

*The*  
**LIGHTHOUSE**

Winter 2005, Volume 8, Number 1



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

## **Reflections**

Looking back, I am aware of how much a part of Christmas Karen, Jon, and David are. It's January 8th, 2005, and the Christmas tree shines in the corner by the woodstove. Tucked in its branches are gold-trimmed hearts, framing the children's photos and shell and glass angels are hung in their memory.

On this snowy afternoon pictures flash in my mind of David at age 9, "I want to see Santa," he had announced. Who could resist those pleading blue eyes, now dimmed by Batten Disease? So on Christmas Eve 1976, behind the red velvet love seat, Mim, Dave and I were hiding, waiting for Kris Kringle's arrival. Stockings dangled off the fireplace mantle. Cookies, milk and a note were ready on the hearth.

Suddenly we heard the tramp of boots and jingle of bells. "He's coming!" Davey whispered. A tall lanky figure in a red suit arrived with a bag full of presents. "Ho, ho, ho, a note from Davey ", Santa exclaimed, "says he wants to see me." His voice sounded strangely like Mim's boyfriend. By now Dave's blond head poked out from behind the settee. He caught a glimpse of St. Nick filling his stocking. "Wow!" he breathed in awe. "That is Santa alright!"

Its memories like this that keep alive in our hearts the children no longer with us. Sometimes there are signs. In this winter edition of the Lighthouse, Sally Stockwell has written a gripping story in memory of Jessica (October 12, 2001) and Matthew (May 15, 2004) "One Rose and a Butterfly" reminds us of Emily Dickenson's words

"This world is not conclusion;  
A sequel stand beyond,  
Invisible as music,  
Yet positive as sound."

A wide selection of personal stories, poems, and informative articles on dealing with grief will help you on your journey. We're in this together.

**Connie Jackson, editor**

## **A Prayer for Courage**

God, make me brave for life,  
Oh, braver than this!  
Let me straighten after pain  
As a tree straightens after the rain,  
Shining and lovely again.

God, make me brave for life,  
Much braver than this!  
As the blown grass lifts let me rise  
From sorrow with quiet eyes,  
Knowing thy way is wise.

God, make me brave. Life brings  
Such blinding things.  
Help me to keep my sight,  
Help me to see aright,  
That out of the dark comes light.

**-Grace Noll Crowell**



*A butterfly lights beside us  
like a sunbeam  
And for a brief moment  
Its glory and beauty belong to our world.  
But then it flies on again,  
And tho we wish it could have stayed,  
We feel lucky to have seen it.  
-Author Unknown*

Through the glass I touch your face.  
I trace your beauty with my fingertip.  
I close my eyes and imagine you sitting next to me.  
Your head is gently resting on my shoulder like it used to.  
I feel your presence with me and I am at peace.  
If only for a few moments, it feels like you're back where you belong.  
Thru the glass I touch your face and I remember what you felt like.  
-**Laurie Lizotte, BP/USA, Bangor, ME**

## **Help for Grieving from “Help Along the Way”**

The person who is grieving has to create a set of tools that will help in dealing with the emotions that arise in grief. Some of these tools are:

- **Awareness**

Each day you can be in touch with what's going on internally and take whatever steps are necessary. Sometimes it is by choosing to be with others, sometimes it is by choosing some time alone. Keeping a daily journal has been helpful to many.

- **Support Groups**

Some choose to take part in grief support groups. When the people around you no longer want to listen, members of support groups are eager to be with others who know the intensity of the feelings.

- **Counseling**

Sometimes there are needs that are greater than can be satisfied in support group. In this case it is advisable to seek individual counseling as an addition to support group, or instead of it.

## **One Rose and a Butterfly**

**By Sally A. Stockwell**

A few years ago, I read a story about a young girl who was losing her mother to cancer. Just before her mother died, the girl had requested that she find some way to send her one red rose, if heaven was even more wonderful than they had imagined. On the day of her mother's service, an older gentleman walked in and placed one red rose in the woman's hand. When the girl asked him why, he replied that for some reason, he just had the feeling that it was something he was supposed to do.

At the time I had read that story, I remembered thinking that I was glad I didn't feel the need to receive some kind of "sign". I felt sure that heaven is an awesome place to be, and that my two youngest children, who were losing their lives to a degenerative disease, would be just fine when they went to live there.

However, on October 12<sup>th</sup>, 2001, a lot of the security in my faith was shaken when Batten Disease claimed our daughter's life. After bathing and dressing Jessica's body for the final time, while we waited for the funeral home to come, the nurse made sure that my husband, Mark, then I, had time alone with her, to say our last good-byes".

As I sat all alone on the bed with her, I held tight to the body that had required extra care for so many years and I realized that I didn't want it all to end. I couldn't imagine our lives without her quiet gentle presence. As I began to sob uncontrollably, I found myself whispering, "Jess, I think I'm gonna need one red rose. Otherwise, I don't know how I am going to do this." By the time the funeral home had taken her away, I didn't think anything more about what I had whispered in her ear.

When the day of Jessica's service came, I remember feeling like I was in the midst of a bad dream. While we greeted people as they came into the church, I didn't feel able to get through the day. Just shortly before the service began, one of Jessica's friends from many years prior, walked in with her parents.

Jamie and Jessica had spent earlier years together in special education classes, but after graduation, they were no longer in touch with one another. After her parents finished hugging me, Jamie's mom said, "Jamie wanted to bring something for Jessica, but she's not sure what to do with it, or where to put it. Will you show her where it should go?"

As I turned to look at Jamie, in her hand she was holding one red rose. It was exactly what I needed to help me through that day. But single red roses didn't end there. It seemed that each time grief sought to overwhelm, we received one additional red rose, from somewhere. Not two or three, just one.

This year, on May 15<sup>th</sup>, our son Matthew, also lost his battle with Batten Disease. Once again, we held to the hope we had, knowing that he, too, was now in heaven. Since I had shared about the red rose with several of my friends, one of them called one day, to say that she was wondering what special kind of comfort God would provide as He reassured us through grief of losing Matt.

On Memorial Day, Hospice held a special service in a beautiful garden, for all the families who had lost loved ones, this past year. The service concluded with a live butterfly release.

About two weeks later, as I sat on my porch, sobbing over the loss of Matthew, one little butterfly flew into the flower bed right next to the porch, and lighted on a flower that was growing at my feet. I was so amazed, because we'd been through a severe drought and it was the first one I had seen in over three years.

A few weeks later, when my husband and I made a trip to Yellowstone, we ended up stopping to sit at a picnic table, surrounded by patches of snow because we were at such a high altitude. Once again, our thoughts turned to Matt, and we both cried as we clung tightly to one another. As we began to dry our eyes, from nowhere, came just one little yellow butterfly, which proceeded to light momentarily on the table where we sat.

In August, we went to see the beautiful, new Batten Memorial that was unveiled in Kansas City. After lighting two candles at the memorial service, we received a blue and pink gift bag, for each of the children we had lost. A few days later, it was my birthday. My heart was breaking, as I pondered the fact, that from this birthday forward, both Matt and Jess would be forever absent from the celebration. I finally decided to look inside the gift bags that we had received. As I opened the boxes, inside, were two porcelain angels. Each one held a tiny glass rose and on each rose, sat one tiny, glass butterfly.

Once again, I had been reminded that Jessica and Matthew are more alive now, than their disease ever allowed them to be while they lived in this world. And constantly, we are reminded of the Heavenly Father who continues to love us through every step of the pain that this life has forced us to embrace.

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### ***Our Precious Children***

***There's a special group of children  
That society needs to be aware.  
That are still so very important  
Even though they are not here.  
The only thing that isn't here  
Are their bodies as we know them;  
We're left with memories and  
Filled with love we want to show them.  
So even though we can't reach out  
And kiss their beautiful faces,  
Their world must know in our hearts  
they always have a place.  
The tender tears,  
the memories we live with every day.  
Our precious children living in our hearts  
really haven't gone away.***

*Toni Hamilton, 1/20/92, TCF, McMinnville, OR*

## What's left?

When a child dies, you ask, among other questions, "What is left?" A beautiful, sensitive, intelligent child has died. What can be left after such a crushing blow? Others will point out that you have a spouse, other children or grandchildren, perhaps relatives or friends; they are left.

You read books of bereavement, scarcely remembering what you have read; you attend meetings, talk with others who have suffered a loss like yours. If you are fortunate, you have one or two friends who, while they cannot fully understand, are there to love and listen. Perhaps there is a therapist who guides you in your search for an answer. But for a long while everything you read or hear has little meaning and certainly cannot provide the answer to your question. Or can it? Does all that you have read and heard and experienced finally come together and answer the question of what is left?

For me it does. The answer was thirteen months in coming, but how clear it comes now. ***I am left.*** That's it! ***I am left*** and I have been left with the love of my child. It is a new love; it is different, more intense-it is understanding; it need not be reciprocated; there are no strings attached. I love this love of my child. It warms and comforts me. It is a wonderful love, but I cannot keep it to myself. I am left with the love to spare and love to share. It will never run out. My child will always be with me to replenish it. I have found my answer. ***I am left to share my child's love with you.***

**-Betty Stevens, BPUSA, Baltimore, MD**



## *The Beauty Places*

*Here she walked and romped about.  
And here, beneath this apple tree  
Where all the grass is trampled out,  
The swing she so loved used to be.  
This path is but a path to you  
Because my child you never knew.*

*“Twas here she used to stoop to smell  
The first bright daffodil of spring;  
And here she heard the robins sing.  
You’d call this but a common place,  
But you have never seen her face.*

*And it was here we used to meet.  
How beautiful a spot is this,  
To which she gaily raced to greet  
Her daddy with his evening kisses!  
You see there is nothing grand or fine,  
But, oh, what memories are mine!*

*The people pass from day to day  
And never turn their heads to see  
The many charms along the way  
That mean so very much to me.  
For all the things here are speaking of  
The babe that once was mine to love.*

*-Edgar A. Guest*

## **Release**

If I were to continue asking “Why?”

I might never:

- sleep through the night
- embark on a career
- smile and laugh with others
- see the sunshine or hear the birds
- give love to my cats and dogs
- trust God again
- get an answer

So I cry my tears and hug my memories and accept that for now I cannot know or understand.

And with this acceptance comes release to:

- sleep deeply
- work for my future
- enjoy life
- appreciate nature
- love our pets
- trust God
- accept what I cannot change

You'd be proud of me, Becky.

*-Angel Nettfelt, TCF, Regina SK, Canada*

**As I look at my beautiful broken shell,  
I see that it has nothing to hide.  
It doesn't pretend to be perfect or whole...  
its brokenness is clear for everyone to see.**

**May I have the courage to risk  
sharing my feelings with others  
so that I may receive support  
and encouragement along the way.**

**Lord, may I be strong enough  
to show my pain and brokenness  
like this shell. May I give myself  
permission to hurt...to cry...to be human.**

From “My Beautiful Broken Shell”, Carol Adams

## **Sibling Page**

### **Farewell to Childhood: Experiencing the death of a sibling as an adolescent**

Adolescence has been described as the “farewell to childhood”, as the teenager lets go of his or her childhood, grieves its loss, and begins to move into adulthood. Loss of a sibling during this period intensifies the issues related to the normal tasks of adolescence.

Adolescents are capable of an adult understanding of death, but the way in which they grieve is related to both children and adults. Since they have the capacity to think like adults, adolescents may suffer more from the effects of the losses the children, who are protected somewhat by their concrete or magical way of thinking.

The main difference between the grief of adults and children is the amount of power or autonomy the individual holds. Powerless children who cannot survive without an adult may not be able to seek sympathy, comfort and understanding from those around them. Autonomous adults can reach out for the help they need through counseling, church or support groups.

Like hermit crabs, which seek a larger shell because their old shell has become too small, adolescents, leave their childhood identity and seek an adult identity. Adolescents, however, are midway between the two domains. On the one hand, they have a strong drive towards autonomy and independence, and they may resent being over-protected by parents. On the other hand, the loss of a sibling is so intense that they may wish to regress like a child and seek support. This conflict is critical to understanding the unique experience of grieving teenagers who have lost a sibling.

Although adolescents know and understand mentally the reality of death, what makes grieving particularly troublesome at this age is the conflict in their feelings. They are just at the point where they are moving away from their families emotionally in the normal separation/individualization process we all go through to form a unique identity. They often appear to know everything and feel that nothing bad can happen to them.

Faced with the death of a brother or sister, however, the awareness of the reality of death and the subsequent sense of vulnerability shakes the very foundation of their still fragile identity. Not only have they lost a loved one, but they are faced with the reality that they, too will die some day. So, they desperately want to regress to get the needed support.

At best, this conflict in an adolescent's feelings is resolved by going to their peers for support. They can get support from their peers without having to regress to what seems to them as a childlike state, when they get support from parents. However, many surviving siblings have told me they could not go to their peers because they felt so different from them.

At worst, their grief is pushed underground and may result in disorders of conduct, such as the use of drugs and alcohol, poor school performance, loneliness, a tendency to withdraw from relationships, low self-esteem, depression, and difficulty in making long-term commitments.

-Pleasant Gill White, PhD

[www.thesiblingconnection.com](http://www.thesiblingconnection.com)

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### ***Please Ask***

*Someone asked me about you today and it's been so long since anyone has done that. It felt so good to talk about you... to share my memories of you...to simply say your name out Loud. She asked me if I minded talking about what had happened to you .or would it be too painful to speak of it.*

*I told her I think of it every day and speaking about it helps me to release the tormented thoughts whirling around in my head. She said she never realized the pain would last this Long...and apologized for not asking sooner*

*I told her, "Thanks for asking." I don't know if it was curiosity or concern that made her ask, but I told her, "Please, do it again...sometime soon."*

*-Barbara Taylor Hudson, Parents of Murdered Children, Cincinnati*

## **Sacraments and Stories...Opening My Eyes**

*(by Linda Tomasello, Bereaved Parents USA-Hinsdale Chapter)*

While Celeste was in the hospital after her accident, our pastor, Fr. Gill came when he could to be with us. He Blessed Celeste with the Sacrament of the Anointing of the Sick, a Catholic ritual that both prays for healing and prepares for death. Laying his hands on her head, he said a prayer over her and then anointed her forehead and the palms of their hands with a special oil called chrism. The ceremony gave me some comfort, a sense that she was now fortified for her tough struggle ahead. It also helped open my eyes to the sacredness intrinsic in everything that was unfolding around us.

Mostly though, when Fr. Bill was with us at the hospital, he just listened. He did not shrink away from our anger, our disbelief, our confusion, our despair, and our raw pain. When Celeste died that Friday, I know he felt our grief because his homily that Sunday was prepared with her in mind and included this beautiful imagery written by an anonymous author:

### ***Gone From My Sight***

*I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until at length she hang like a speck of white cloud just where the sea and sky come to mingle with each other.*

*Then someone at my side says: "There, she is gone!"  
"Gone where?"*

*Gone from my sight. That is all. She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear her load of living freight to her destined port*

*Her diminished size is in me, not in her. And just as the moment when someone at my side says, "There, she is gone" there are other eyes watching her coming, and other voices ready to take up the glad shout, "Here she comes!"*

*And that is dying.*

This little story offered a new way for me to think of Celeste's death. It gave me a hope that things may be very different than the way they seemed. I'm very glad I went to mass that Sunday. Thanks, Fr. Bill.

## **A Note to the Newly Bereaved (and a reminder to the rest of us)**

The first months and years after bereavement can be terrifying. It seems as if the pain stays at a mountainous peak; it seems as if one's mind will be lost at any moment. And although most of us "get better: after the first terror, we usually do not realize that until we look back, years later.

When we think about it, this state of affairs is almost "reasonable". After such an overwhelmingly traumatic experience, we can fall-as it were- to the end of the world. Coming back from there is bound to be slow beyond our imagination and fraught with reversals. So far, no one has found a method to avoid this painful journey back. But perhaps it will help to know you have already begun to travel. You will find it is a long journey and desperately hard and you may almost want to stay where you are. But you will realize later that the wind of tomorrow is already stretching your sails, and life awaits you across the sea. If you only knew....  
-Sascha-Twice-bereaved mother and a very prolific author and poet

**God Heals Through Faith.** As Dr. D. L. Dykes expressed it so magnificently in my mother's funeral service, a worship service:

God is on both sides of the grave. Death is not really death at all. Rather, it is movement from one dimension of life with God to a deeper dimension of life with God. He is the Father who loves his children and who has prepared a place for us. He is the Good Shepherd, and because of him, we can walk through the valley of the shadow of death without fear, for he is with us.

In many ways, it is harder to lose a loved one at Christmas. On the other hand, the message of Christmas is hope, it brings our glad tidings of comfort and joy, our good news. In his telling of the Christmas story, Matthew captures the message in one word: "Emanuel," God is with us. Christ came to underscore this "good news of great joy" that God is love, that God is with us, and that nothing can separate us from God-not even death!

This is our faith; this is our hope; this is God's promise: Emanuel, God is with us!

from "When Grief "Breaks Your Heart" by James W. Moore

## **The Face of Grief - Death**

***“What man is he that liveth, and shall not see death? Shall he deliver his soul from the hand of the grave?” Psalm 89:48***

A few years ago some English archaeologists exploring a cave near the site of an ancient Egyptian community came upon a carved coffin. It was the mummified remains of a little girl. When the inscription was deciphered it read “O my life, my love, my little one! Would God I had died for thee!”

The writer of an account of this discovery tells how these explorers “uncovered their heads and from the darkness of the cave went back with dim eyes into the blazing sunshine of the Egyptian desert.” This discovery reminded them again of one of the oldest of all human experiences—death and grief.

“We become shockingly aware that death is a normal part of every life. No life is exempt. Death is the most important thing to prepare for, discuss, and understand. Actually life is not lived to the fullest when we think of having it stretch on forever.... It is thrilling to know that I am in God’s powerful hands and sorrow cannot separate me from His love and goodness. What connections!”

The above words from a young mother who lost both her husband and a promising, cheery, blue-eyed child startle us to an awareness—an awareness of death as a part of life. Death is that which we do not want to discuss. Yet it is death which all of us shall face sooner or later.

Death is a reality for us. We must face it or we do not face life itself. No one can avoid the certainty of death. “Everywhere, every day someone longs for the “touch of a vanished hand and the sound of a voice that is still.”

An Eastern legend tells of a woman who lost her child. In her grief she went to the prophet and begged him to restore her child to her. The old man looked long and understandingly at her and then tenderly counseled. “Go and bring me a handful of rice from some house where sorrow has not entered and I shall grant your wish.”

Here and there she went but everywhere the reply was the same in every home was an empty chair. Slowly the sorrows of others touched her own sorrowing heart. Soon her sympathy went out to others. Not only did her own sorrow subside but she found again purpose for living.

Death is the most certain of all certainties. This fact must be faced with candor and faith. The ultimate hope of the Christian lies beyond death and the grave. The Christian lies beyond death and the grave. The Christian rests in the promises of God for eternal life. He does not look at death as the grim reaper, hooded and hostile, stalking mankind with a scythe. Rather death is the invitation to the fuller life. We cross the mysterious river to the other side with our hand in the hand of the One who said, "Because I live, you shall live also."

So we are called in death to think not so much on the lifeless body but on the liberated spirit. We believe as the Scripture says, "To die is gain." The Bible insists that "Eye hath not seen, nor ear heard, neither have entered into the heart of man, the things which God has prepared for them that love him."

Such hope does not remove the sorrow from the heart but it does remove the sense of dread and fear. It means that we do not sorrow as those who have no hope. We see it as Scott says, "Is death the last sleep? No, it is the last final awakening."

### **Prayer**

**O God, Creator of us all, we know, since the beginning of time, generation after generation has gone through the experience of death. Yet to each death is new. Thank You for the deep assurance that as we have trusted You for our salvation in life, we can know that to die is to be in Your presence. Amen.**

**From "In Grief's Lone Hour", John M. Deshcer**

**"O thou untaught! what manner is in this, To press before thy father to a grave?"**

**-William Shakespeare, *Romeo and Juliet***

*My heart...was an open, bleeding wound. I didn't need clichés. Most of all, I didn't need anyone telling me there was something wrong with the enormous rage I was feeling. My daughter dies in a mass murder, and I'm not supposed to feel anger?*

**-Susan Cohen - "Rage makes me strong"**

**From Care Notes Abbey Press with permission**

## THE GEESE AND I

It was a thrilling sight. Our flock of domestic gray geese were winging in for the night feeding, and the majestic grace of their flight was uplifting, stirring. Once again, winter had dropped a cold, cheerless blanket on the pastureland. All natural feeding areas had been choked off. For survival, the geese again depended upon their human providers.

For years, the providers had been my wife Frannie and me. Frannie loved watching the regal arrival. It was almost something spiritual for her. Even when she became too ill for the cold outdoors, she would go to a window and watch.

Last New Year's Day I was once more out in the snow covered fields, calling my searching cry. "Hey, boys! Come, boys!" Their familiar response came from somewhere on the farm.

On they flew. Some were at chest height, some above my head, all of them dropping their legs to break their speed and land at my feet. Now we were all waiting respectfully for the old gander. No one ever stirred or ate until he arrived. There was a reason.

On a windy day the previous October, a stray bird dog had savagely charged into the flock. In a wild flurry, the terrified geese had all scrambled or flown to safety—all, that is, except the old gander. A leader does not run. Undaunted, he lowered his head and spread his wings to meet the challenge. Standing his ground, he hissed at the predator that threatened to destroy his wards.

The battle raged for just a few moments, the gander beating off the dog with blows from his powerful wings. But in the fight, one of those wings was broken. Quietly the old bird slipped into the farm pond, there to remain alone for three weeks until nature's healing hand restored him to his position of leadership in the flock.

That New Year's Day I watched the injured gander respond to the feed call. he could not fly, but he used his good wing to hop across the snow to where his followers patiently awaited him.

As I watched, an odd thought struck me. We were both cripples, the gander and I. He was grounded by an injury. I was grounded by grief. Back in May, my precious Frannie went to Heaven after a two-year struggle with cancer.

Seven months later, I was still sorrow bound. How could I ever fly again? My hurt was too paralyzing.

But now the old gander's struggling approach was flashing a clear message. Yes, fate had been cruel to him, but with determination and instinct he was carrying on. I, though blessed in faith and intelligence, was helpless because I had been unwilling to be reconciled to the perfect will of Providence. And the firm foundation laid by His sustaining Word was all but ignored.

Suddenly, by observing the gander, the full light of conviction shone on me. Quickly a lifting was granted on the wings of penitent prayer. I was upward bound far above the deep abyss of sorrow. And I could hear the feed call, "Come unto Me. Come unto Me."

Clear and strong I was hearing My Provider. And I was obeying-I would fly again.

**-From "Life After Loss"**

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**Being a Friend to a Friend in Grief**

**Sympathy is for the living.** The letter that touched Marilyn Helleberg most deeply after the death of her mother was the one that evoked a happy memory. Relief from the numbing pain of grief can come through a comforting image of the loved one *in life*. In a letter of condolence, it doesn't need to be much. If you have never met the deceased, a letter sharing you're your friend's sorrow is enough. A few words will do.

**Friendship is a welcome comfort.** Just as we don't philosophize with our friends in happier moments, lengthy advice isn't helpful during times of grief. Watch our for clichés like: "I'm sure you'll feel better in time," or "After a while you'll forge," or "Don't worry. Everybody goes through this." On the contrary, no one feels quite like the one in grief. A listening ear from a quiet friend says more than words can ever tell.

**From "Life After Loss"**

**NOTES OF JOY** by Marilyn Morgan Helleberg

I sat at my desk, trying to write thank-you notes to the many people who had sent flowers and cards and letters when Mother died, but the pages kept blurring as I blinked back tears. People had been so kind. Their letters were laced with such caring words as “Can’t tell you how sorry I am”...”Our prayer in your time of sorrow”...”Words can’t express how sad we were to hear”...”The poor dear, how she must have suffered”...

I really appreciated such loving concern, but the more I read, the deeper that blade of grief stabbed into me.

Then I picked up the letter from Mom’s roommate at that little Baptist college in Kansas:

“ Whenever I think of your mother, I remember the day we went canoeing with our dates on the little lake by the campus. We spent all morning getting ready. Helen had curled her hair with the curling iron and put on her band-new white organdy dress, and she looked like a princess. It was a delightful spring afternoon, but we were all pretty stiff. The fellows were so proper and polite, and we girls were trying so hard to be as coy and prim as we could. Then, as Helen climbed out of the canoe, she missed her young man’s outstretched hand, the canoe tipped, and in she went! If it had been me, I would have cried on the spot, but not your mother. She just stood there, her soaked organdy dress clinging to her like a kid glove (she was so skinny in those days!), and we all laughed till the tears rolled down our faces! What a joyful sound that was!”

Well, that picture of my mother at such a happy, fun time in her life got inside of me, and I laughed, too, even in the midst of my grief. There she was, young and pretty again, instead of gray and bent and wrinkled. And happy and laughing, instead of moaning in pain. It was as if I’d been given a glimpse of the past and the future, too, because that’s the way I want to think of Mother, always.

From now on, whenever I write a note of condolence, I'm going to try to think of some happy incident to recount, and tuck it in with my words of sympathy, because I know what a joyful sound such words can make in a grieving heart.

Of course, a letter can't *erase* grief, but I've found my mind returning to certain special letters I received, because they gave me specific things to take hold of when I felt the currents of grief pulling me under.

Probably the worst part of my early grief came with the realization that I'd never again be able to see or touch or talk with my mother. There was a letter, however, that helped me with this. It came from an elderly lady who'd had a stroke and could only write laboriously with her left hand. She'd managed to write just five words at the bottom of a sympathy card: "You will see her again." No fancy words. No sermon. Just a simple statement of fact, but it was a truth I desperately needed to be reminded of at that dark time. How often I repeated those words to myself in the early weeks after Mother's death-and what blessed comfort they brought!

On top of the sense of loss, I also had some guilt feelings when Mother died. She had called, the week before, and asked us to drive to McCook (about 100 miles) for the weekend. We were very busy at that time, so I promised her we'd come the following Saturday, but, for Mother, Saturday never came. She died on Wednesday, and I wept remembering how disappointed she had sounded when we postponed our visit. *if only I'd known, if only I had canceled our other plans, I could have seen her again, if only....* The guilty thoughts just wouldn't leave me alone.

I've since learned that such feelings are not unusual, that almost everyone who loses a loved one suffers some feeling of guilt. There's always something we would have done differently if we had it to do again. That's why the letter from Mother's friend in Colorado meant so much to me. She wrote:

“Your mother often mentioned how much she appreciated your devotion to her. She was especially grateful that you gave up your vacation plans to take her to Mayo’s that time. “

Those words seemed to put things in perspective again, and I could see that, although I hadn’t been a perfect daughter, Mother really did know how much I cared about her.

Finally, there was the letter from Mother’s lifelong friend who, though she was grieving, too, was able to see the future through positive eyes:

“Your mother will always be a part of me. Whenever I see bright geraniums in a window box, or notice someone wearing a hand-knit sweater, or fix her back bottom pie recipe, or sit on the porch to watch the sun set, I’ll think of her and feel the touch of her life on mine. When I sit in church, I’ll look at that fifth pew, left side, and I’m sure I’ll feel that sweet spirit of the one who sat there so faithfully for years.”

I think what made this letter so helpful was that Mother’s friend had taken the time to single out some of Mother’s special interests and to show me, in this way, that her influence would go on, even though she was no longer here. The message was so *personal*, because it could only have been written about *my mother* and no one else.

Looking back, I can see that there was one thing all of these special letters had in common—one thing that made them stand out from the other expressions of sympathy and hold out a truly comforting hand to me. *They all focused on positive things.* I used to think letters of condolence had to be somber and mournful in order to show respect for the grief of those who had lost a loved one, but now I know that isn’t so. A caring letter that sounds a joyful note can offer the greatest solace of all.

I know because sometimes, when I’m feeling lonely and missing Mother, I think of that letter from her college roommate. Then I begin to sense that somewhere, beyond time, beyond space, there’s a skinny girl in a white organdy dress, making a joyful sound unto the Lord...forever.

## **Mourning the Loss of an Adult Son or Daughter**

*by Carol Luebering*

You hovered over the crib to check the rise and fall of an infant's chest. You held your breath when the bicycle first rounded the corner and disappeared. You fretted over violated curfews and the smell of cigarettes or alcohol. Finally, you breathed a sigh of relief because the focus of all your worries had safely reached adulthood. And then the unthinkable happened. An accident, and act of violence, a terrible illness struck, and the person you nurtured through the perils of childhood is dead.

**Working your way through** “Would I had died instead of you, O Absalom, my son, my son!” So wept King David of Israel when news of his adult son's death reached him (2 Samuel 18:33). So have grieving parents wept through the ages. You are not supposed to outlive your child. At the root of the overwhelming pain you feel lies the conviction that you, not your child, should have died first.

I realize that this CareNote will not relieve your pain. I can only hope to address some of the particular needs that attend the death of an adult daughter or son. May you find it useful in your pain.

**Expect slow—very slow—healing.** Grownup kids are a special delight. Overnight, defiant teens turn into likable adults. Many of them leave home, get jobs, go away to school, start families of their own. The hurts you may have inflicted on one another during the growing-up years often begin to yield to new appreciations. You can enjoy the opportunity to come together in a new way, in an adult relationship—in short, to become friends.

Death shatters that unfolding relationship. This time your son or daughter is really gone. And so is what was supposed to live on after your death: the genetic heritage you passed on, the mannerisms and the values your offspring picked up from you.

Not even death can change the fact that your child, whether born of your own flesh or made yours through adoption and nurture, is part of you. You invested much of your treasure—financial, emotional, spiritual—in this person, and you cannot recover from such a loss overnight. Recovery will take years—and, in a sense, you will never fully recover.

One woman whose daughter died seven years ago puts it this way: “My nephew lost a leg 20 years ago. At 43, he lives a full and active life without it, even though he limps a bit when he is tired, even though he still feels pain. Losing my daughter has been like that for me. At first I couldn’t bear to put my feet on the floor in the morning. It still hurts. Sometimes the pain is sharp, sometimes I limp quite badly. But, I go on. Sometimes I even run or dance.”

**Find support wherever you can.** “No one knows how I feel” is the common complaint of grieving parents. And it’s true: No one does. Neither did you until the day death took your son or daughter. Such a loss is beyond the reach of a parent’s imagination. We can go so far, and then our minds shut down in the face of the unthinkable.

Some of your friends--the same people whose presence was such a comfort at the funeral—may well begin to avoid you as though you carried the plague. They may grow uncomfortable if you mention your child’s name. They don’t always understand your need to keep the memories alive. Some will be so afraid of making you cry that they won’t let you cry.

Neither can you necessarily count on your family—not even your spouse, if you are married. However tightly you may have clung to one another at the time of death, each of you mourns a different person. Your son’s relationship with his mom was not the same as with his dad. Your daughter was dear to her siblings in varying degrees and for various reasons.

Each of you will handle your sorrow in a uniquely personal way. One of you may need to talk, the other to be alone; one to cry, the other to rage.

Some people find great comfort in their religious traditions; others can only shake a fist at God. Your spouse may crash on the day you feel up to an outing. Old sibling rivalries may surface among remaining children, if there are any, as they begin to wonder if you care whether they're still around. And no one knows what to do with an approaching holiday.

Support groups for grieving parents can offer comfort. Your church community may be able to link you with someone else who has been through a similar loss. Most grief therapists will adjust their fees to meet your budget, although finding one with whom you are truly comfortable may take some shopping around.

Finding support requires a lot of effort at a time when putting your shoes on in the morning seems effort enough for one day. But in the long run, it is well worth the work. the support can be a lifeline.

**Claim your heritage.** From the moment you began to anticipate your child's arrive, you dreamed of all you would share with him or her. Now it is your turn to be on the receiving end. Your son or daughter has left a heritage for your—everything his or her life meant.

The people your daughter or son may have added to your life, such as friends, a spouse, or children, are a very important bequest. You will want to keep as close as possible to those who possess this bank of shared memories. To lose a relationship with your child's closest friend or life partner would only double your tragedy. Nurture the ties with care.

At the same time, allow your child's loved ones the freedom to get on with life in their own way—even when that is hard for you to do. When Dottie attended her daughter-in-law's second wedding, she wept throughout the ceremony. "It was the hardest thing I've done since we buried our son," she admits. "But it would be harder to lose her, too." The new husband eyed her warily at first, but now Dottie is an extra grandma to the couple's toddler.

If your child had children, these grandchildren are a precious legacy as well. Not only do you need them to keep your place in the chain of generations, they also need you to keep them in touch with their roots. No one else can tell them about Dad's childhood interests or when Mom's sense of humor first emerged. No one else remembers their ancestors or what life was like in the "olden days."

Find a way to touch others' lives with the legacy of love your daughter or son left you. Some parents adopt their child's interests. Harold and June began a scholarship fund for gifted music students at their son's high school with memorial gifts. Cathy coordinates the schedule of volunteer reading tutors on the school where her daughter taught. Sam devotes his spare time to training young volunteers at the local science museum, his son's favorite haunt.

Death, as well as life, can give you new direction. When someone asked Mario to collect donations for the American Cancer Society in his neighborhood, his first response was bitter. Why should he help someone else live when the disease killed his daughter? But he's now an area coordinator. Latoya is active in MADD (Mothers Against Drunk Driving), founded by a woman whose daughter, like Latoya's, was killed by a drunk driver. Susan, whose son was shot in a holdup, works for handgun control.

**Take Heart.** You buried a part of yourself with your daughter or son, and the loss will ache for a very long time. Nonetheless, your adult child will always be a part of you, living in your memories and in your heart. Better than any of the people who offer you the cliché, you know that the value of a life cannot be measured in years.

*The early months of grief are characterized by disorientation and emotional numbness, volatile emotional swings, loss of appetite, inability to sleep, and loss of short-term memory.... One of the first questions parents ask.... is: "Is this normal or am I going crazy?" One of the easier tasks in working with bereaved parents is to assure them that what they are experiencing is normal and that they need not waste energy on the fear of craziness.*

-Dennis Klass, Ph.D. - Parental Grief: Solace and Resolution

## **Remembering Our Absent Family Member(s).**

### **Scholarship.**

The gift of education a needy student in memory of a loved one is a wonderful way to perpetuate the deeper values in our society. You may wish to establish a fund that grows on a yearly basis, or make a one-time award. You may be as specific or general as you wish when you establish the guidelines for receiving this honor.

### **Shadow Box.**

This project is one the children will cherish. Ask each contributor to find a special piece of jewelry, a trinket, or some other small object which reminds them of an event, talent, or funny moment about your loved one. Collect them in a shadow box—a wooden box made up of small compartments in which you can display miniatures. You can set the shadow box up in a prominent place in your home, where it can become a center of discussion when guests arrive. Not only will you enjoy recalling stories about your loved one, but this will let your friends know that you want to talk about the person who has died.

### **Story.**

Take time to tell your favorite story about your loved one. Stories build legends, which pass down values from generation to generation. You may want to gather these stories and put them in written form so others may read and enjoy them.

### **Table Setting.**

The meal is a time of gathering, nurturing, and sharing. Whether your table is set with paper plates or elegant china, the table is a powerful place of memory and, often, pain. It is especially difficult to know what to do with the place at the table where your loved one used to sit. You may wish to set that place and leave a single flower or an empty glass to signify the presence in spirit of the person who died.

## **From “Holiday Help”**

August, 1976

Dear Sarah:

*I will never be exactly the same, but I know I am ready to go on. Even though our love stretches beyond any grave, my life here is without you. You’ve become the seed of a new beginning, somewhere I’ve yet to know. I still cry for you and your daddy, and maybe that will always be so. Some days and some times may always bring tears. I understand and accept that as part of love. But can you see what I’m trying to say: I’m saying goodbye.*

*Do you remember, from our trip to the ocean, the way the water yields the sunlight in the morning? It contained it, and yet never possessed it for it for its own. I will always hold you as the ocean holds the sunlight. I hold the lullaby we sang together, your voice so little and clear. So say a prayer for me. As I say one for you. And let go.*

From “Song for Sarah” by Paula D’Arcy



***Undertake new activities and create new rituals out of the past. Through them you can maintain the memory of your loved one, Even as you embark on a different chapter in your life.***

## **Do It Your Way-Mary Cleckley, BP/USA, GA**

It is not possible to lose someone as vital as one's child and not have the pain of deep grief. You will find a great many non-bereaved people who will encourage you to play the old game of, "If you'll pretend you're OK and it's not really so bad we'll let you come play with us. But if you're going to cry and talk about your dead child, then you can't play."

This is one time in your life you don't have to meet anybody else's standards. There is nothing more unique about you than the way you express your grief- and you have the right, however it is manifested. A real deal of how you go about it is determined by how you have handled previous losses.

So if someone tries to influence you to play the old game by rewarding you with attention because "you're doing so well", tell them you're not doing well. Tell them your child has died and you're hurting. Let them know it doesn't help you for them to pretend everything is OK. Do whatever it is you need to do to survive this trauma and don't worry about whether it pleases or displeases other people. **DO IT YOUR WAY!**

**The Batten Disease Memorial was unveiled and dedicated at the conference in Kansas City last year. This year the Memorial will again be at the conference and new names will be added. If you would like your child/ren's names included on the Memorial, call the BDSRA office at 1-800-448-4570 or email [bdsrc1@bdsrc.org](mailto:bdsrc1@bdsrc.org)**

**In closing: Why not send a long something you've read that has touched your spirit? Or a memory of your special child? Your personal touch can make the Lighthouse special.**

**Peace and joy.**

**Connie Jackson  
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