your child
- Attend a memorial service
- Sponsor a fundraiser
- Make a donation to your local organization for special days, such as holidays, birthday and anniversary

THE MENTION OF THEIR NAME

The mention of my child's name may bring tears to my eyes
But never fails to bring music to my ears
If you are really my friend, let me hear the beautiful music of their name.
It soothes my broken heart and sings to my soul.

Anonymous

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A JOURNEY TO HEALING

PREGNANCY AFTER A LOSS- A NEW BEGINNING

At the SCNJ, we often get asked “When the right time to have another child.” It is such a personal choice. Many parents want to fill their hearts again with the love of a child. Many parents feel that it may be a betrayal to their infant/ child who has died. Many families believe getting pregnant soon after the death of their infant/child will ease their grief. Some parents feel it may complicate grief process more. Many parents have a mix of all feelings throughout their decision process. Some parents had no choice and found out they were pregnant soon after the death, or were pregnant before.

We do know that another baby does not speed up the healing process. It is still a long, personal journey. We know that a new baby will not replace the child that you lost. Try to seek support around your changing feelings to try and be prepared to handle the different feelings that may arise during the pregnancy and after delivery. Seeking support can also help you in your decision making.

If you become pregnant again, the thought of a new baby may bring many different feelings such as fear, sadness, guilt, excitement, and anxiety. Many mothers have plans to do everything differently with the new pregnancy, as well as the new baby. Others decide they do not want to buy or do anything for this new baby until after the baby is born. Some mothers share that they have difficulty bonding with this new baby due to the fear of losing this baby too. Some mothers find writing about their feelings and concerns in a diary or journal can be very helpful. It can be very helpful to share your feelings and concerns with your partner, as well as your physicians. Seeking professional support is another good way to process your feelings.

During pregnancy, every symptom or change in the pregnancy may worry couples more than it ever did before. Do not be afraid to share your fears with your doctor. It is very important to find prenatal care with a provider who will listen to your concerns. You and your provider should be knowledgeable about the risks for SIDS. Be sure you, your partner, and your infant care providers are aware of risk reduction so your new baby will have the right start.

If you have any questions or want more information about risk reduction, do not hesitate to call the SIDS Center of New Jersey at 1-800-545-7437.

Safe to Sleep

<http://www.nichd.nih.gov/sts/Pages/default.aspx>

Consumer Product Safety Commission

www.cpsc.gov

National Action Partnership to Promote Safe Sleep

<http://nappss.org/>

**THE SIDS CENTER OF NJ
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A JOURNEY TO HEALING

GENERAL RESOURCES

SIDS Center of New Jersey
New Brunswick
1-800-545-7437
Hackensack
551-996-3219

CJ Foundation for SIDS
1 – 888- 8CJ-SIDS
www.cjsids.org

First Candle
1-800-221-7437
www.firstcandle.org

Bereaved Parents of the USA
800-273-8255
<http://www.bereavedparentsusa.org/index.htm>
Information is also offered in Spanish.

Compassionate Friends
1-877-969-0010
<http://www.compassionatefriends.org/home.aspx>

Sudden Infant and Child Death (SICD) Resource Center
1-800-336-7437
<http://www.stonybrookmedicalcenter.org/sids>

Cribs for Kids
1-800-721-7437
<http://www.cribsforkids.org/about-us/>

The Miss Foundation
The MISS Foundation C.A.R.E.S. for families experiencing the death of a baby or child at any age and from any cause
1-888-455-MISS (6477)
<http://missfoundation.org/>

A Place to Remember
1-800-631-0973
<http://www.aplacetoremember.com/>

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

GENERAL RESOURCES (cont'd)

American Academy of Pediatrics

www.aap.org

Safe to Sleep

http://www.nichd.nih.gov/sts/Pages/default.aspx

Consumer Product Safety Commission

www.cpsc.gov

National Action Partnership to Promote Safe Sleep

http://nappss.org/

Grief Share-

Locator for support groups www.griefshare.org

Grief Net. Org

Locator for groups, resources and books <http://www.griefnet.org>

The SUDC Foundation

800-620-SUDC www.sudc.org

MAILING LISTS

The Direct Marketing Association is the main organization that distributes information about consumers to its 4,500 member companies. Let the DMA know you want to be removed from their lists. Your name will remain off the lists for five years. **When requesting deletion from the telephone list, you may need to consider the different ways your name may be listed. John Doe; Parents of Baby Doe** Please note this process can take up to three months or longer to become effective. The companies suggest you send a second follow-up letter to assure your name is removed from their mailing and telemarketing lists.

Mailing Lists

Fill out this [Mail Preference Service](#) online form to be placed on the "delete list." Submitting the form online costs \$5, but mailing it to this address is free:

Mail Preference Service

Attn: Dept. 6150403

Direct Marketing Association

P.O. Box 282

Carmel, NY 10512

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

Telemarketer Lists

Register with the [Telephone Preference Service](#) to remove your name from telemarketer lists. Fill out the form and send it to this address:

Telephone Preference Service

Attn: Dept. 6150486

Direct Marketing Association

P.O. Box 282

Carmel, NY 10512

E-mail Lists

Submit your e-mail address to the [E-Mail Preference Service](#), and DMA members will remove you from their e-mail lists. Also see GovSpot's instructions on [reporting Spam](#) to the FTC.

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

REQUEST TO REMOVE NAME FROM MAILING LIST

Direct Marketing Association
Mail Preference Service
P.O. Box 282
Carmel, New York 10512

Dear Sir or Madame:

Due to the loss of my child, I am requesting that my name be removed from your telemarketing list immediately. Thank you for your understanding during this difficult time.

Sincerely,

Name

Address

City, State, Zip

Area Code & Telephone Number

Today's Date

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

HOW TO REQUEST AN AUTOPSY REPORT

This fact sheet covers some important information that will need about how to obtain the final diagnosis of the cause of your infant/child's death as well as a copy of the autopsy report.

The final cause of death will be available only after a thorough death scene investigation and a complete autopsy has been done. A doctor who is trained as a pathologist does the autopsy in a professional manner. The Medical Examiner should be able to determine the final cause of death within 120 days. You may contact your county medical examiner to obtain the final cause of death. You can also request the help of your infant/child's pediatrician in getting the report and interpretation.

Each family has individual needs, and some families may choose not to obtain a copy of this report. Others find the report to be extremely helpful. The report may be overwhelming and confusing. If you obtain a report and have any questions, you may call the medical examiner's office. The SIDS Center of New Jersey recommends that if you obtain a copy of the report you review it with a health professional such as your pediatrician, the medical examiner or a nurse or physician from the SIDS Center of New Jersey. If you require additional information or assistance, please call the SIDS Center of New Jersey at 1-800-545-7437.

**THE SIDS CENTER OF NJ
STATEWIDE HOTLINE 1(800) 545-7437**

A JOURNEY TO HEALING

PARENT REQUEST FOR COPY OF AUTOPSY REPORT

(Name of medical examiner), MD

(Address) _____

Dear Dr. (name of medical examiner):

Medical Examiner's Case Number: _____

Date of Request: _____

I am requesting a copy of the autopsy report of my son/daughter, _____

Please mail to:

Print Name

Street

City

State

Zip Code

Telephone Number

Please advise me of any charge for this service. Thank you.

Sincerely,

(Sign your name)