

The

LIGHTHOUSE

Autumn 2007



A Publication of **BDSRA** –
Batten Disease Support and Research Association

FROM THE EDITOR

Today is a beautiful autumn day, with mid-80 temperatures, warm sun and no rain in sight for now. Yet the trees remind me that it is fall, for me a difficult time of the year emotionally. I know that many others are feeling that as well. There is a sadness in the air, the beauty of spring and youth has grown into summer and now autumn makes us think of the loss of many natural things with winter's approach. It is reminding us of the cycle of life, of nature, of birth and death.

Members of families experiencing the loss of a child are living through the cycle of life in different ways, and each has to make the journey through grief at his or her own pace. This edition of THE LIGHTHOUSE will hopefully address something specific for each who reads it. It is my hope that with the various holidays approaching every person may find something useful to help in their individual journey. You might be a suggestion as to how to handle the holiday; you might be moving on and be encouraged by the inspiration of a fellow traveler who has created a way to deal with grief in a positive way by helping others. You might be a sibling mourning your departed brother or sister and find that you could express yourself in a story of memories or a poem to share with others. We welcome and encourage participation by contributing your thoughts and memories of a loved one or suggestions or something that helped you travel on your journey.

As the new editor of THE LIGHTHOUSE I would like to introduce myself and thank Connie Jackson for her many years of inspiration, heartfelt writing and sharing her time and talents with us. I am so fortunate to live near Connie and have the privilege of seeing and visiting with her. I hope to continue to include Connie's writings and wish her good health.

My name is Ann Salladin and I live in Bradford, NY. I am the mother of 8 children which includes 2 step-children and our two Batten children. Victoria (1970-1976) and Victor (1972-1984) were our introduction to this dreadful disease and the grief that was for a long time indescribable, raw and, after 30 years still surfaces.

At the time of their diagnosis there was no B.D.S.R.A. for support for our family. In retrospect I realize that my other children were silent victims of mourning. We traveled the journey as a family with very little support. I am so thankful for my B.D.S.R.A. "family" because I know what it was like to be basically alone with no one who really understood how we felt or what we were experiencing.

One of our daughters found information about the organization on the internet around 1997 and I called the 800 number. It was too late to attend the Conference that year and the first one we attended was in Richmond, VA. I will never forget the experience of meeting families and again seeing other Battered children. Although 20 years had evaporated from my life I was determined to do all that I could to help our families. I have served 2 years on the Board of Directors (and would welcome the opportunity to have that honor again) and 3 years as President of the New England Chapter. I must confess that in Richmond many more tears fell as my memories were refreshed and feelings, hidden and long buried (I thought) were uprooted and resurfaced. I began to learn more about the grief that had never been addressed as I tried bravely to "get on" with life and be what everyone expected.

I look forward to contributions from you, your family and friends as they express feelings, sorrow, joy and memories in tribute to the beloved children who have died. I encourage suggestions of what has helped you to celebrate their life. Please send me the names of books or articles that you have found helpful. There will also be articles about past and upcoming Bereavement Retreats and Life Goes On Group activities from Conference.

We plan to print THE LIGHTHOUSE four times a year: February, May, August and November. Please email your contributions to me at aswildchild@yahoo.com, send it to my attention to the B.D.S.R.A. office, or mail it to 9909 Carmen Road, Bradford, NY 14815. Please try to get it to me by the 5th of the preceding month (January, April, July and October).

REFLECTIONS from Connie Jackson

In the Spring 2007 issue Connie bid us farewell as editor. Her words have given many families hope and inspiration: "As parents of children with Batten disease whom we cherished and watched helplessly to see the changes, we remember the LOVE. That's the legacy our dear ones have left us: to share that love with others who are hurting."

Karen – In Memoriam - Dec. 12, 1951 – March 3, 1968

She slept,
Eyes tightly closed as infants do,
One small hand
Lightly held in mine, fragile fingers
Miraculously fine,
Her face solemn in sleep for one so new.

I counted toes,
I checked our first newborn
And wondered that this one
Tucked warmly in my arm
(We two locked in meditative calm)
Was mine to love and nurture
Mine to form.

I held her grateful,
Wholly unaware,
The seed of death, by strange genetic law,
Was planted deep
On unseen flaw,
I did not know how few the years
We two would share.

I grieved to see
The slow incipient change
That scarred those eyes which could not see,
And brought her understanding
Back to infancy.
How little of her life I could arrange!

Immutable,
Her core of joy was there,
The inner peace we only sensed in part.
God's love
Was beating deep within her heart.
She could not speak;
Her smile became a prayer.

She left us that last day,

Her spirit free,
 To meet the source of Life
 Who gave it birth,
 And carry with her
 From her bit of earth
 A seed of joy to blossom in eternity.
 Connie Castor, her mother

GETTING THROUGH THE HOLIDAYS WHEN YOUR'VE LOST A LOVED ONE

(With permission from Abbey Press By: Darcie D. Sims)

The Holidays are coming and I'm not sure I'm ready. I'm not sure I'll ever be ready again. It's winter and I feel as frozen inside as the landscape is outside. I tried making out my gift list today, but the tears kept getting in the way. It is so hard to think about gifts and fun and the holidays when a loved one has died.

As I get out the dishes and count the silverware, I am acutely aware of the empty place at the family table. I'm trying to find the holiday spirit, but when the family circle has been broken by death, the only things that sparkle this season are my tears.

WORKING YOUR WAY THROUGH

When you've lost a loved one, the holiday season can be a painful reminder of the terrible loss you are feeling-instead of bringing warmth, love, and excitement. The first few years are perhaps the most difficult, but even years later, the holidays may lack the joy they once held for you. There are steps you can take however, to help give the holidays a new meaning. The holidays can become a time of peace and reflection, a time to cherish the gift your loved one has been-and continues to be-in the life of your family. Here are a few ideas that may help you begin the journey.

- **Be Patient and Realistic.** Sometimes our own high expectations of the holidays make the pain and frustration more acute. We have a mental picture of how things ought to be. Often, however, those expectations are based more on fantasy than reality. Remember that you are grieving. Be kind and gently with yourself, and realistic about what you expect. Leave the word OUGHT out of the holiday season this year.
 It is difficult to be realistic while you are grieving, but it is also an important strategy for health and well-being. Plan ahead so that you are not overwhelmed by responsibilities at the last moment. When you are grieving, it is difficult to concentrate, so make lists. Prioritize things. Decide what is important to you this holiday season, and scratch the rest off the list this year. You can always add things back in years to come.
- **Listen To Your Heart and Acknowledge Your Limits.** Spend some quiet time before the rush of the holidays listening to your heart. Become aware of your needs and express them to family members and friends with whom you plan to spend the holidays. Encourage others to share their feelings, too, so that everyone affected by the death of your loved one has an opportunity to express his or her wishes about holiday plans.
- **Remember that it is O.K. to say no.** You do not have to accept every invitation or fulfill every responsibility that comes your way this holiday season. Accept invitations and take on

obligations only as you have the energy and the desire to do so. Make all your “yeses” tentative this year.

Do what you can this holiday season, and let that be sufficient. If you can’t decorate the yard, decorate the house. If the house seems too big to tackle, decorate a room, a corner, or a table. There is nothing wrong with simplicity.

- Meanwhile, take care of yourself physically. Grieving is hard on the body and is a great source of stress. Eat well and wisely. Avoid the temptation to numb your pain through overindulgence in the season’s many culinary delights. You will only feel worse later. At the same time, do not deny yourself the pleasures of good food and the companionship out of a sense of obligation to the deceased. Remember that your loved one would want to see you smiling, happy, surrounded by those whom you hold dear. If you are alone this year as a result of your loss, find a way to share a part of the holidays with others. Visit a soup kitchen or stop by a nursing home. You may find yourself forging new bonds out of shared losses.

- Adapt Cherished Traditions. When loss and grief overwhelm us at the holidays, we are sometimes tempted to scrap the whole thing, to do absolutely nothing. But you can keep traditions alive in ways that make sense given the new reality of your life. For instance, if the fact that you won’t be buying a gift for your departed loved one this year saddens you, buy a simple gift that you know he or she would have liked and give it to someone who otherwise would not have a gift. Many charities are eager to accept such gifts at this time of year, and some will even arrange for you to present the gift in person if you wish. Remember that it is the exchange of love—the giving—that matters most.
Hang the stockings by the fireplace if you wish; place a wreath on the grave if that seems appropriate. Do whatever feels right for you and your family. Try a new twist on old traditions—have Christmas dinner on Christmas Eve, open presents on New Year’s Day or on the sixth of January, as is done in some traditions. If you are alone this year as a result of your loss, find a way to share a part of the holidays with others.

- Allow the Tears to Come, but Look for Joy Amidst the Pain. As you unpack and sift through holiday decorations, understand that along with the warm, loving memories, you will be unpack-ing some heartaches as well. Don’t deny yourself the gift of healing tears. Lay in a supply of tissues and don’t be surprised if you find tears coming when you least expect them. . Sometimes all we can remember are the painful details surrounding our loved one’s death. This holiday season, try also to remember all the wonderful moments of your loved one’s life. Think of all the gifts your loved one has given to you—joy, laughter, affection, companionship. Write these gifts on strips of paper. Put them in a gift box or place them in a stocking. Decorate the tree with them or keep them in a memory book or a private drawer. Whatever choice you make, you will be celebrating the joy your loved one has brought into your life.

- Focus on the Spiritual Dimension of the Holidays. When you are ready, and it feels right, one way to refashion the holidays is to focus on the underlying religious meaning. In the Christian tradition, Advent can be a time of quiet reflection and spiritual preparation. Let this season of hopeful anticipation touch the yearning within your heart for a final reunion with your loved one in the life to come.
In this season of light, remember the light your loved one has brought to your life. Light a special candle—not in memory of a death, but in celebration of a life and a love shared. Spend a moment in a quiet prayer of thanksgiving for having loved and been loved by this person. Holidays of other faith traditions are also steeped in religious significance. However you observe the season, let your grief lead you to a deeper appreciation for the time-honored

traditions of the holiday season, traditions that bring home the meaning of God's promise of everlasting love and life

- Take Heart. Right now, you may feel like the scattered pieces of a broken puzzle. Honor that feeling, but also take comfort in knowing that the pieces of the puzzle can be reshuffled, rearranged, and pieced together to form a new picture. As you learn to create a new reality for your-self, temper your expectations with compassion and gentleness. You will heal, but only as you allow yourself to experience the full range of emotion on your journey through grief. I know the pain of moving through the holidays after the death of a loved one. But slowly, gently, I have begun to focus on my loved one's life-not the death-and that has made all the difference.
May love be what you, too, remember the most.

A GIFT SUGGESTION

With holidays approaching, remembering and gift-giving might pose somewhat of a problem. There are two thought books that I might suggest for your consideration. Purchase them as a gift for your-self or to give another person who has lost a child.

Two years ago, following the death of my husband of nearly 40 years, I began to travel another journey in grief and was still numb at Christmastime. One day in the grocery store I saw a book lying on top of a box of "SPECIAL-\$3.00 each" books. The title was *MIRACLE OF THE CHRISTMAS BOX*, by Richard Paul Evans. I tossed it in the basket and returning home, shelved it along with several other books that folks had sent dealing with "loss" and "grief" still unread. I wasn't ready to read until a year later.

One evening last year, actually Dec. 6th, which is significant in one of the books, it caught my eye. I stood there by the shelf, read, transfixed, practically devouring every single word until the book was done. I was totally captivated by that book. The next day I was compelled to search for the original book that was being written about, *THE CHRISTMAS BOX*. It was right on the shelf in the library where I work. That night I read it, without stopping, just like the first one. It seemed that I couldn't tear myself away from the message it was sending. The following day, after not finding it in any bookstore unless they ordered it, I requested the director of the library to order a copy for me. I needed to send it as a special remembrance to a dear friend for Christmas. I would've driven hours to purchase that book. I strongly believe that everyone who has lost a child should be the recipient of at least one, if not both of these books. Holiday time would be ideal to present this in memory of a special child. I'm certain that at the right time the parent will read it, non-stop, just as I did. It is powerful, magnetic, and draws you into Mr. Evan's world.

THE CHRISTMAS BOX is described as a work of fiction, however it appeared to me that it has autobiographical overtones. Mr. Evans lives with his family in Salt Lake City, UT. It is a short book so from the jacket cover I quote Mr. Evan's telling of his writing this book, which was never intended to be published. "When I wrote *THE CHRISTMAS BOX*, I never intended to publish the story-it was simply an expression of love for my two young daughters, Jenna and Allyson. Though I often told them that I loved them, I didn't believe that they could ever really understand the depth of those feelings until they had experienced the joy of rearing their own children, and by that time our relationship would have already changed. Forever. In writing *THE CHRISTMAS BOX*, I hoped that at some future time they could read this book and know of their father's love.

As I began to write, I was amazed at the inspiration which flowed into my mind and heart. I completed the book in less than six weeks and, when I had finished, I produced twenty copies of

THE CHRISTMAS BOX to give as Christmas presents to my family and a few close friends. In the next four weeks those twenty copies were shared from family to family, and to friend.

Now I share the message of this book with you in hope that we can all remember what is most precious to us, and that you, too, may experience the magic of *THE CHRISTMAS BOX* and pass it on.

A short book, the story begins with a young family who moves in with an elderly widow. The living arrangement in her huge home helps both parties and a close friendship develops. As the story develops the father discovers a carved box in the attic and its contents. "Together they discover the first gift of Christmas and learn what Christmas is really all about. *THE CHRISTMAS BOX* is a Christmas story unlike any other".

The book is also available in a Spanish-language edition EL REGALO de NAVIDAD as well as in English from Simon and Schuster Audio Simon & Schuster, Rockefeller Center, 1230 Avenue of the Americas, New York, NY 10020 in the event your local bookstore is unable to get it for you. I also recommend Mr. Evan's website at www.richardpaulevans.com.

FOR THE SIBS from Sara

Sara Thompson has sent this message to all the Sibs out there and would like it to be repeated here.

Ann Salladin, the new editor of *THE LIGHTHOUSE* has provided a page for the Sibs group to use. We are encouraging siblings to submit poems, songs, memories or stories about their siblings.

For this first page, I am using the poem that was presented at the 2007 conference in Rochester, NY. I came across the poem online and thought it was appropriate for our group

WHEN YOU SEE A BUTTERFLY
 When you see a butterfly
 Think of me.
 When you feel like no one is there,
 Make sure you know I am.
 When you feel like I am gone forever,
 Make sure you feel like I am there.
 When you think you have grieved too much,
 I know there is always another tear.
 Think of me.

When you see a shadow
 Don't be afraid.
 When you see a light,
 Think of good times.
 But when you see a butterfly,
 Think of me.

For you know I am always with you,
 In every way, shape and form.

I am always there to protect you,
 Even through dangerous storms.
 Know that I am right beside you,
 In whatever fate decides to put you through
 For I may be gone,
 But I am around,
 So when you see a butterfly,
 Know I am always there.

By Brytani Russell

HELP IN MOVING ON

Submitted by Bob Wilhelm

“You’ll never know, dear, how much I love you,
 my Sunshine away.” Please don’t take

We know the song and we have all lived the loss of our beloved “Sunshines”. In my life she was named Carolyn and, despite the plea contained in the melody’s lyric, my Sunshine was taken away in 1998. On that spring day Laura and I experienced the emergence of what has been aptly called a hole in the heart that can never be filled. I still kiss the air when I walk into Carolyn’s room almost ten years later.

In all honesty, I don’t really want that hole to be filled. Relief from that helpless, suffocating feeling of that awful day?—of course. But total healing? Not if that were to email forgetting.

I find comfort in reading and re-reading lines I had begun to record in a large journal-like book soon after Carolyn’s diagnosis. It is a compilation of thoughts, memories, favorite expressions, and anecdotes about her. I continue to add to it as thoughts occur to me, and it is a reassuring link to my little girl. Isn’t it remarkable how even the stresses of being a care-giver can take on a positive light when we reflect on those days gone by?

None of us could or would ever forget our precious Batten kids, though we do inevitably move on. One opportunity that presented itself has allowed me to both get on with my life while still feeling a special connection to those “care-giving” days. That would be involvement in the volunteer program at the Cincinnati Children’s Hospital Medical Center. Since my time is spent with children in the bone marrow transplant unit, the patients may not exhibit the symptoms of Batten children. Nonetheless, many of the hurdles faced by the kids and their families are certainly familiar to all of us.

CHMC’s volunteer program provides for many types of involvement: reading to patients, playing games, crafts, making quilts one of which is given to every child upon admission.

As a former junior high school teacher, I found helping kids in keeping up with their schoolwork to be a natural. For many kids it furnishes a welcome diversion from endless hours of TV and video games. It also carries the implied message that “if they’re trying to keep me from falling behind in my schoolwork, that must mean that I’m going to be leaving this hospital”.

If I cannot be of help to my Carolyn anymore at least I can do so for these kids in need—and for their parents. The range of emotions reflected in their mom’s and dad’s faces reflect our past

experience. How we appreciated the efforts of adults who entered our children's lives in those fragile times.

I know I'm able to be of help to the kids and their families. What they don't know is that by allowing me to assist Carolyn's "buddies" they are helping me recapture a little ray of my sunshine.

"Thank you", Bob for revealing to us how your grief has been used in a positive way. We, as many other parents, are grateful to him for sharing and hope that some other parents may feel inspired, in time, to turn grief into hope and joy for others. Please send us your story to include here.-----Editor

CREATING YOUR OWN MEMORIALS (Joseph's Penfield—Grief Support Group)

We invite you to enjoy your own creativity. You may wish to adopt part of the traditions we have told you about, tailoring them to your family's tastes and needs.

You may wish to venture out on your own. The important thing is that rituals are part of learning to cope. We follow with a few suggestions for the Thanksgiving feast, Yuletide or the New Year.

Most of these suggestions are adaptable for any of the holidays or throughout the entire season. Developing a new ritual takes planning, care and love. The thought you put into it will reap you many benefits in the days ahead.

1. **THE LIVING CHRISTMAS TREE** to plant in the yard after the holidays. Invite friends and family to the planting ceremony and even follow with refreshments.
2. **TOAST YOUR LOVED ONE** using his/her favorite beverage with others or alone.
3. **BUY OR MAKE A MEMORIAL CANDLE** to light every day of the holiday season.
4. **PLACE A SINGLE FLOWER ON THE TABLE** in honor of your loved one.
5. **OBSERVE A MMOMENT OF SILENCE OR PRAYER**
6. **SPEND TIME TOGETHER AS A FAMILY WITH THE FAMILY ALBUM**
7. **RESERVE TIME TO TELL A FAVORITE STORY** about the loved one at the table.
8. **BUY A CHRISTMAS PRESENT FOR YOUR LOVED ONE** which is a gift for the home and will have a special meaning and place on future holidays.
9. **BUY OR CREATE YOUR OWN ADVENT CALENDER** which has a photo of family members, close friends behind each date. This tradition anticipates coping slowly, day by day as the season passes.
10. **CREATE LUMINERES** to light the sidewalk or driveway with a soft glow. These are a Mexican tradition, simple to

make and signify a warm welcome.

11. DECORATE THE ALTAR at church in memory of your loved one.

12. MAKE A DONATION TO CHARITY in the name of your loved one.

SNOWANGEL

Since Christmas is approaching I would like to present a portion of a piece written by Arnthrudur Karlsdottir entitled "Snowangel" expressing the feelings of a parent on the first Christmas following the death of the child. Fannar Bjarki was born Jun. 6, 1993 and was named Fannar because of the snow that night and Fannar means snow in English, Bjarki means tree. His name was a kind of poem of what his parents saw and remembered the night he was born.

"We like the snow, it is so pure and lightens up the darkness we have in wintertime. It reminds us of an beautiful brave boy who enjoyed the snow so much even when he was too sick to play outside.

Last three months have been very hard for us. Shortly after Fannar's death Christmas was coming and after Christmas it was the Millenium and then in the beginning of January it was Fannar's birth-day. How can we be happy when we miss him so much? We know he is watching us and we try hard to be brave like he was. Every day we think of him and we want to have him back but then we realize he would be sick again and we don't want that. This can really tear you apart when you grieve this much but still you are relieved that you child is not sick anymore and in no pain. We must trust in God, he will take good care of our baby from and it seem Fannar Bjarki is having fun as a Snowangel." ----Arnthrudur Karlsdottir

Thank you to Sue Sivulka for suggesting "Healing After Loss-Daily Meditations for Working Through Grief" and "I Will Not Leave You Desolate-Some Thoughts for Grieving Parents" both by Martha Whitmore Hickman.

WE REMEMBER

Time passes quickly, like before,
We are already in the month of November,
And you are not with us anymore.
But we still love you, as we remember.

The days have gotten shorter by a lot,
It is also, since a while, a lot colder.
But we still go to cemetery plot
Quite often, Dad and I, to remember.

Soon the snow will cover your grave,
The ground will be frozen over,
The fresh flowers, til spring, we'll save
When once again, we'll go there to remember.

But every day, be it long or shorter
We cannot leave it go by, without

Finding something to say “Do you remember?”
And that is what love is all about.

In Memory of Nancy, From Mom (Nancy Savoie)

In each issue of **THE LIGHTHOUSE** I will offer a review of a book or article that I have read and hope that some of the information might offer help and suggestions as you travel through your journey of grief. Everyone is at a different level in their travel so some of you will recognize that you’ve already been there and some will not have arrived yet. Perhaps you know of someone who may benefit from reading that segment and I hope that you feel free to pass it along, or keep it to read at the appropriate time in your journey.

In her book *PARENTING THROUGH CRISIS*, Barbara Coloroso suggests ways that parents comfort and nurture children, as well as themselves, through tough times—the suffering, adversity, chaos and losses that are a part of life. It moves parents along on the journey of integration, healing and connection which was begun in her earlier book, *KIDS ARE WORTH IT!*

Although this book covers other types of losses (terminal illness, divorce, different types of families, mistakes, mischief and mayhem) the first two chapters are: “Finding a Path Through Grief and Death: Helping Kids Mourn”. Emphasis is placed on describing “the TAO of Family”, TAO being the Zen Buddhist word for “way” or “path”. It is to be neither a source, nor an absolute; yields no truth or answer, and can be used again and again in different situations. The author’s TAO of Family is a way and a path. It includes 3 parts: 1. Time, 2. Affection, and 3. A sense of Optimism.

Parenting takes TIME. During a parents’ own grief it may be difficult to find time for their kids but they must, even if it is time to share in the grieving, lest the children become the hidden mourners. By spending some time with their children parents can help them handle their own mourning.

In times of grief affection each day helps everyone get through their own mourning.

1. a smile lifts spirits
2. hugs let everyone know they are in this together
3. hearty laughter can be contagious and provides brief respite from grief. Add to that unconditional love; to hang in there through good and rough times. Our likes and dislikes can be conditional but parental love needs to be something our children can rely on.

Optimism is not easy during times of great chaos and grief if it has not been part of our approach to everyday ups and downs. This is basically a grateful attitude and the willingness to look at adversity and adversaries from a new perspective. Anger, frustration, sadness and intense sorrow are not denied. Although we cannot always control what happens to us we can be in control of our response to it and how we use it.

By accepting realities for what they are, looking at ways to use those realities for good, and beginning to busy ourselves in solving problems they created we are helping to reaffirm our optimism. Each time optimism is reaffirmed a parent sets the example of a good way to approach adversity for the child.

In times of loss, suffering and chaos parents need to use a combination of mind, heart and intuition together to respond to their own suffering as well as their children’s grief in an active, self-aware, compassionate way. This combination causes not just a reaction but forms a powerful triangle of influence. Parents then become mindful with a wise heart.

Intuition helps us to know when to reach out or refrain from it; when to reach out or refrain from it; when to speak or be silent and when to hold on or to let go. As parents we need to continually rely on responding to large and small crisis with a generous spirit, wisdom, discernment, empathy, lots of kind-ness, mercy and compassion in the journey with our children through losses in our lives.

CHAPTER 2: DEATH; HELPING KIDS MOURN

Confronting the reality of death honestly and directly with children is difficult at best. Our society is basically “death-denying, fix-it-fast and cure-it-now” oriented which makes the task painful but necessary. That plus a variety of our own belief systems, feelings, faith traditions, morality questions, suffering and our understanding of the abilities of children to handle loss and grief can help or hinder us in the process of helping children mourn. No matter how parents try to conceal the loss or shield them, children will still grieve; but they will not receive the necessary knowledge and tools, comfort and support they need.

The Circle of Life

Before the death of a family member or friend a child usually learns first about death from everyday events. This can be the changing seasons, a dead bird in the yard or the death of a pet. Talking about the life cycles observed in everyday living matter of factly helps prepare for inevitable death of loved ones.

Inevitable questions that children ask about the basic attributes of death are more easily answered calmly in a setting of burying the dead robin than at grandfather’s gravesite.

The use of euphemisms may confuse or frighten a child. Dead is dead, not “just away for awhile” or “sleeping a long time”.

Even toddlers can and do mourn a death. Although they don’t have the language they have feelings and intuitive sense of loss. All children experiencing loss of a family member feel helpless and lost; however at all ages and stages of development a child has ways to cope with loss and is able to grieve.

Four year olds can begin to understand that living things have “beginnings and endings” and there is living in between as Bryan Mellome and Robert Ingpen wrote in their book *LIFETIMES; THE BEAUTIFUL WAY TO EXPLAIN DEATH TO CHILDREN*. Elliot Kranzer describes four attributes of death which are understood by children as young as five. They are:

1. It has a specific cause
2. It involves the cessation of body functions
3. It is irreversible
4. It is universal

As the adult and parent you may find deaths that you have not grieved as you explore the concept of death with your children. You may begin to reflect on how you learned about death as a child and this will raise questions you asked yourself then.

Passages Through Grief

There is no destination, arrival or ending place in the journey of grief. We have no map or formula to follow, ways to hurry up the journey or bypass the pain. There are passages we live through, each one at our own time in our own way.

Dr. Elisabeth Kubler-Ross has suggested we have two choices: “to live in grief, remorse and guilt--or to face those feelings, work them through and emerge with an acceptance of death and a commitment to living.”

In the journeys through losses we repeatedly experience three passages;

1. The piercing grief of good-bye
2. Intense sorrow
3. Sadness that shares space with a quiet joy and a gently peace.

At someone’s death we, and our children, need to go through these passages in our own time and way if we are to choose “an acceptance of death and a commitment to living”. It is possible to share our path with others (children as well) but we each must create our own path.

Passages are fluid, overlap, and don’t always occur in a set order. They can be present in one day or barge into our lives without notice even when we thought we had moved beyond a stage.

1. The piercing grief of good-byes

In this first passage numbness and shock provided by the body helps us to slowly face the impact of our loss.

In the first few days a child may feel isolated, confused, scared with routines upset and their lives alter-ed. Talk to them about what will happen the next hour, today, tomorrow, the rest of the week. Just as adults, children choose to be alone or not, they feel, think, eat and play mind games. The nature of shock is that logic makes no sense.

Share your feelings. Let your children express theirs as well as the real feelings of anger, rage and panic. Give them time to just be, cry, think, talk, question, complain and help. Your words can help them express their emotions.

Grief swamps everyone from the time of the death until the funeral or memorial service. The order and customs of the ceremony can help children find a sense of order in chaos. Children should be encouraged but not forced to attend the ceremonies, but it is important that you tell them what to expect: Who? What? When? Where? And How?, fundamental questions as the details relate to your cultural or faith customs.

Let children, even young ones, take part in rituals by drawing a picture or picking out a flower, help in planning by asking their ideas and respecting their thoughts and feelings that made up those opinions. Let them help in little tasks, answering the door or phone. Human touch can be a healing touch, helping both the giver and receiver. It creates a peaceful space for both.

At this time giving shelter to one another is important individually and as a part of a family and community. It enables the circle journey to slowly continue from piercing grief to intense sorrow.

2. Intense sorrow as we reorganize our life

As the reality of the death seeps into the bones numbness wears off and the mind is no longer on hold. Yet a dull constant pain replaces it.

The logistics of everyday routine, now changed, replace the chaos immediately following the death. Sorrow envelops with no respite in stone-cold grey-colored mornings, evenings and nights. The impact of the loss hits at every turn and now the first passage “Oh, no” reaction gives in to the nagging attempt to understand “Why”. This is fruitless. No amount of understanding will dull the pain. You have asked yourself that many times. When your children ask you they are not just

looking for an answer-and none will be good enough-but they are searching for ways to get rid of the pain and make sorrow vanish along with the grayness in their lives.

This sorrow needs to be expressed, can't be rushed or denied. This is the time to speak through art, poetry, dance, music, running through the fields, walks in the woods, along the beach or just being in silence at the table. Perhaps this is the time expression comes gushing silently through the arts and creativity springs forth from within you.

Often "Oh, no" turns to feelings of anger, which in and of itself is neither good nor bad. Anger needs understanding and expression in a healthy way. Children should be able to speak this anger to you without fear of being castigated or reprimanded. You can help them explore the roots of their anger when they speak it by asking:

"Where did it come from?" (Inside myself)

"Is it masking another feeling?" (Am I hurt, frustrated, disappointed or afraid?)

"Why be angry at all?" (I care)

After children explore the root of their anger they can judge whether the anger is an appropriate response-does it give them energy to take a strong stand on an issue or make some important changes that arise from a feeling of compassion or sense of concern. If so, the anger can be transformed into something constructive.

Children expressing anger in violent or aggressive ways only experience increased pain and suffering. Bitterness and pessimism develop from unexpressed anger resulting from feeling overwhelmed, helpless and being incapacitated.

Often going back over the questions and realizing the deeper feelings of caring and loss that are masked is constructive when you look at them with a wise heart from a different perspective. Angry feelings may dissipate and compassion is allowed to come through. Although compassion doesn't eliminate suffering it makes it more bearable. Children are enabled to avoid being overwhelmed by the loss and to continue their passage of grief.

People around you seem to pick up their pieces and go on with their lives. They often no longer seem to realize your need to tell of your loss again and again and get impatient with you. Be as patient with your children's stories as you wish friends and relatives would be with you. Both adults and children need others to listen, talk to them, hold and care for them.

First anniversaries—holidays, anniversary of the death and days of special meaning to you—will need to be gotten through during the second passage. Make plans to do something to help you and your children get through these days in a meaningful way. If you pretend the day is just another day you deny the loss and grief. Grief will still sneak up so you might as well expect and plan for it.

During this second passage we slowly begin to feel a desire to be done with disorganization, disorientation, the sorrow and pain. One way to move through it is to reach out to others who are suffering. This gives a reason to get up, get dressed and get involved in life again. You can put new meaning into your life knowing how helpless you felt and not wishing another parent that feeling. Older children may observe this and want to actively take up a cause that has personal meaning to them.

Courage is needed to travel through this second passage. Do not deny, inhibit or rush it. Confronting pain honestly and directly opens you to the lessons. It gives you the desire to let go of the intense grief and get on with your future.

3. Sadness that shares space with a quiet joy and a gentle peace as we recommit to life ourselves, tempered by the loss and wiser.

When you are tired of being tired, ready to go on with your life and no longer preoccupied with despair you laugh more. You are able to concentrate better and are moving into the third passage of grief signaled by not feeling bad for feeling good. Memories bring more warmth than pain and that relationship has “carved a holy place deep in your soul”. You can go there in quiet solitude that was elusive in the second passage.

You move from asking “Why?” to “What will I do now?”. Sadness is there sharing a place with quiet joy and gently peace. Children might move into the third passage before or after you.

They will need your support and reassurance that it is good to get on with their lives, but this doesn’t mean forgetting trivializing or getting over the death of the loved one. It does mean to always remember, honor the relationship, and know that one doesn’t get over a death-----but gets on with life.

Humor is the potent medicine for the heart, body and soul, releases tension, provides energy to deal with potentially overwhelming feeling and is life-affirming. It is a tribute to the one who has died and celebrates joy once shared. As adults use gallows humor to help handle grief our children may do the same.

No matter what discussion you have had with your children about death, there is no easy way to get through breaking the news. Use simple, honest words. Honesty doesn’t need to be cold, harsh and unfeeling. Your tone of voice, what and how you say it speaks with warmth, caring and sadness.

The use of euphemisms, platitudes and proclamations keep death obscured, mask the truth and don’t smother the pain. They do cover our own uneasiness with death and self-doubt about what we claim to be feeling. Thus we increase confusion and fear.

Children need gentle honesty, caring silence, headlines, facts, your presence to hold and cry with them. They need answers for their questions, although they generally are less interested in lots of details than knowing you will be there for them and their questions. Assure them that you will all get through this together; that you will cry, they will cry and you’ll even laugh and talk about the good times that were shared with the loved one who died.

Quoting Ms. Coloroso: “Time spent with our children giving them affection and optimism, even as our own lives are thrown into chaos and confusion, affirms that both grief and joy are vital and inevitable parts of life. Six critical life messages-the ones we often use to help our children get through the everyday ups and downs of life-now become our life raft as we are all swept up in this “tidal wave of grief”.

- I believe in you.
- I trust in you.
- I know you can handle this.
- You are listened to.
- You are cared for.
- You are very important to me.

The TAO of Family combined with these six messages becomes the TAO of Mourning.”

The TAO of Mourning as described by Ms. Coloroso will follow in the next issue of **THE LIGHTHOUSE**. It indicates 5 factors that greatly influence children’s grieving and positive suggestions for meeting the needs based on the developmental level of the child from the unborn child through adolescents. Ms. Coloroso concludes the chapter by presenting a checklist of warning signs that indicate a need for concern when grieving is no longer mourning. A short section dealing with suicidal deaths and resulting additional concerns for mourners follows but will not be covered.

PARENTING THROUGH CRISIS by Barbara Coloroso, Copyright 2000, Special Markets Department, HarperCollins Publishers Inc., 10 East 53rd Street, New York, NY 10022 ISBN 0-06-095814-6 (pbk.)

SIGNS by Lance Johnston

I am often asked if I have ever received a “sign” from my children after their deaths. I can honestly say YES.

Lorena died in Sept. 1993. Knowing that the first Christmas without both our children would be difficult, Elaine and I decided to go to California.

We ended up at Point Reyes National Seashore. One afternoon we were walking along the beach remembering how much Lorena loved collecting seashells and that there weren’t any for miles on this beach. Having said that, something caught my attention out of the corner of my eye. Unbelievably, there at the high water mark was a conical shaped shell the size of a baseball. It was the only seashell we found in three days of beach walking.

Two years later we were again at Point Reyes and as we were walking along a stretch of beach I said “Lorena, I’d sure like to find a glass float from a fishing net.” A quarter of a mile farther, there laying on the sand in plain sight was a heavy green glass ball used as a float for fishing nets. Coincidence? I think not. I believe Lorena was telling us she was with us.

Lee’s signs were different. As a boy and young man he loved wildlife, especially birds. Lee died in Sept. and his birthday was three weeks later in Mid-October. On his birthday I stopped at the cemetery on the way home. It was rainy, cold and blustery. I sat in the car for a long time just remembering. I noticed a squirrel coming down a tree about 60 feet away. It came across the grass towards me, stop-ped beside the car, sat up and just looked at me. After a bit it turned, ran back across the grass and disappeared up the tree. Odd, I thought.

A short time later I left and started home. Instead of taking the usual route home I went by back roads, driving slowly. As I was passing between two cornfields a big male pheasant walked out of one corn-field into the road and stopped right in front of me. I stopped and we stared at each other. Then it hit me. “I understand, Lee.” The pheasant then walked on into the opposite cornfield. It took Lee two tries before I understood that it was his way of telling me that he was OK.

For Elaine, his message has been different. Each year around Christmas a Cooper’s Hawk appears either sitting on the deck railing or in the Redbud tree outside the kitchen window. It stays there until it is assured that Elaine has seen it.

Then it flies away, not to be seen until the following Christmas time. Again, it’s Lee’s way of telling Elaine that he’s OK and he hasn’t forgotten her. I’ve heard stories from other parents, each carrying a special meaning and message from their child. Have you had similar experiences ?

3rd Annual “Life Goes On” Midyear Retreat

In 2005 during a National BDSRA survey of chapter needs it was decided that we as an Organization were leaving a part of our population out. The idea came up to do a midyear retreat at the same time as the National Board did their face to face meeting. This gives everyone the opportunity to meet members of the board and find out what is going on with the organization. Many families stop attending the annual conference after the loss of their child or feel there is no longer a place at the conferences for them. The Midyear Retreat gives us a place to share with others, someone to talk to, new bonds formed, and the healing process to begin or continue. Coming together to deal with the “life goes on” part of this disease, sharing the stories heartaches and help each other find answers to some of our questions about day to day survival.

Our first Midyear retreat was in February 2006 in Orlando Florida, we reached out to several families that had either never attend a conference or had stopped coming to the annual conferences for whatever reason. Being the first year everything was an experiment in what is needed and wanted. Some comments after that retreat were:

“What a great get-together it was the right time for me to reconnect with all of you. I’m richer this week for the experience with all of you.”

“The retreat was just what I needed having appropriate breakout sessions for my needs, great talking with old and new friends, the memorial service was lovely and I will most likely attend another retreat in the future.”

In January 2007 we held our second Life goes on Midyear Retreat. Again reaching families that needed the retreat to reconnect with others. It was held in Dallas Texas. We really had a good time sharing together and helping each other through difficult times. Some of the thoughts afterwards were:

“The retreat gave me an opportunity to share my experiences with people who truly understand because of their own similar experiences. It was a much needed emotional release for me.”

“The Life Goes On Retreat offered a tremendous opportunity for several things; 1. A unique environment where a single basis “the loss of a child” is the substance of commonality. 2. a chance to refocus, remember and relive the joy, sadness and special life of our child. 3. Time with my significant others to update our lives. 4. An environment where every emotion and thought was valid and there was a very relaxed association with people who understand.”

Our Third “Life Goes On” Retreat is again being held in Orlando Florida. The Renaissance Orlando Hotel Airport is very happy to host it this year. This is a different hotel then we have used in the past. There is a Reception on February 8th and the rest of the weekend (9th, and 10th) 2008, will be meetings and a memorial service. This is a very low key event and the only structure is what we make of it. Reservations can be made by contacting the Renaissance at 1-407-513-7222 or 1-800-228-9290 and signing up under BDSRA. The rooms are \$99.00 a day and the price is good for three days before and after. This is a Marriot Hotel so you can earn your points. To register for the retreat please contact Karen Upchurch at kupchurch@prodigy.net or call her at 727-894-4318 or 727-515-8359.

WE LOOK FORWARD TO SEEING ALL OF YOU THERE.



Children who have received
their angel wings in 2007.

John Potterfield

Rastego Howell

Adam Pederson

Kevin Duncan

Austin Simmons

Grace White

Jacob Ehrisman

Tyrel Witt

Logan Witt

Linda Sivulka

Amy Seerman

Lauren Parker

Joshua Spencer

Amber Whaley

Doug Schmidt

Kaitlin Middlemiss

Sandy Royalty

Linsay Wolter

Andrew Griffin

Derek Trimmer