

A Guide to Supporting Bereaved Families

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INTRODUCTION

The purpose of this resource is to help you provide that vital link of support to bereaved families in your communities.

We encourage you to use the material freely, copying what you may need to distribute within your agency. Please let us know how we can enhance this guide to meet your needs by providing us feedback for updates and future editions.

The manual was compiled by the Infant Death Center of Wisconsin staff.

For more information on the Infant Death of Center click on this link [Infant Death Center of Wisconsin](#)

TABLE OF CONTENTS

I. Infant Death Center of Wisconsin Background and Services	
A. The Challenge of Cultural Competence.....	4
B. Who Am I Now?.....	5
C. Do's and Don'ts.....	6
D. Meeting with the Family.....	7
E. Caring for Yourself.....	8
II. Resources	
A. Parental Grief.....	10
B. The Tasks of Grieving.....	11
C. Grief and Grief Reactions.....	12
D. The Journey of Grief for the Professional.....	14
E. Caring for Oneself as a Caregiver.....	16
F. Brief Bereavement Caregiver Burnout Survey.....	17
G. Writing your Child's Story.....	19
H. Taking Care of Yourself.....	21
I. For Grandparents: Suggestions for Helping Yourself.....	23
J. When a Grandchild Dies.....	24
K. Children's Understanding of Death by Age.....	25
L. Children – Ten Common Myths.....	27
M. Self Care.....	32
III. Bibliography.....	33
IV. Online Resources.....	38
V. Online Pamphlets.....	39

The Challenge of Cultural Competence

Many communities offer opportunities to interact with people from a wide range of cultures around the world. Many are very different from the Northern European culture that has been predominate in the United States. It is this diversity that gives the United States its richness and strength but also creates a challenge for the health care professional providing crisis intervention and bereavement support.

Being aware of cultural differences is imperative when working with families experiencing a sudden infant death. Identifying one's own cultural bias can assist the professional to be more sensitive to a family's unique needs when a cultural difference exists. Assessing one's own level of response to different cultural groups can heighten awareness.

The following outlines five levels of response to a cultural group:

- 🔗 **Greeting:** One can greet this person warmly and welcome him or her sincerely.
- 🔗 **Accepting:** One can honestly accept this person as he or she is and is comfortable enough to listen to this person's perspective on a given issue or problem.
- 🔗 **Helping:** One can genuinely try to help this person with problems in ways that go beyond commonly held mainstream stereotypes.
- 🔗 **Having background:** One has the background, experience or knowledge to help this individual.
- 🔗 **Advocating:** One can honestly advocate for this person based on both cultural group affiliation and individual qualities and circumstances.

Knowing one's cultural bias based on these five levels of response is the first step to becoming culturally competent. Cultural competence is expected of professionals. It implies not only awareness of a culture but also the ability of the health care professional to intervene appropriately and effectively.

As health care professionals, we are continually challenged to provide appropriate care to many diverse families. One must keep in mind the uniqueness of cultural mores and how it interplays in the health of an individual and family. This is a challenge. Having an understanding of one's own culture offers insight into the potential for conflict or ineffectiveness that often occurs when working with families of different cultures.

Although a family may be "Americanized", when an infant death occurs, the family may demonstrate more traditional cultural activities and expectations. It is not uncommon for more intense identification with one's own culture during times of crisis. Although generalizations about a culture may equip the professional with a basic understanding of the social unit, it is important the professional not stereotype the family.

It is nearly impossible to have a thorough knowledge and understanding of each culture within our diverse communities. When working with different populations, having a resource guide available outlining basic information about a culture or population can give the health professional some insight into the beliefs, values, customs, and traditions of a family prior to the initial interaction with them. Using the following questions also may give the professional specific insight into the needs of the family.

Cultural Awareness Assessment of Sudden Infant Death Families:

- 🔗 What concerns do I have regarding this family?
- 🔗 What concerns may the family have regarding me, the home visit, or other related support services?
- 🔗 What information do I need in order to understand and assist the family?
- 🔗 What questions might I ask the family in order to obtain this information?
- 🔗 What can I do to make this family feel as comfortable and understood as possible?
- 🔗 Do I feel that I can respect the cultural values of this family and work with its members effectively?
- 🔗 What other resources might I utilize to better understand and assist this family?

The family's reaction to a sudden infant death incident will be influenced by the family's meaning of death, their customs surrounding death and the funeral as well as the role an infant plays within their culture. Assisting the family to seek out resources within their own community and among their relatives will help provide what is needed at the time of the initial crisis and during the grief and bereavement process.

Having the opportunity to become aware of new cultural mores and working with diverse family enhances the sensitivity of the health professional when interfacing with other parents in the future. Families remember and appreciate respect, sensitivity, and caring regardless of cultural differences.

Reprinted with permission from "HORIZONS" Newsletter – California SIDS Program, June 1999.



WHO AM I NOW?

The guidelines below were developed by parents to assist professionals in meeting the needs of bereaved families.

We offer the following as basic principles for responding to parents, caregivers, and others bereaved of a child:

C is for Caring: empathize with the parents' grief. Tell them you are sorry. Tell them your emotions. (Do not say "I know how you feel.") Allow the death or compare this to other tragedies.)

H is for Humanize: treat the family the way you would want to be treated. Be compassionate. Explain what you are doing in a considerate way. Allow the meet face-to-face, rather than on the phone.

I is for Inform: explain what you are doing. Give the information you know to be correct, but do not pass on information that may be misleading. If you know the child's status and the parent does not, you must ensure they are aware of the seriousness of the situation and supported until the appropriate person can inform them.

L is for listen: allow the parent to speak about their child and to tell their story; this is a powerful need at all stages of grief. Acknowledge the parents' emotions (guilt and anger may be very powerful in early grief). Do not try to rationalize the child's death. Realize that people grieve differently. In particular, there may be a more masculine and more feminine approach to grief.

D is for Do Your Job: ensure you are performing in a professional and ethical manner. Explain to the parents, caregivers, and family if your job brings them emotional difficulty. Every aspect of the early response to a child's death will be deeply remembered for years to come. A professional, caring attitude will be long appreciated.



We endorse the following Do's and Don't for Professionals:

DO say you are sorry. If you express your emotions, it helps to validate the parents' grief and respect the child's memory.

DON'T try to find a silver lining. Other children in the family or the possibility of future children does not erase the loss of this child. Don't impose your religious views on the parents.

DO stay with the parents or caregivers as long as you are able. Do not leave parents alone; ensure someone will stay with them.

DON'T be afraid to use the child's name.

DO allow parents to be with their dead or dying child. Holding their child for the last time, collecting a locket of hair or footprints may have enduring meaning.

DON'T withhold information. Try to help the parents to be as well informed as possible, sharing sources of support. But don't give information that you are uncertain about.

DO remember to speak slowly. You may have to repeat yourself.

DON'T tell the family over the phone that their child has died. Let them know they need to be present for a serious situation, but allow them to arrive safely and be informed of the worst news with appropriate support.

DO be aware that people grieve differently. The stoic individual may harbor as much pain as the one who is sobbing.

DO seek support for yourself in coping with the tragedy of a child's death, which affects everyone. Speak with fellow professionals, attend crisis debriefings, and contact bereavement counselors to help you cope in your personal and professional lives.

Meeting with the family

As you prepare for the meeting the following are points to consider:

- Encourage the expressions of feelings by active listening.
- Avoid guilt reinforcing questions: such as, “Did you feed the baby regularly?”
- Emphasize *it is not your fault*.
- People in grief do not always hear or remember what has been said. Be prepared to repeat.
- Discuss common symptoms of grieving including the physical manifestations of grief.
- Validate feelings and reassure when appropriate comments such as *This is a normal part of the grief process – you are not going crazy* can be very helpful.
- Listen to each family member and give feedback when indicated. Encourage listening among family members.
- Assess where each family member is in the grief process including young children. Each member of the family will work through the grief process in their own way. Encourage family members to be patient and understanding of one another.
- Note the mood of the family and how they support or do not support each other.
- Identify and emphasize family strengths.
- Give family information on how to contact you and encourage them to talk if they have questions. Ask if they would mind if you called in a few weeks to see how they are doing or set up another meeting time for your next visit. Thank them for their time.

CARING FOR YOURSELF

Caring for bereaved families and helping them cope with their pain can be very stressful. It is important that professionals are able to care for themselves as well as following the provision of services. Taking responsibility for your personal replenishing is important for your own health and well being as well as for your ability to be an effective professional now and in the future. We offer these thoughts for your consideration.

- Identify stressors in your life. What tasks or behaviors are most frustrating or anxiety producing? What could you do to help reduce the frustration or anxiety they produce? Consider and plan responses to these situations.
- Know your strengths and limitations personally and professionally.
- Be aware of your reactions and emotions and when they change from positive to negative.
- Know when to say “NO”.
- Be aware you are not indispensable.
- Take responsibility for your own needs, before caring for others.
- Learn and practice stress management techniques. Relaxation exercises such as deep breathing, meditation, and visualization as well as physical exercise can be helpful.
- Get adequate rest.
- Eat nutritiously.
- Set realistic goals regarding what and how much you can do.
- Use your sense of humor – it relieves stress and is a positive emotional release.
- Maintain your own physical, emotional, and spiritual health. Find sources for personal satisfaction.
- Use exercise to improve general health, sleep, and overall sense of well being.
- Write feelings and thoughts in a journal. It helps put things into a better perspective.
- Identify a support system you are comfortable to call on.
- Make a list of things that you do that replenish your spirit and use that list proactively.
- List the top five things that deplete your energy and spirit and develop a plan to address them when this occurs.
- Participate in activities that are fun and with people who are special to you. Don’t underestimate the effects of small pleasures.
- Use religion, philosophy, poetry, music, art, gardening, tennis, walks at nature centers, reading or other activities for rejuvenation.
- When appropriate utilize the employee assistance program, critical incident stress debriefing, or other service offered through your agency.

- Avoid using alcohol or drugs that will reduce your ability to think clearly.
- Realize that caffeine is a stimulant and will only add to the sense of stress.
- Learn it is also blessed to receive as well as give.
- Support each other as caregivers.
- Learn to accept what you cannot change, work to change what you can, and develop the wisdom to know the difference.

PARENTAL GRIEF

The theme of parental mourning has been a universal one throughout the centuries. In the literature on bereavement, writers repeat certain themes, thoughts, and reflections; they talk of the powerful and often conflicting emotions involved in “the pain of grief and the spiral of mourning; [they refer to] the heartbreak at the heart of things...grief’s contradictions”; they speak of parents devastated by grief (Moffat 1992, xxiii).

It is frequently said that the grief of bereaved parents is the most intense grief known. When a child dies, parents feel that a part of them has died, that a vital and core part of them has been ripped away. Bereaved parents indeed do feel that the death of their child is “the ultimate deprivation” (Arnold and Gemma 1994, 40). The grief caused by their child’s death is not only painful but profoundly disorienting – children are not supposed to die. These parents are forced to confront an extremely painful and stressful paradox; they are faced with a situation in which they must deal both with the grief caused by their child’s death and with their inherent need to continue to live their own lives as fully as possible. Thus, bereaved parents must deal with the contradictory burden of wanting to be free of this overwhelming pain and yet needing it as a reminder of the child who died.

Bereaved parents continue to be parents of the child who died. They will always feel the empty place in their hearts caused by the child’s death; they were, and always will be, the loving father and mother of that child. Yet, these parents have to accept that they will never be able to live their lives with or share their love openly with the child. So they must find ways to hold on to the memories. Many bereaved parents come to learn that “memories are the precious gifts of the heart... [that they need] these memories and whispers, to help create a sense of inner peace, a closeness” (*Wisconsin Perspectives Newsletter*, Spring 1989, 1).

Sociologists and psychologists describe parental grief as complex and multi-layered and agree that the death of a child is an incredibly traumatic event-leaving parents with overwhelming emotional needs. They also agree that this grief must be acknowledged and felt in its intensity. These experts repeatedly state that dealing with parental grief involves deep pain and ongoing work as the parents attempt to continue their “journey down the lonely road of grief” (*Wisconsin Perspectives Newsletter*, February 1997, 1).

Grieving parents say that their grief is a lifelong process, a long and painful process...”a process in which [they] try to take and keep some meaning from the loss and life without the [child]” (Arnold and Gemma 1983, 57). After a child’s death, parents embark on a long, sad journey that can be very frightening and extremely lonely – a journey that never really ends. The hope and desire that healing will come eventually is an intense and persistent one for grieving parents.

The child who died is considered a gift to the parents and family, and they are forced to give up that gift. Yet, as parents, they also strive to let their child’s life, no matter how short, be seen as a gift to others. These parents seek to find ways to continue to love, honor, and value the lives of their children and continue to make the child’s presence known and felt in the lives of family and friends. Bereaved parents often try to live their lives more fully and generously because of this painful experience.

To those outside the family, the composition of the family may seem to change when a child dies. A sibling may become an only child; a younger child may become the oldest or the only child; the middle child may no longer have that title; or the parents may never be able to, or perhaps may choose not to, have another child. Nonetheless, the birth order of the child who died is fixed permanently in the minds and hearts of the parents. Nothing can change the fact that this child is considered a part of the family forever, and the void in the family constellation created by the child’s death also remains forever.

In a newsletter for bereaved parents, one mother wrote, “It feels like a branch from our family tree has been torn off.” Another grieving mother continues, “I felt that way too. A small branch, one whose presence completed us, had been ripped from our family and left a large wound. Without it, we were lopsided and off balance. When subsequent children are born, [they] do not replace the fallen branch, but create a new limb all their own.” (*Wisconsin Perspectives Newsletter*, December 1996, 1)

Reprinted with permission from, “The Death of a Child – The Grief of Parents: A Lifetime Journey.” By the National SIDS Resource Center.

The Tasks of Grieving

In Dr. J.W. Worden's theory of bereavement, grief as a series of 4 tasks, which a person must work to complete.

▶ Task 1

Accepting the reality of the loss

The first task is accepting the death and that their loved one will never return.

Bereaved persons often:

- Express feelings of disbelief, and of wanting their loved one back at all costs.
- Search for a cause (or blame) for the death.

▶ Task 2

Experiencing the pain of grief

The initial pain often is not as intense as the pain which comes later, when the bereaved has begun to accept the loss and is trying to resume "normal living."

Often when the pain is the most intense, bereaved people:

- Receive less comfort, as society is uncomfortable with grief.
- May try to stop feeling to avoid the pain of the loss.

▶ Task 3

Adjusting to a life without the baby

As the pain of grief is released and begins to subside, bereaved people once again begin making decisions and weigh their options for the future.

Bereaved persons may:

- Have difficulty dealing with the feelings of detachment.
- Find decision-making difficult.

▶ Task 4

Reinvestment of their Emotional Energy

Bereaved persons once again begin to enjoy the people and activities that brought them pleasure before the death.

Families may have:

- Periods of contentment interspersed with periods of guilt and/or regret.
- Concern that they are forgetting their loved one.

An indication of the completion of the tasks of grief is the realization that:

"There are other people in the world to be loved and loving them doesn't mean I love my loved one any less."

From: Grief Counseling and Grief Therapy

By J. William Worden, PhD (1982)

Springer Publishing Company.

GRIEF AND GRIEF REACTIONS

I. Definitions

A. Grief - process of experiencing the psychological, social and physical reactions to the perception of loss. (Rando, 1988).

B. Mourning - **conscious and unconscious processes that:**

- a. gradually undo the psychological ties that had bound the mourner to the loved one.
- b. help the mourner to adapt to the loss.
- c. help the mourner learn to live healthily in the new world without the deceased. (Rando, 1988).

* **Grief** is a passive reaction to the loss; **mourning** is an active process of working through the loss, integrating the loss into life and accommodating the change. The mourner makes a shift from a relationship of presence to a relationship of memory.

An acute grief reaction is somewhat time-limited; mourning may take a lifetime.

II. Common psychological, social and physical characteristics of parental grief response

A. Psychological Effects of Grief:

Fear	Despair
Anxiety	Confusion
Guilt	Lack of ability to concentrate
Sadness/Depression	Decreased self-esteem
Vulnerability	Denial/Disbelief
Anger	Hearing the baby cry
Resentment	Preoccupied with the deceased
Dreaming	Loss of control
Bitterness	Sense of failure
Apathy	Spiritual crisis

B. Social Effects of Grief:

Social Withdrawal	Uninterested in usual activities
Isolation	Avoidance

C. Physical Effects of Grief

Anorexia	Sighing
Overeating	Exhaustion
Decreased energy	Heart palpitations
Decreased sexual interest	Weakness
Hypersexuality	Nervousness/Restlessness
Sleep difficulties	Shortness of breath
Weight loss	Chest pain
Aching arms	GI disturbances
Feelings of emptiness	Headaches

The majority of observed grief responses are NORMAL, but vary greatly in expression and intensity. Grief response is individual and cannot be compared. We as caregivers must not make assumptions nor judge the appearance of the loss.

The Journey of Grief for the Professional

Do professionals grieve? Yes, they do! Grief for the professional is different from that of the bereaved parent or family members, for they cannot feel the same pain, or mourn the same loss.

Worden (1982) refers to four tasks of mourning: to accept the reality of the loss; to experience the pain of grief; to adjust to an environment in which the deceased is missing; and to withdraw emotional energy and reinvest it in another relationship.

For the professional, these same four tasks of mourning must be accomplished in order to live and continue to work effectively with a family's loss and grief.

Accepting the Reality of the Loss

Involvement by professionals in a sudden infant death is personally difficult for many of the same reasons that it is for parents.

- Desire to protect or save lives.
- Our orientation to “fixing” things – infant death is the ultimate “unfixable” situation
- Our sense of order and safety gets shaken up.
- We go home to families of our own which often include infants and young children
- Professionals also ask, “What could I have done differently?”
- We become emotionally drained – always having to be “the strong one”.
- Even while maintaining a professional stance, we repeatedly face our own death issues.

Experiencing the Pain

An emotionally charged issue such as sudden infant death can give new meaning to the professional's experience with *burnout*. Working on a regular basis with death, especially infant death tends to “run down our professional batteries” rather than burn us out. With *burnout*, professionals may go back to their offices and have bursts of anger at coworkers. When we are “used up”, coworkers and even our own families might prefer being “yelled at” rather than experience the emotional detachment and isolation that is often exhibited.

How can we re-charge our professional “batteries”?

Some helpful suggestions include:

- Take ownership of your own feelings. Evaluate and express the “stressors” being experienced.
- Seek out support. Supervisors need to provide a clear role of expectations and support; and assist professionals in setting limits. They need to determine what the limits should be and when the needs are beyond the limits of the professional.

Adjusting to the Environment

Professionals can make the necessary adjustment to the sudden infant death loss within their work environment by engaging in networking activities such as:

- Seeking out sudden infant death information including visual aids and printed materials.
- Attending infant death conferences and workshops and participating in case-conferences and/or de-briefing sessions with peers and supervisors.

Reinvesting Energy

Just as parents ask the question, “What can we do to help find the answers to why our baby died?” Professionals also ask similar questions and are anxious to reinvest energy through an advocacy role. Advocacy must go beyond the provision of information and consultation. Professionals can advocate through their agency for the following:

Making departments and agencies aware of how infant death services fit into the job descriptions of their staff (i.e. allow more than one visit to a family); supporting periodic follow-up and contact with sudden infant death families; encouraging staff to be active in the community and allowing time to do so; participating in training other professionals, hospital staff, and childcare providers. We know that consequences follow if families do not go through the grief process and complete the tasks of mourning. The same applies to the professional. Wolfelt (1997) identifies some common consequences of adopting grief avoidance patterns:

- Deterioration in relationships with friends and family.
- Symptoms of chronic physical illness – either real or imagined.
- Symptoms of chronic depression, sleep difficulties, and low self-esteem.
- Symptoms of chronic anxiety, agitation, restlessness, and difficulty concentrating.

What can professionals do to avoid these consequences and take care of themselves?

The following are just a few suggestions and activities that most of us already know about, but it doesn't hurt to be reminded again.

Foster self-awareness; review what is toxic in your life; develop meaningful relationships; exercise, rest, and maintain a healthy diet; include humor in your diet; meditate, go to that special “place” and reflect on what is really worthwhile and meaningful in your life. When will I heal? One clergyman expressed it this way: “The healing began when a friend embraced me; leaving some of his tears on my cheek.”

Reprinted with permission from “HORIZONS” Newsletter – California SIDS Program, June 1999.

Caring for Oneself as a Caregiver

In a previous article, this author outlined what was defined as “Bereavement Caregiver Burnout.” We noted that few helping situations are more challenging, or more rewarding, than the opportunity to assist persons impacted by loss in their lives. We also acknowledged that no caregiver to the bereaved can avoid the special stress that comes with entering into the helping relationship.

There is very little documented research available that compares levels of stress and potential burnout across different professions. However, there is a general consensus that helpers to the dying or bereaved experience burnout on a routine basis. This article attempts to allow you to acknowledge if you are experiencing “Bereavement Caregiver Burnout” and provide suggested guidelines for caring for yourself as a caregiver.

Am I Experiencing Bereavement Caregiver Burnout?

A bereavement coordinator for a hospice recently inquired, “How is burnout different from stress?” We might overhear a volunteer or staff person comment, “I’m really feeling burned out today.” All of us may have occasional days when our motivation and energy levels vary. While this fluctuation in energy states is normal, burnout is an end stage that typically develops over time. Once a person is “burned out,” dramatic changes become vital to reversing the process.

Psychologist Christina Maslach, a leading authority on burnout, has outlined three major signs of burnout.

- **Emotional Exhaustion** – feeling drained, not having anything to give even before the day begins.
- **Depersonalization** – feeling disconnected from other people, feeling resentful and seeing them negatively.
- **Reduced Sense of Personal Accomplishment** – feeling ineffective, that the results achieved are not meaningful.

Step back for a moment and complete what we will term the “Brief Bereavement Caregiver Burnout Survey” (BBCBS), which is found on the following page. As you review your life over the past twelve months answer the survey questions.

To monitor your potential for burnout, ask yourself to how many of these questions you answered “yes.” In general, if you answered “yes” to two to four of these questions, you may be in the early phases of burnout. If you answered “yes” to five to seven of these questions, you are quickly moving in the direction of total burnout. If you answered “yes” to eight to ten of these questions, you are burned out!

Brief Bereavement Caregiver Burnout Survey (BBCBS)

Alan D. Wolfelt, PhD

1. Do you generally feel fatigued and lacking in energy?
2. Are you getting irritable, impatient, and angry with people around you (home and/or work)?
3. Do you feel cynical and detached from the people with whom you work?
4. Do you suffer from more than your share of physical complaints like headaches, stomachaches, backaches and long-lasting colds?
5. Do you generally feel depressed or notice sudden fluctuations in your moods?
6. Do you feel busy, yet have a sense that you don't accomplish much at all?
7. Do you have difficulty concentrating or remembering?
8. Do you think you have to be the one to help all those people experiencing grief?
9. Do you feel less of a sense of satisfaction about your helping efforts?
10. Do you feel that you just don't have anything more to give to people?

Guidelines For Caring For The Caregiver

The following practical guidelines are not intended to be all-inclusive. Pick and choose those tips that you believe will be of help to you in efforts to stay physically and emotionally healthy.

Remember, our attitudes about stress and burnout in general sometimes make it difficult to make changes. However, one important point to remember is that with support and encouragement from others, most of us can learn to make positive changes in our attitudes and behavior.

You might find it helpful to have a discussion among co-workers about bereavement caregiver burnout. Identify your own signs and symptoms of burnout. Discuss individual and group approaches to self-care that will help you enjoy both work and play!

- Recognize you are working in an area of care where there is a high risk for burnout. While helping other people has its rewards, it also has its dangers. Keeping yourself aware that you are "at risk" for burnout will help you from denying the existence of stress-related signs and symptoms.
- Create periods of rest and renewal. The quickest way to burnout is spreading yourself too thin – trying to help too many people or taking on too many tasks. Learn to respect both your mind and body's need for periods of rest after helping other people.
- Be compassionate with yourself about not being perfect. After all, none of us are! As people who like to help others, we may think our helping efforts should always be successful. Some people will reject your help while others will be invested in minimizing the significance of your help. This is particularly true where many survivors like to see themselves as "being strong." Also, remind yourself that mistakes are an integral part of learning and growth, but are not reflections of your self-worth.
- Practice setting limits and alleviating stresses you can do something about. Work to achieve a clear sense of expectations and set realistic deadlines. Enjoy what you do accomplish in helping others, and do not berate yourself for what is beyond you.
- Learn effective time-management skills. Set practical goals for how you spend your time. Don't allow time to become an enemy. When working on projects remember Pareto's principle: 20 percent of what you do nets 80 percent of your results.
- Work to cultivate a personal support system. A close personal friend can be a real lifesaver when it comes to managing stress and preventing burnout. If you have already reached the crisis state of burnout, realize you may well need the help of others in making lifestyle changes. Many caregivers have trouble asking for help. If this is the case for you, practice giving yourself permission to seek outside support. Remember, recent research has demonstrated that human companionship and connectedness helps you live longer.
- Express the personal you in both your work and play. Don't be afraid to demonstrate your unique talents and abilities. Make time each day to remind yourself of what is important to you. Act on what you believe is important. If you only had three months to live what would you do? Use this question to help determine what is really important in the big picture of life and living.
- Work to understand your motivation to help others with grief. As caregivers we strive to restore happiness to other people's lives. Does your need to help others with grief relate in any way to your own unreconciled

losses? If so, be certain not to use your counseling relationships to work on your own grief. Find trusted resources to help you work with any old and new losses.

- Develop healthy eating, sleeping and exercise patterns. We are often aware of the importance of these areas for those we help; however, as caregivers we sometimes neglect them ourselves. A well-balanced diet, adequate sleep, and regular exercise allows for our own physical, mental and emotional well-being.
- Strive to identify the unique ways in which your body informs you that you are stressed. Do you get tightness in the shoulders, backaches, and headaches? Becoming conscious of how your body communicates stress signals to you allows for awareness of stressful situations before they overwhelm you. A constant state of physical tension often results in deterioration, which results in physical breakdown.

Final Thoughts

Again, be aware that the above practical guidelines are not intended to be all-inclusive. This author suggests you and your colleagues develop your own list of how to prevent and work with bereavement caregiver burnout.

Each one of us has our own unique style of relating to the stress of living. Sometimes we manage that stress well, while at other times we need people who care about us to help us to acknowledge the potential of burnout. Hopefully, this article will assist you in assessing your own stress level, and, if appropriate, help you begin to make some changes.

There is no doubt in this author's mind and heart that to help other human beings survive and actually grow during times of loss is a true privilege. Perhaps, we can be proud that we want to help make a difference in people's lives, while at the same time remembering the importance of taking care of ourselves as caregivers.

Caring about our life's work, even enjoying it, will probably seem strange if we only see it as a way to make a living. However, if we can see our work as a way to enrich each moment of our living, we may well discover a deep caring within our souls that teaches us to learn and grow each and every day.

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Writing Your Child's Story

Margaret Gerner, TCF, St. Louis, Missouri shares the following thoughts about writing as healing

The possibility of forgetting even the smallest detail of our child's life is a fear most of us have. In truth, over the months and years many of these details do dim. Writing them down is a way to keep from losing these memories. This way we will not only have a permanent remembrance of our child for ourselves, but this will be a legacy for the other brothers and sisters. Here are some suggestions:

- * Write in a spiral notebook. This way nothing you write will be lost.
- * Begin at the beginning. Write all the details of your child's life from his/her birth.
- * Use your child's pictures to help remind you of occasions and happenings.
- * Ask friends and relatives to tell you anything they remember about your child.
- * Record the bad things you remember about your baby as well as the good.
- * Write about your child's death. Record as many details surrounding it as you do care to retell. Write about the days before the burial, the funeral, the days after, two weeks, a month and so on. Record how others helped.
- * Write a letter to your child. Include:
 - What I wish I had said to you.
 - What I wish I had done.
 - What I wish you would have done.
 - What I wish I could ask you.
 - What I wish I had not done.
 - What I wish you had not done.
 - What I would like to tell you.
- * Pour out your feelings to your child. Tell him/her of your anger, your guilt. Tell your child how you love him/her. Tell your child, **GOODBYE**.
- * Don't worry about whether you write well or not. Don't worry about form or grammar. Just write.
- * Keep the notebook handy. Write anytime you feel you want to say something to him/her or when you remember some detail that suddenly comes into your mind. The many times you have trouble sleeping, write down the things that keep coming to your mind.

Writing about your child or to your child will be emotional. It will probably make you cry. Don't let this stop you. Crying can be extremely helpful in releasing your tensions and will help you with your grief work...**REMEMBER - WRITING IT IS JUST TALKING WRITTEN DOWN.**

Joy Johnson and Dr. S.M. Johnson, Co-directors of Centering Corporation offer these additional tips:

- * Write what you feel, what you think, and what you want to write.
- * Make sure that whatever notebook or book you use for a journal has room for clippings, drawings, and meaningful things.
- * Consider your journal a friend...one with whom you can share all.

- * Think of your journal as a paper psychiatrist...cheaper and more fun.
- * Write every day, if you can.
- * Make your journal a record of what you are doing in your life as well as what you are feeling in life.
- * Be free! Use colored pens; make crayon drawings, if you want.
- * Write only to write...not to publish. If you write to publish you may try too hard.
- * Start now!
- * Know that you will catch yourself grow and change and that your journal is likely to become part of a quiet time sharing you with you.

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TAKING CARE OF YOURSELF

In caring for ourselves, we need to identify those activities which are healing to us as well as all those areas that may hinder our healing, and cope with each appropriately.

- * Give yourself permission, time and space to grieve
- * Don't pretend that death doesn't hurt
- * Feel free to protest the "why" of the death
- * Don't judge your level of grief and healing by how others are grieving and healing, but by your own internal awareness
- * Understand and accept your limitations
- * Respect your spouse's timetable and method of grieving
- * Don't escape into loneliness
- * Get rid of imagined guilt and "if onlys"
- * Laughter doesn't mean you are being disrespectful to your child's memory
- * Confront the fears of your death and the death of other loved ones
- * Cry
- * Honestly express your feelings about this death to people who will understand, who will not be judgmental and who will not be hurt by your honest expression of feelings.
- * Recognize that seeking professional counseling doesn't mean you are weak, inadequate or crazy
- * Use religion, philosophy, poetry, music, art, gardening, tennis, walks at nature centers, reading, volunteer work to gain relief and understanding
- * Talk about your experience to friends who were involved and to friends who were not involved with the death
- * Accept your friends with all their imperfections and occasional bad advice; you too have your moments of imperfection
- * Tell others what you want from them: help, emotional support, time sharing
- * Continue to participate in activities that are fun for you and with people who are special to you; don't underestimate the effects of small pleasures
- * Recognize that you may not always want to talk about your baby; sometimes there is a great relief being where no one knows your child has died
- * Eat nutritiously; consider using a vitamin supplement

- * Not crying doesn't mean you don't remember
- * It is fine to either enjoy being around other people's babies, or to be uncomfortable
- * Exercise to improve sleep
- * Set small goals
- * Accept others' verbal, non-verbal and physical expressions of caring for you
- * Postpone major decisions such as selling your home or changing jobs
- * The decision to have or not have another child is yours alone
- * The question "how many children do you have?" is a difficult one and you may find yourself answering it in the manner which best fits the situation and/or your own needs at that time
- * Take a break from intensity and exposure to pain
- * Consider participation in support groups; grief shared can be grief diminished
- * Avoid masking the pain with drugs or alcohol
- * Give yourself permission to backslide
- * Realize that you cannot prevent, cure or skip the grief process; the only way out is through

*The above is a compilation of excerpts of articles by the following and is reprinted with their permission:
 "Caring for the Caregiver", Barbara Swenson, RN, MS, PNP, Seattle
 "Ten Guidelines for Dealing With Grief", TCF, Austin, TX.
 "Parent Contact Workshop", Washington State Chapter, NSIDSF*

Reprinted with permission of Washington State Chapter, NSIDSF from the March/April 1987 Newsletter.

FOR GRANDPARENTS: SUGGESTIONS FOR HELPING YOURSELF/YOUR GRIEVING CHILD

- υ Read about grief (Hope for Bereaved Handbook, The Bereaved Parent, Living When A Loved One Has Died). It is important to understand what you and your child are experiencing.
- υ It helps to be open and share your feelings. Your openness sets a good example for your child. Share the good memories and good days, as well as the pain of grief and the bad days.
- υ Talk about the dead grandchild. Mention his/her name.
- υ Find someone with whom you can talk freely – a friend, support group member, clergy or counselor.
- υ Be available to LISTEN frequently to your child. Respect your child's way of handling the pain and expressing grief. Don't tell your child how he or she should react.
- υ At special times (anniversary of death, birthday, holidays) write and/or call your bereaved child (and their spouse). Mention that you realize what day it is. You are calling to say you love them and you wish that you could take some of their pain away.
- υ When adults are grieving, remaining siblings often feel neglected...plus they don't understand the grief that they are experiencing. Try to spend extra time with your other bereaved grandchild(ren), offering to listen and reminding them that they are very important and much loved.
- υ If possible, offer to take surviving grandchild(ren) for an afternoon or a day, help with practical matters, such as preparing food, doing laundry, shopping, and spend time alone with your child.
- υ Most of us need hugs even if we don't recognize that we do. It helps to hug and hold your child if you both are comfortable doing so.
- υ Allow yourself and encourage your child to cry when needed. Crying offers relief.
- υ Let the family know that you care, that you love them.
- υ Hold onto HOPE that eventually you/they will enjoy life again. Offer HOPE to your grieving child and family.

Reprinted with permission: Therese S. Schoeneck, Hope for Bereaved. Syracuse, NY 1988 (315) 472-4673.

When A Grandchild Dies

No one expects to outlive their own children, much less their grandchildren. It is so difficult to raise a family, see your children do the same, and then see the cycle broken in this out-of-order way. No one is prepared for the grief that follows. As grandparents you have a double grief. You grieve for your grandchild who has died, as well as for your own child who is now a bereaved parent. You not only feel your own pain and sadness, but feel helpless and frustrated at not being able to help your bereaved child. It helps to remember that there is no timetable for grief. Don't expect too much of your child, their spouse or of yourself. At first no one believes it. When the reality "hits" everyone feels even more devastated. It is important to consider your needs as well as those of your bereaved child. Acknowledging and working on your grief will help you and, indirectly, your grieving child.

As a bereaved grandparent you may feel great sadness, loss, guilt and anger. Some older grandparents have said, "I've lived my life. It should have been me." The fact that they are still alive while a young child or young adult is dead is difficult for many to bear. You may feel guilty if you live a distance from your child and, due to health or finances, you are not able to be with them at this painful time. Realize that you would be there if you could. It helps to write supportive letters and to make loving phone calls. You may experience anger at God, life, those in the medical profession, or any person you feel is responsible for your grandchild's death. You might even feel angry toward your own child for "letting it happen." Such guilt or anger is not always rational but may temporarily go with the territory of grief.

Some of you who now find yourselves grieving for a grandchild may have experienced the death of your own child years ago. Your grandchild's death may trigger memories and pain that you thought were long since forgotten. If your child died more than ten years ago, you may not have resolved your grief. In earlier years, and in some cases even today, grieving people were not allowed or encouraged to grieve. There were no support groups or books on grief. You were supposed to go on as if nothing had happened. If this is the case for you, it is important to allow your grief to surface. If you can, talk about it with your grieving child. It may help both of you.

Be careful not to suppress your grief, and encourage your child not to suppress grief either. Suppressed grief can cause physical as well as emotional pain. In addition to being harmful to you, it may seem to your bereaved child that you don't really care and are not hurting, too. In reality, when our child suffers, we suffer. It is important for everyone to face the grief and work through it. Life will never be the same, but with time, effort and much love....grief will ease.

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

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CHILDREN’S UNDERSTANDING OF DEATH BY AGE

Children of all ages are affected by a “significant” death. This ranges from the newborn’s reaction to emotional or physical change in the caregiver to the teenagers confused attempt to make sense out of their world. The operative word describing children’s grief is change - whether positive or negative. The “C” student becoming an “A” student is looking for as much help as the student whose grades drop. Below are highlighted ages with corresponding cognitive patterns. Also listed are suggestions for helping your child. If you feel your child’s behavior warrants professional attention, it is best to err on the safe side.

NEWBORN TO AGE THREE

- sense that something has happened in the family
- realize that people are often crying and sad
- notice that there is much activity in the household

HELP

- be sensitive to child’s needs
- try to maintain consistency in routines
- maintain consistency with significant people in the child’s life

THREE TO SIX

- does not have concept of the finality of death (believes that the person will return and will continually ask when the person will return)
- believe in magical thinking (child feels he was responsible for the death)
- may believe that everyone else he loves will also die

HELP

- emphasize to the child that he was not responsible for the death
- reinforce that when people are sad they cry (crying is normal and natural)
- encourage the child to draw pictures of his feelings or talk about his feelings

SIX TO NINE

- understand the finality of death
- seek out detailed explanations for the death
- afraid other significant people in their lives will die as well
- uncomfortable in expressing feelings (may act silly or embarrassed when talking about death)

HELP

- talk about the normal feelings of anger, sadness and guilt
- explain the difference between fatal illness from “just being sick”
- share your own feelings about death (do not be afraid to cry in front of the children, this gives them permission to express their feelings)

NINE TO TWELVE

- aware of the finality of death
- concerned with practical matters affecting the child's lifestyle
- want to know all the details surrounding the death
- try to "act like an adult", but then show regression to an earlier stage of emotional response

HELP

- set aside time to talk about feelings
- encourage sharing of memories to facilitate grief response

TWELVE TO ADULT

- separation issues - defining self apart from family
- aware of the finality of death
- seek support from peers
- struggle to understand death as well as their own mortality

HELP

- parental advice and role modeling important
- provide books to help them through the tough times
- use teachers, counselors, and support groups
- encourage journal writing
- encourage friendships that are healthy

CHILDREN

Ten Common Myths About Children and Grief

By: Dr. Alan D. Wolfelt

While many people have a desire to be helpful to bereaved children, and that desire is admirable, there is a responsibility to distinguish facts from fiction. Many well-intentioned, yet misinformed, adults are the victims of some widely held myths regarding children and grief.

The purpose of this article is to identify, describe, and dispel ten common myths about children and grief. Providing quality care to bereaved children requires that compassionate adults work to dispel the myths outlined below. Adults who have internalized these myths become incapable of helping children move toward healing.

These myths are not intended to be all-inclusive. Our task is not to condemn adults who have internalized these myths, but to supportively encourage them to broaden their understanding of the complex experiences of children's grief and mourning.

Reviewing the Myths:

- Myth #1: Grief and Mourning are the same experience.
- Myth #2: A Child's Grief and Mourning is Short in Duration.
- Myth #3: There is a Predictable and Orderly Stage-Like Progression to the Experiences of Grief and Mourning.
- Myth #4: Infants and Toddlers are Too Young To Grieve and Mourn.
- Myth #5: The Grief and Mourning of Adults Surrounding Bereaved Children Doesn't Have Any Impact on Them.
- Myth #6: The Trauma of Childhood Bereavement Always Leads to a Maladjusted Adult Life.
- Myth #7: Children are Better Off if They Don't Attend Funerals.
- Myth #8: Children who Express Tears are Being "Weak" and Harming Themselves in the Long Run.
- Myth #9: Adults should be able to Instantly Teach Children About Religion and Death.
- Myth #10: The Goal in Helping Bereaved Children is to "Get Them Over" Grief and Mourning.

Myth #1: Grief and mourning are the same experience....

Have you ever noticed how people tend to use the word "grief" and "mourning" synonymously? Many people are unaware that there is an important distinction between grief and mourning. This distinction is particularly important when working with and learning from bereaved children.

More simply stated, grief represents the thought and feelings that are experienced within the child when they have a relationship with someone whom dies. In other words, grief is the internal meaning given to the experience of bereavement.

Mourning means taking the internal experience of grief and expressing it outside of oneself. Another way of defining mourning is to state that it is "grief gone public," or "sharing one's grief outside of oneself." Of course, bereaved children mourn more through their behaviors than they do through words.

We often refer to children as "forgotten mourners." Why? Because they do grieve – the question is: do we create conditions that allow them to mourn? Only when we as caring adults encourage children to mourn, do we become catalysts for healing.

We have learned that children move toward healing not by just grieving, but through mourning. We must help children not just grieve inside themselves, but also mourn outside themselves!

Myth #2: A child's grief and mourning is short in duration...

Many adults simply do not understand that grief and mourning is a process, not an event. Those adults who want the bereaved child to “hurry up” and “get over it” usually project that the child needs to be “strong” and stoic.

Of course, who are these adults really protecting?

The obvious answer is themselves. Why? Because if they can assume the child's grief and mourning is short in duration, they don't have to walk with them and encounter the pain of the loss.

I continue to read in professional texts comments like, “If the child's symptoms persist past six months, they should be referred for professional assistance.” Inherent in this quote is that something is “wrong” with the child. Actually, nothing could be further from the truth. This period around six months after the death is when it is not unusual to see some more of the visible signs of outward mourning, which is healthy, and is moving the child toward healing.

John Bowlby and other investigators demonstrated years ago that children's mourning behavior is anything but short in duration. It is easy for many adults to mistake an apparent lack of feeling as evidence that children are “over” grief or are incapable of mourning. In reality, these children are simply protecting themselves from the initial hurt of the loss in the only way they know how.

Myth #3: There is a predictable and orderly stage-like progression to the child's experience of grief and mourning...

Have you ever heard a well-meaning, misinformed adult say something like, “That child is in stage two.” Well, if only it were that simple! Somehow the “stages of grief” have helped people try to make sense out of an experience that isn't as orderly and predictable as we would like it to be.

The concept of “stages” was popularized in 1969 with the publication of Elizabeth Kubler-Ross' landmark text “On Death and Dying.” Kubler-Ross never intended that people should interpret her “five stages of dying” literally. However, many people have done just that, not only with the process of dying, but with the process of bereavement, grief, and mourning, as well.

Some well-intended adults adopt a rigid system of stage-like beliefs about children's grief and mourning experiences. Yet, no two children are alike. As caring adults, we only get ourselves in trouble when we try to prescribe what a child's grief and mourning experiences should be.

Instead of a prescriptive approach, in my experience, an attitude that allows the child to be the true expert, is: “Teach me about your grief, and I will be with you. As you teach me, I will follow the lead you provide and attempt to be a stabilizing and empathetic presence.”

To think that one's goal is to move children through the stages of grief would be a misuse of counsel. A variety of unique thoughts, feelings, and behaviors will be experienced as part of the healing process. We must remind ourselves to not prescribe how children should grieve and mourn, but allow them to teach us where they are in the process.

Myth #4: Infants and toddlers are too young to grieve and mourn...

In my experience, any child old enough to love is old enough to grieve and mourn. Toddlers and infants are certainly capable of giving and receiving love. Of course, how many times have you heard, “They're too young to understand?”

While infants and toddlers cannot verbally teach us about their grief, if we pay attention, we will note that they protest the loss in a variety of ways. A few practical examples are regressive behavior, sleep disturbances, and explosive emotions. I see children as young as eighteen months old in my clinical practice.

John Bowlby's research has taught us how even babies will protest when threatened with separation, death or abandonment. No doubt, we need more research with this young population. However, it is clear to me in my work that we should not assume that infants and toddlers are too young to grieve and mourn.

Unless we support and nurture these young children when they are confronted with the loss of a primary relationship, they can potentially develop a lack of trust in the world around them. By providing both verbal and nonverbal support, we can and should be certain that adequate maternal and paternal care is provided to bereaved infants and toddlers. Holding, hugging and playing with them are the primary ways in which we can attempt to help these lovely children. We can also serve as support to the parents of bereaved children in teaching them about these ways of helping. In doing so, I truly believe we are doing preventative mental health care.

Myth #5: The grief and mourning of adults surrounding bereaved children doesn't have any impact on them...

Many adults attempt to conceal their own grief and mourning from bereaved children. While these adults are well-intentioned, they are also misinformed. Modeling is a primary way in which children learn.

My experience has taught me that the significant adults in children's lives are the most important factor in allowing and encouraging children to mourn. If adults deny their own grief, they teach children around them to do the very same thing.

When Mom and Dad are sad, children can learn that it doesn't mean it is their fault. However, if they don't learn this, they will often assume they are responsible for the emotional environment of the household. When bereaved children can acknowledge that adults around them are sad, and that it isn't their fault, they can become free to express their own wide range of emotions, including sadness.

One of the most loving things we can do as bereaved adults is allow ourselves to mourn. With our own capacity to love, comes our own necessity to mourn. The first step in helping bereaved children is to help ourselves. We help ourselves by permitting the open expression of our own life hurts!

Myth #6: The Trauma of Childhood Bereavement Always leads to Maladjusted Adult Life

Since the 1930's, numerous studies have attempted to establish relationships between childhood bereavement and later adult "mental illness" (depression, psychosis, sociopathic behavior). While a number of clinicians and researchers have tried to demonstrate this relationship, more recent critical reviews of the research literature have questioned the results. Why? Because there seems to have been a number of methodological problems with the studies. Numerous studies failed to control for such influences as social class, age of parents, and nature of the emotional relationship between the child and the parent that died. Retrospective research has not been able to evolve a definite answer to the question of whether early childhood bereavement (most studies have focused on death of a parent) is able to predict the later onset of mental health problems.

While many studies that attempt to make the above link have been rejected, some well-meaning, misinformed people perpetuate this myth. You may have witnessed this when you see adults approach bereaved children with a patronizing attitude that projects the following, "You poor child, you will be forever maimed by this experience."

These more recent critical reviews of the literature suggest that the death of a parent alone is not necessarily a determinant of later mental health problems. Interestingly, a study by Rutter on maternal deprivation has suggested that psychopathology is not necessarily linked to the parent-child bond, but instead to the lack of bonding initially.

My own clinical experience has resulted in a personal bias on this important issue. I believe the quality of care provided to bereaved children as they are helped to do the work of mourning is a major influence on their healing, or rather what I have termed "reconciliation."

In sum, do not assume that because a child experiences the death of someone that they will have maladjusted adult life. Instead, work to create societal and familial environments that help them participate in the work of mourning and go on to live meaningful lives!

Myth #7: Children are Better Off If They Don't Attend Funerals.

The unfortunate reality is that many adults firmly believe in this myth. The result is that many children are denied the opportunity to confront the reality of the death with the support of loving adults. Adults who have internalized this myth create an environment that moves children away from grief and mourning prematurely. The funeral provides a structural way of allowing and encouraging both adults and children to comfort each other, openly mourn and honor the life of the person who has died.

Since the funeral is a significant event, children should have the same opportunity to attend as any other member of the family. They should be encouraged to attend, but never forced.

I emphasize the word “encouraged” because some children are anxious when experiencing anything unknown to them. Through gentle encouragement, loving adults can help bereaved children know they will be supported during this naturally sad and frightening time in their young lives. The funeral can even provide an opportunity for children to express their unique relationship with the person who has died by including a ritual of their own during the service.

Myth #8: Children Who Express Tears are Being “Weak” and Harming Themselves in the Long Run

An important way in which children learn is through the modeling of a primary caregiver. If bereaved children are in an environment where adults are living out this myth, they will often follow suit.

Children may repress their tears either because they have internalized adult demands for repressing feelings, or they have identified with how the adults surrounding them repress their own tears. Unfortunately, many adults associate tears of grief with personal inadequacy and weakness. Crying on the part of bereaved children often generates feelings of helplessness in adults. Out of a wish to protect the children (and themselves) from pain, well-meaning, misinformed adults often directly inhibit the experience of tears. Comments similar to, “You need to be strong for your mother,” or “Tears won't bring him back,” and “He wouldn't want you to cry,” discourage the expression of tears. Yet crying is nature's way of releasing internal tension in the body and allows the child to communicate a need to be comforted.

Another purpose of crying is postulated in the context of attachment theory, wherein tears are intended to bring about reunion with the person who has died. While reunion cannot occur, crying is thought to be biologically based and a normal way of attempting to reconnect with the person who has died. The frequency and intensity of crying eventually wanes, as the hoped-for reunion does not occur.

The expression of tears is not a sign of weakness in adults or children. The capacity of bereaved children to share tears is an indication of their willingness to do the “work of mourning.” As loving adults we can better assist children by modeling our own expression of tears.

Myth #9: Adults Should be Able to Instantly Teach Children About Religion and Death

Perhaps you have heard an adult say, “I'll just tell them he's gone to Heaven and that will take care of it.” If only it were that simple! As one eight-year-old girl said, “If Grandpa is in Heaven, why did we put him in the ground?”

Teaching abstract religious and spiritual concepts is no easy task. Children's capacity to understand will grow with them as they mature. While we can only teach what we believe, be careful not to expect too much of yourself in this important area.

A challenging adult responsibility is to clarify for children abstract ideas about death. Such ideas are often misused to avoid providing explanations about the nature of the death or to deny feelings. Religious and spiritual belief systems can

be sustaining, but children's capacity to assimilate their beliefs over time must be respected. The child need not, and often cannot, understand the total religious philosophy of adults around them. Whatever the specific beliefs of the family, the child must be helped to understand that the person has died and cannot come back.

A sometimes-witnessed misuse of religion is to suggest that children need not mourn because the person who died "is in a better place, anyway." To discourage children from mourning in this way can set them up for a multitude of complications in their continued living.

In sum, caring adults need not feel guilty or ashamed if they cannot give specific definitions of God and Heaven, or what happens after death. Openness to mystery is valuable not only in teaching about death, but in teaching anything about life!

Myth #10: The Goal in Helping Bereaved Children is to "Get Them Over" Grief and Mourning.

We have all probably had the experience of hearing an adult talk about a bereaved child in the following way: "Shouldn't she be over it by now? I think it's been over a year." To think that we as human beings, adults or children, "get over" grief is ludicrous!

Adults who have internalized this myth often lose the most important quality of an effective caregiver – the loss of patience. Why? Because they are always trying to get the child "over it." Children don't overcome grief; they live with it and work to "reconcile" themselves to it.

As the child participates in the work of mourning, a natural realization follows that life will be different without the presence of the person who has died. Hope for a continued life emerges as the child is able to make commitments to the future, realizing the dead person will never be forgotten, yet knowing that one's life can and will move forward.

No, children do not get over it, but instead they become reconciled to it. Those people who think the goal is to "resolve" bereaved children's grief become destructive to the healing process.

Final Thoughts

Again, be aware that the above myths are not intended to be all-inclusive or mutually exclusive. We must supportively encourage people to broaden their understanding of the complex experience of children's grief and mourning.

Being surrounded by adults who believe in these myths invariably results in a heightened sense of isolation and alienation in bereaved children. The inability to be supported in the "work of mourning" destroys much of the capacity to enjoy life, living and loving.

Bereaved children will experience the healing they deserve only when we, both as individuals and a society, are able to dispel these myths.

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SELF CARE

How to Help Yourself and Others When Loss is No Longer New

A few months after our son Tyler died from SIDS, a well-meaning neighbor bent down to four-year-old Jennifer's eye level and asked, "Well, are you feeling better now about your brother?" and with a four-year-old wisdom and candor, Jennifer replied, "Nope. He's still dead."

As the mother of a baby who died 16 years ago, I might offer the same reply today. Even though time has softened the jagged edges of grief, my son is still gone. In examining my own feelings about a loss that is no longer new, I questioned if I was alone in wondering what has been the effect of my son's death on me and on my family..years later.

When grief is new, it is overwhelming. It invades every part of our lives and refuses to be ignored. Thank goodness it is true that time helps, and even heals a great deal, but it doesn't erase the fact that a child lived and died. In my many discussions and correspondence with families whose loss has been five, ten, twenty, or more years ago, this is clear – no matter how long it's been, we don't forget. We may not think of our child every day, but we remember. And we'd really like it if others would remember too.

"After the first birthday and anniversary, no one called," a mother shared with me. "I felt I was the only one who remembered she had lived. Do we get to remember for only one year?" Many parents realize that the responsibility for remembering seems to rest on their shoulders, and they have come up with touching, creative ways to honor their child's memory. Candle-lighting, tree planting, balloon releasing, kite flying – all are tangible ways to quietly say "I remember you." Other families donate to medical research or to charities of their choice in their baby's name. For Tyler's seventeenth birthday, our family donated a children's book to our local library. It's not much, but it helps us remember that his brief life mattered, and it makes us feel good to know other living children will pick up this book and enjoy it.

Although my grief is no longer new, I find that it sometimes comes back with strength that surprises me. My ears still perk up, and my heart still races each time I hear a newsflash about infant death, each time I pick up the paper and see a too-small headline briefly describing the latest research theory. I've been involved long enough within the community to realize that theories come and go, but I'm still an optimist, and my heart still plummets when I reach the end of the broadcast or article and realize we've not yet solved the mystery. I don't think I'm alone as I revisited the "if onlys, what ifs, I should have" that new risk reduction information brings up. And yes, of course, I am grateful and supportive of ongoing research efforts, and I do know I did the best I knew to do with my son...but still...

Other milestones can trigger those memories of pain. Wonderfully happy events such as family birthdays, graduations, weddings, births, often bring tears of joy, but for some of us the tears sting as we look with love at the celebration and realize that one important person is missing. As the years go by, we will rarely mention his or her name at these happy occasions, but please be sure that although we are delighted and relieved that life does, indeed, go on, we still miss our child. We still see the empty chair.

One of the hardest parts about being a 'seasoned griever' (as someone in our Years Later session described us) is that there are so few people with whom to talk about our child. As the years pass, there are fewer opportunities to just reminisce. One father had this to say, "Everyone in my family still talks about my grandfather who died at 80. No one thinks it's unusual to say his name and to talk about our memories of him. And yet it feels somehow 'strange' for us to bring up the few memories we have of our son, especially now that it has been so many years."

It has been so many years...but it still hurts. Not the agonizing, blinding pain of the early days, but sort of a soft ache, with occasional deep pangs of grief. We will always be the parents of a child who died; our family will always be missing an important member. It is impossible to realize the many ways in which the loss of a child continues to impact our lives....perhaps it is enough to accept that it has forever changed us, for better or for worse. We understand that death is a part of life, and that acknowledging our losses is a necessary part of living and moving on. And we are...but we are carrying our memories with us.

Reprinted with permission from "HORIZONS" Newsletter – California SIDS Program, June 1999.

SELECTED BIBLIOGRAPHY PARENT LITERATURE ABOUT DEATH

The Bereaved Parent

As a bereaved parent, the author explores common issues related to bereavement.
ISBN: 0-14-00.5043-4

Harriet Sarnoff Schiff

Don't Take My Grief Away

How to walk through grief and learn to live again.
ISBN: 0-06-065417-1

Doug Manning

A Man You Know Is Grieving/When A Man Faces Grief

Practical ideas for helping men heal from loss.
ISBN: 1-885933-26-6

Thomas R. Golden & James Miller

Men and Grief

Explores issues for men grieving the death of a loved one.
ISBN: 0-934986-72-X

Carol Staudacher

Swallowed By a Snake

Addresses differences in men's and women's grief.
ISBN: 0-9654649-0-3

Thomas R. Golden

Time Remembered

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ISBN: 0-8070-2704-9

Earl A. Grollman

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ISBN: 0-9612310-3-3

Rana Limbo & Sarah R. Wheeler

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Darcie D. Sims

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Provides strength and comfort for those who have suffered the loss of a loved one
ISBN: 0-380-77338-4

Martha W. Hickman

How To Go On Living After the Death of a Baby

Provides more understanding on the depth of pain of losing a baby.
ISBN: 0-931948-69-X

Larry Peppers & Ronald Knapp

A SELECTED BIBLIOGRAPHY FOR TALKING ABOUT DEATH AND GRIEF WITH CHILDREN

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Children's Literature About Death

The Accident

Carol Carrick

An honest look at a boy's feelings of anger, sadness and his memories of joy as he prepares to bury his dog.
ISBN: 0-89919-041-3

Am I Still A Sister?

Alicia M. Sims

Written by an eleven year old, Alicia Sims asks the questions and expresses the feelings expressed by all bereaved siblings. She asks and answers with honesty and with hope.
ISBN: 0-9618995-0-6

Annie and the Old One

Miksa Miles

Indian story of life and learning about inevitable death.
ISBN: 0-316-57120-2

Charlotte's Web

E.B. White

This book explores with the child the different cycles of life through relationships with her pets.
ISBN: 0-06-440055-7

Daddy's Chair

Sandy Lanton

Jewish family observing shiva and a boy dealing with his fathers death.
ISBN: 0-929371-51-8

The Dead Bird

Margaret W. Brown

A book for children explaining death by an example of finding a dead bird.
ISBN: 0-201-09167-4

Fire In My Heart, Ice In My Veins

Enid Samuel Traisman, MSW

A journal for teenagers experiencing a loss.
ISBN: 1-56123-056-1

Geranium Morning

E. Sandy Powell

The story of a boy whose father was killed in a car accident.
ISBN: 0-87614-380-X

The Giving Tree

Shel Silverstein

A tender children's story about giving and taking.
ISBN: 1-06-025665-6

Homeboy

Joyce Hansen

A book for adolescents on gang fighting and the aftermath.
ISBN: 0-89919-114-2

I Had A Friend Named Peter

Janice Cohn, DSW

Talking to children about the sudden death of a friend.
ISBN: 0-688-06685-2

The Kids Book About Death & Dying – By And For Kids

Children to children perspective on death for children and their parents.

ISBN: 0-316-75390-4

Eric E. Rofes

No Bigger Than My Teddy Bear

Information for siblings on the premature infant.

ISBN: 0-687-28028-1

Valerie Pankow

On The Wings of a Butterfly

Provides a start for the task of talking with children and listening to them talk about death and dying. A girl who is dying of cancer. Elementary – Middle School.

ISBN: 0-943990-69-6

Marilyn Maple, PhD

The Patchwork Quilt

Black family whose grandmother becomes ill and the young girl who wanted to help.

ISBN: 0-8037-0097-0

Valarie Flournoy

Saying Goodbye Activity Book

Activity Book

Boulden Publishing. Weaverville, CA 96093 (800) 238-8433

Jim Boulden

Saying Goodbye to Daddy

Children's story of coping with her fathers death.

ISBN: 0-8075-7253-5

Judith Vigna

A Taste of Blackberries

A story of a boy whose best friend dies unexpectedly.

ISBN: 0-06-440238-X

Doris Buchanan Smith

Timothy Duck

The story of two children and the death of their friend. Elementary School Age level.

ISBN: 1-56123-013-8

Lynn Bennett Blackburn

Where's Jess?

A book for preschoolers which explores what it means to be dead.

ISBN: 1-56123-009-X

Joy and Marvin Johnson

Why Did Grandpa Die?

Story shows children the comfort of sharing feelings. Elementary.

ISBN: 0-307-12484-3

Barbara S. Hazen

ONLINE RESOURCES

Wisconsin Perspective – the newsletter of the Infant Death Center of Wisconsin is available on the Web site and has articles on grief and loss.

Following are links for families and those impacted by infant death:

- **A Place to Remember** Support materials and resources for those who have been touched by a crisis in pregnancy or the death of a baby.
- **Bereavement Magazine (A Magazine of Hope and Healing)** A bi-monthly publication providing articles on grief and loss. Articles from current and past issues available online include personal perspectives as well as articles on grief and loss.
- **Camp HOPE (Helping Others' Pain End)** A place where children and teenagers gather to work through the grieving process after a loved one dies. Children and teenagers are guided through the complex emotions by showing them that they are not alone.
- **C J Foundation for SIDS**
- **Children's Hospital of Wisconsin Bereavement Program**
- **The Compassionate Friends** A national nonprofit, self-help support organization that offers friendship, understanding and hope to bereaved parents, grandparents and siblings. The Web site features information on grief and online versions of its quarterly magazine.
- **The Dougy Center for Grieving Children and Teens** Provides information in the "Grief Support" section on supporting adults, children and adolescents in their grief.
- **First Candle - Helping Babies Survive and Thrive** Contains bereavement materials for miscarriage, stillbirth and infant death.
- **Infant Death Center of Wisconsin** Contains information on grief and loss, links and research in the "For Families" section.
- **Kyle's Korner** Provides information about the program's support groups, which feature an innovative approach to non-pathological grief involving expression through play, art and sharing.
- **March of Dimes** Contains a special grief and loss section related to perinatal deaths
- **Margaret Ann's Place** A nonprofit, community-based organization dedicated to providing peer support groups and services for grieving children, teens, families and communities who are coping with death and dying.
- **Men and Women Grieve Differently** Article on the description of the difference between men's and women's grief.
- **National Institute of Child Health & Human Development** Information on Back to Sleep, research and other areas related to children's health information.
- **The Sibling Connection** A resource regarding the death of siblings that features information on grief and loss with resource listings.
- **SIDS Network, Inc.** Provides information on sibling grief, pregnancy and infant loss, chat rooms and discussion boards as well as a list serve.
- **The Compassionate Friends** Provides on line chapters through virtual support, a series of brochures available through the web site, as well as links to other programs and services.
- **The National SIDS/Infant Death Resource Center** Contains publications on bereavement support, a section on pregnancy loss and an extensive bibliography on bereavement and bereavement resources. Bibliographies can be found on the following link <http://www.sidscenter.org/TopicalBibliographies.html> the website provides additional bereavement support material, a bibliography of printable material and links to additional web resources.
- **Web Healing** A place men and women can discuss, chat or simply browse to understand and honor the many different paths to heal strong emotions.

ONLINE PAMPHLETS

Grief:

- **Grief: The Death of a Child.** (PDF: 76KB)
Spanish (PDF: 76KB)
- **Helping Children Understand Death.** (PDF: 60KB)
Spanish (PDF: 88KB)
- **When Your Child Dies.** (PDF: 77KB)