

The

LIGHTHOUSE

Winter 2008, Volume 12, Number 1



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Batten Disease Support and Research Association

FROM THE EDITOR

The holidays of Thanksgiving, Christmas, Winter Solstice, Kwanzaa, Hanukkah, and others with various customs and celebrations are now behind us. The New Year has begun and we are looking ahead to Valentine's Day, Lent, and Easter celebrations, Passover and the beginning of Spring. There will always be birthdays and other special days we want to observe and remember. It might be necessary to create some new traditions and ways to celebrate our lives as we continue on the journey of grief from the death of loved ones.

Although these holidays that are ahead of us are of a different meaning, they will nevertheless require some planning and thought as to ways we want to institute in our lives, and families, meaningful traditions. Let us remember that the New Year and Spring is a time of new beginnings. We will have constant reminders of this in the natural world around us. And, Nature will sleep in grayness and cold awhile longer, just as some of us continue to have periods of crying and sadness as we search for understanding and significance in the grief process. Perhaps for some of you this is the ideal time to begin to take the next step in your individual journey of grieving. Do not be concerned that everyone around is at this step. Try to remember that every person and every life is individual.

I have tried to submit a variety of articles written by persons familiar in counseling and alternative ways that others deal with grief. This is in no way intended to influence or be judgmental of any person's method of handling their own grief. It is simply intended to present ideas for those who are possibly at a crossroad in their life and searching for healing of their own grief and loss.

In this February 2008 issue I have several articles submitted by family members whose children or siblings have died. I want to thank every one who has taken the time to express their feelings and thoughts to share with us through their articles. As you read through this issue I hope that you may want to express yourself in some way—a story remembering your child/children, a poem, or sharing a book or article that has been helpful to you. I welcome anything that you wish to contribute and encourage you to attempt to put your feelings on paper. There is no right or wrong in expressing your emotions/feelings, or sharing something special that you remember about your child/children. Please feel free to send your contribution, (or those of your children or other family members to me. You may send them to Ann Salladin at either my email: aswildchild@yahoo.com or to my attention for THE LIGHTHOUSE, B.D.S.R.A. office or email: bdsral@bdsra.org. Again, if you wish to speak with me please call me, or leave a message, at (614) 755-2986. To submit it directly to me at: 1194

Foxcreek Lane, Reynoldsburg, OH 43068. Please try to submit it to me by mid-April for the May issue.

May the New Year bring you peace, comfort and solace to your aching heart.



Cry. Your tears testify to your love. And tears that spring from love help bring healing and renewal.

REFLECTIONS FROM CONNIE

It's an amazing thing how grief for a child who died 39 years ago can suddenly surface. I'm thinking of Christmas morning 2007. The clan was gathered, 13 of us, in the family room. Peach, my 15 year old granddaughter in a Santa hat, was distributing presents. "Here's one for you, Gram", she said, passing me a small package from my daughter Cathy.

I could feel the frame and glass under wrapping paper. "A new photo of my grandkids", I guessed. What was this? My eyes gazed in wonder at a picture of Mary holding her son Jesus, a baby, perhaps three months old. Her shadowed face depicted a mother's love as she tenderly kissed his cheek. He responded with a little smile and sparkling eyes. Mother's hands, drawing him close, spoke of her strong protecting instinct.

Suddenly I was drawn into the scene. I was holding newborn Karen, born Dec. 12, 1968, my first child, a miracle of delicate beauty. The poem, published in the last *LIGHTHOUSE*, described the love and hope and awe I was feeling. Tears flowed, unchecked. I was speechless. Laurel, my new daughter-in-law, looked over at me, eyes brimming. I knew she understood.

Now I am holding in my hand the artist's portrayal of Mary and baby Jesus. Was there a shadow of suffering to come....At the child's

dedication in the temple. Old Simeon had looked directly at Mary when he prophesied: "A sword shall pierce you own soul, too."

That Christmas morning kinship happened between Mary and me. It was the bond of pain and love that only a mother who had lost a child could feel.

Connie Jackson

Life after 5-09-07

May 9th is the day that we lost our beloved Angel Linda to the Lord. She had Battens, of course, but in the end, sepsis is what she succumbed to. Thinking back, what a blessing that she went the way she did. God knows best, but he must have known how we were all suffering with Linda and no more seizures. The morning of the 9th she arrived at the hospital not breathing, but was resuscitated. Within 2 hours the doctors told us what was wrong and she probably wouldn't live through the day. Though all through that awful day the nurses were never able to get a blood pressure or pulse, during the first few hours she lay with her eyes open holding our hands and responding appropriately with a nod or shake of her head. So our last memories of Linda will always be those beautiful blue eyes, so clear and free from seizure activity, looking at us as if knowing she was going to die and wanting to say see you later. What a beautiful thing it was.

So now we go on with our lives, learning to live in a different way as before our lives were always planned around Linda. I miss it still, even though at the time lots of times it was so hard. She was 42 when she passed away, and lived in a long term care facility for 6 years. That was a daily challenge, as well, as she was there because we were no longer able to care for her, but wanted to be as much a part of her life as possible.

Most of my support during this grieving process has come from reading many books, both religious and inspirational; maybe one of the ones I enjoyed the most was "Chicken Soup for the Grieving Soul". I went to a few grief support group meetings but found them not to be as helpful as I had hoped so found my own ways. Joe, my husband found his most helpful thing was WORK. He has always been what I call a work-a-holic, so that's how he dealt with losing Linda... On what would have been her 43rd birthday, we all gathered at her gravesite, sang Happy Birthday and released purple balloons, her favorite color. At Christmas we changed things around a bit by going to a different mass than we usually did. We have a 21 month old grandson, and he was a wonderful help by just being himself. What a great thing it is to see little children's eyes light up during this most special time. We also have a 18 year old grandson and a 14 year old granddaughter, AND a new grandchild expected in July. So these all made the Holiday Season a little bit easier to get through. We decorated her headstone and gravesite as well, and I made ornaments to give to all of our relatives and friends [2]. I also made the Christmas cards we sent out. We

received many special cards from friends and family, but one especially was sent by the 9th grade CCD class at our Church.[1] Now it's 2008, a new year and new challenges, but we will deal with them as they come.

I hope this has helped someone deal with their grief, and I would be more than happy to talk to anyone who would like to share their stories of their loved ones. Oh, what heartache it is to endure, but I wouldn't change anything if it meant I wouldn't have had all of the happy times that we did have with Linda through the years. She will be forever missed and in our Hearts.

Mom, Sue Sivulka
262-835-1364
soo43@msn.com



Stay connected to others. You need their presence, their support, their concern, their listening, their hugs.

In Memory of My Precious Son, Michael

Each year as I anxiously approach the anniversary of my son's death I desperately hope to honor his memory in a special way. On January 11th it will be 11 years since his death. As the day approached this year, two significant things happened that allowed me to do just that, honor his memory...

On Monday of this week I was presented with my "10 Year Pin" in recognition of the years that I have served the very population that my son was once a part of, and it was even presented to me in the very building where he attended school for many years. What perfect timing. And the second was to submit my story. The last thing any of us want is for our child life to be forgotten. They were here, they were and still are loved, and their lives did and continue to have purpose!

So today I have the privilege of continuing to live out the legacy of my son and many others before him. They fought the good fight. Michael was my teacher and my hero! He taught me the true value of life, that it is a gift from God, and is to be lived with purpose and appreciation. We are to honor our Creator with this gift of life. We know too well that there are no guarantees and that we must not take the precious lives of our children for granted. They are a blessing, a very different kind of blessing.

I consider it a privilege to do the work that I do working with children with special needs. Each day is a new challenge and a new opportunity to be a part of building up these children and assisting them in reaching their highest potential. It is also very important to me to reach out to parents with respect and empathy, for I was once there. I have felt the frustrations and fears that they have felt day to day. I feel I am more able to connect to the hearts of the families because of my own struggles. I know they want so much for their children, but must continually accept that they are limited. I am forever thankful for those who came along side of me to guide me through. I hope I can pass this along in my work. This is one of many gifts from Michael, the gift of empathy.

On June 22nd 1976 I gave birth to my beautiful son, what a joy! And what a blessing! It's difficult for me to imagine that Michael could be 32 years old. Sometimes I imagine his peaceful presence and I am comforted. Some days I miss him so much I can hardly stand the pain of knowing he was here with me and then he died. There will always remain a void in my life, but I know I will see him again, and until then I hope to continue to honor his life and give thanks to God for the precious gift of "him". His life was complete; his purpose is being lived out and continues to be through me and those who loved him.

I no longer hold him in my arms but he is safe and free in the loving arms of his Creator...

I Love you Michael, forever unto eternity

The above was submitted by Lita Ciacciao. I am so grateful to her for sharing her thoughts and memories with us.

As you read **TODAY'S INSPIRATIONAL STORY** from Beliefnet.com you will find things that have both helped and not-helped a grief counselor at the death of her own child. Perhaps you might be able to relate to this and they could become suggestions that you might ask of your friends and family at the appropriate time in your journey.



Your loss is not God's punishment or God's attempt to test you. Know that God shares the hurt in your heart and wants to lead you to new hope and peace; know that God grieves with you.

GRIEF COMES TO THE GRIEF COUNSELOR

A pediatric chaplain receives helpful tips on grieving the death of a child. By Norris Burkes

It's a terrifying and morbid thought, but in my line of work it's sometimes impossible to keep it at bay: I've wondered what I might do if one of my children were killed. I've wondered if I could somehow miraculously remain a minister and comfort those who were also grieving horrific losses? I'm grateful I haven't had to endure that experience but I still wonder.

I'm sure my friend Sue Wintz wondered too. Like most of us who serve as pediatric chaplains, Sue has long known the meaning of the scriptural admonition foretelling the "rain on the just and on the unjust" (Matthew 5:45 NKJV), but somehow she'd always managed to carry a good umbrella.

Then, on December 2, 2003, Sue's seventeen-year-old daughter, Sarah, was killed in a car accident. As they struggled to survive this unimaginable blow, Sue talked to me about the ways she and her minister husband, Mike, have learned to better align their professional roles with the lessons they've learned from losing a child.

In the days and weeks after the accident, Sue said, "We didn't sleep or eat; we felt like we were in a fog. I had absolutely no idea how deep and dark the hole of parental grief would be."

Yet, despite the fog, the Wintz family knew, from her professional perspective, that their "feelings were normal and OK," she said.

But the heartbreaking ordeal also demonstrated to her that some professionals “just don’t get it sometimes.” In fact, a day after the accident, one colleague told her, “You aren’t reacting very professionally.”

Some even told the Wintzes their grief should be “over” in a matter of months, and soon those acquaintances stopped mentioning Sarah by name. Unbelievably, one colleague even told Sue, “The honeymoon year” is over, so you should move on.” Sue described these people as “toxic” and noted that grieving parents become very adept at recognizing the ones who are helpful “and the ones who should be avoided.”

Gradually Sue has regained some of her former confidence. “I was a good chaplain before my daughter’s death,” she said, “but through our experience I’ve learned some things that did and didn’t help.”

Twenty-five days after Sarah’s death, Sue listed those things in her journal. And now, she’s asked me to share part of that list with you.

HELPED: People who checked on us without an agenda and took care of details like answering our phone, keeping lists of what people brought, cleaning our house, and making sure our cars were running well.

DIDN’T HELP: Trying to micromanage aspects of our grief by telling me when I needed to eat and rest or take anxiety medications.

HELPED: Food brought every other day, beginning the second week of the accident.

DIDN’T HELP: So much food brought all at once.

HELPED: People telling me, “My child died too. I’m here for you.”

DIDN’T HELP: People claiming to know how I feel because their father/friend/dog died.

HELPED: The hundreds of people who came to the service and our amazing son, who put together the slide show of Sarah’s life.

DIDN’T HELP: Giving me advice on when I needed-or didn’t need-to go through Sarah’s room and things.

HELPED: Carolers and Secret Santa gifts. Sara loved Christmas.

DIDN’T HELP: Telling me I needed to realize there are also “others having a bad time in their lives right now.”

HELPED: The people who listened and never told us to stop crying.

DIDN’T HELP: Questions asking us who was at fault in the accident.

HELPED: Taking me out to lunch and back into the world.

DIDN'T HELP: Asking when we're going to get our "lives and work back to normal."

HELPED: All the wonderful donations to the memorial scholarship fund, the live plants reminding us of Sarah, and the flowers brought to the site of the accident.

I find it nothing short of miraculous that Sue remains in her job as a pediatric hospital chaplain. She says she finds in that work a gift for sharing with those who have endured similar losses.

She also says she finds a lasting lesson in Thomas Attig's writing about grief and how relationships with loved ones change after their death. Sue adds, "The truth is, it doesn't end; the relationship is miraculously transformed. I knew that concept before Sarah's death, but now it really hits home."

A MESSAGE FROM THE EDITOR FOR SIBS

I am including several pieces of writing from a book by John Bramblett, *WHEN GOOD-BYE IS FOREVER: LEARNING TO LIVE AGAIN AFTER THE LOSS OF A CHILD, Chapter 7 Brothers and Sisters*. Mr. Bramblett has included pieces written by his other children after they experienced the loss of their little brother. I would encourage you to read these excerpts and hope that you might try your hand at expressing your own grief. Sara Thompson would welcome any thing that you might wish to share with others. She would send them to me to include in future issues of *THE LIGHTHOUSE* in this section for the SIBS. Sara, who is the SIBS Leader, can be reached at sarathompson@hotmail.com. Or you can send them directly to me in care of the BDSRA office, marked for THE LIGHTHOUSE.

I, too, had several other children. Now I realize, looking back over 30 years, that I do not believe that my other children were given adequate time or opportunity to express how they felt. I was too overwhelmed with my own grief, and they became the "silent mourners". I deeply regret this now that I realize the importance of what happened, in overlooking my other children's feelings at the time of the deaths of their brother and sister from Batten Disease. Therefore I encourage you to either contact Sara with your expressions, or ask a parent, grandparent or sibling to help you. (Sometimes we need help in actually writing our thoughts down and would like someone else to do it, or maybe we just need a little encouragement to express what we would like to get out.) It could be a poem or just thoughts about how you felt when your sibling died, similar to these thoughts from Mr. Bramblett's children.

MY FEELINGS ABOUT CHRISTOPHER'S DEATH

MEGHAN BRAMBLETT AGE 8 7/9/88

Megan was only 5 and in Kindergarten when her little brother died.

FACING THE FACTS

“Me and my parents stood there hugging until we looked like a sandwich. Then my brothers came home with red eyes. Brian, John, Mom, and me lied down on the couch as my Dad bravely called relatives and said “Hello...this is John...there's been a tragedy.” Then he would burst into tears. With faith we all prayed that the phone would ring because our grandparents were not home. Suddenly it rang...my Dad let it ring about five times and then breathlessly picked it up.”

MEMORIES

In the months just before her tenth birthday, Meghan wrote down some additional thoughts about her brother's death.

About a month after Christopher's death I started wondering why God took him away. Every time I prayed at night, I asked God “When are you going to bring Chris back?”

Well, soon I found the answer to that question, and I didn't like it. I felt lonely and every time anyone said “Do you miss your brother?” I just stood and cried.

Things have changed a lot since I was in kindergarten. Now if someone asks that I just say “Yes, but I'll be with him someday.” I used to hope that I was just having a bad dream. The one thing I am glad about is I'll be with him soon.”

JOHN'S THOUGHTS

John was 15 1/5 when his little brother Christopher died.

“Sitting in my dorm room in the spring of my sophomore year in college I am reflecting back on another very different sophomore spring. I will always view my sophomore year in high school as a turning point in my life. For the first time I had truly fallen in love and subsequently, as first loves often turn out, I was left brokenhearted. Although at the time I thought that I had suffered the loneliest and coldest moment that life could present me, I would be quickly and abruptly exposed to hard reality. Fortunately, my lost love's enduring friendship and support turned

out to be one of my greatest assets during the time I was struggling with Christopher's death.

My first recollection of the things that happened on the day of the accident was waking after two or three uses of the snooze bar on my faithful radio/alarm clock. Christopher's bedroom was located directly across the hall from mine and in the morning I would habitually pop my head in his doorway to catch a glimpse of his small figure. I don't know why I did it-maybe it was just because I needed to see an image of peace and innocence that was so far removed from the world that we all subject ourselves to every day when we make the decision to get out of our beds

----a voice penetrated the silence of a midclass dictation asking me to the office.---my brother Brian was also headed for the office. It was at that moment when I realized that something was seriously wrong.

---my brother and I were greeted with numerous painfully blank stares. We were quickly shuffled into the office of the vice principal----a conglomeration of the school's top officials and a state police officer. The classic line "You'd better sit down" was delivered, and my feeling that something was gravely wrong was reaffirmed.

"Boys, there's been a terrible accident...your brother has been killed." When those words were uttered, I felt my soul, as if it were an invisible inner suit of clothing, fall from my body and rest draped around my feet. Then there was a stillness that encompassed the room as my body was engulfed in a bizarre numbness.-----"Boys, your parents need you. I'll take you home" uttered the state trooper.

The next emotion that I remember feeling was sympathy...when I saw my parents (my father who I had never seen cry) oblivious to anything other than my brother's and my arrival and their own intense pain.

Soon after our arrival the house was a teeming mass of faces.....All I wanted was to be alone, so I fled to the seclusion of my room. While there I was visited once again by the state policeman, who had been the officer on the scene as well as my escort from school. He told me to think about whether or not I wanted and felt that I needed to view Christopher's body at the funeral home.

-----I eventually decided that it was important-if not a necessity-for me to go and see him. (I'm not suggesting that this is the best choice for all situations but that it was for me.)

It was at the moment that I walked into the funeral parlor and saw...a tiny white casket that held the broken body of my brother, that the reality of what had happened finally struck me for the first time. For that reason, if no other, I am glad that I did what I did-that I made the decision to Christopher for one last time.

The next phase was that which concerned the funeral and burial. My parents decided that Christopher should be buried in a family plot in Ohio. When I was told of this intention, I became irate. I

was upset that I had not even been “consulted” as to what my opinion or feelings on the matter were.-----This was one of the major “anger points” with which I had to deal.

I eventually came to peace with the issue by realizing that Christopher was not the tiny, blond-haired, blue-eyed frame of a child that we were burying in a distant piece of ground. He was instead, the joy, love, and memories, and a part of each and every person he had come in contact with during his short life. He was a special place in the hearts of those who had experienced his time with us—a special place that would always be with me no matter how far away he might be buried.

I had a difficult time writing this. Why? I’m not sure. I do know that through this experience I questioned my faith and through that questioning, I learned what it truly meant to me on a personal basis. Hopefully my relating these reactions will help someone who is dealing with or has been forced to deal with a similar situation.” A poem, one of three that John wrote just a little over 2 weeks after Christopher’s death follows:

MEMORIES

*Sometime in the future when I am old and gray
I'll look back in time to when I was young and gay.
I'll see you there, your white hair blowing
And ask myself why you were so quick in going.*

*The love we shared has endured the test of time
If I had a choice, it would have been your life for mine.
I sit in my room and think of us as we were
But then fantasy, sweet fantasy.....
....fades and I am again without you.*

BRIAN’S THOUGHTS

Brian was 13 when his younger brother, Christopher, died.

“My brother was puzzled as to why we were both being asked to the office.----Thoughts shot through my mind until the state trooper told us what happened. My mind was in a total blur. Nothing he said made any sense to me.

“----your parents and sister need you at home”, and took us out of the school to his car.-----My thoughts were too scrambled to feel sorrow. Not only was I confused and angry at the world, but most of all I was lonely.

When we finally got home, my parents came out the door in hysterics. It was at this point I thought to myself maybe this was really happening.---I needed some time to sit and sort things out so I went over to the living room couch and sat down.

I watched all our neighbors and friends trying their best to help us. That was the one good thing I could see.

I began to go into my own little world and think. I began to ask myself questions about Christopher’s death. Was he happy? Was he in heaven yet? Would I ever see him again? Why him? As I

thought about these things, I began to get angrier and angrier. It was so unfair and so wrong that he was dead.

I kept on wishing that I could see him one more time. I kept myself apart from others in this little world I had found. When I was in this world, I could block things out—whether they were people, emotions, or pain.

That night we went down to the funeral home to see my brother's body. I couldn't look at him for long.-----

When I went to bed that night, I had finally begun to accept that Christopher was dead. I thought about it a lot that night.....I didn't sleep much that night. I kept dreaming that I was talking to Christopher and then he would change into the way he was at the funeral home and disappear. I never told anyone about this because it was so weird. The next day I just sat around and wept for my brother.

At the memorial service I was in a huge group of people and still I felt alone. I tried to talk to my friends after the service, but it seemed like we weren't on the same wave of thought. I had put myself in this separate world but now I couldn't get myself out of it. For some reason dealing with Christopher's death was much easier by myself. Although I needed my family's support this was something I had to deal with on my own.

I am not really sure if I had dealt with my brother's death in full, but I had been able to accept the fact he was dead by the time he was buried. I think that his burial was the end of his concrete body, but that was not what I loved.

I had come to many conclusions: I had decided that Christopher's death was not going to destroy my life. Instead it was going to be a turning point in my life. I was not going to let life go by without experiencing all life had to give. I still feel the same way today as I did then. I often wonder why Christopher was taken from me, but there are no answers—only faith.

I still feel anger but it is not at anyone or any thing. I guess I am angry because of the things Christopher never got to see or do. But when I think about it, he must have gotten all of the experience from this world that he needed.

Sometimes I still feel along. When I get this feeling I like to sit in a quiet place and enter my little world where I can hold my memories of Christopher.

I think of Christopher today as my little guardian angel---the same way he used to follow me around when he was alive---only now instead of me watching over him, he watches over me.”

A LETTER FROM RICK

Sometimes we are able to comfort others by sharing our own experience of grief. Here is a letter Rick Castor wrote to friends whose twin baby boys were born prematurely and lived only 4 hours. Rick had lost a sister Karen and two brothers to Batten disease.

Dear Joslyn and Brian:

Thank you for your courage and honesty in sharing with us the joy and pain in the loss of your twins. I've just finished a reflection on the killing of the innocents after Christ's birth, and you were very much on my mind. Do what you want with these thoughts. They are only the reflection of a man who also has a hole in his heart.

My son Jake just returned from a 10 day trip, mountain biking in Peru. I am a believer in life as adventure, but I couldn't keep by fatherly fears at bay. My only boy," my pride and joy," as I used to tease him, was headed into wild terrain in a country with an unsettled political environment.

As I thought about natural instincts to preserve and protect, I realized how little power I actually have to influence outcome in my kids. "They are my gift to you, but you will never own them. They are not yours." The message came so clearly to me as I worked alone while Jake was gone. Truths like these come easier in the abstract than when the real deal comes knocking at the door.

I thought about you, Joslyn, having to let go of what literally you were so attached to...having to let go of dreams and scenarios that you and Brian played out in your head. I think some of the most intense and lashing grief for me in the loss of a sister and 2 brothers, has been the pain of what might have been. Who would these people be today if.....?

A big part of my life has been distancing myself from that pain, or "the wave", as I call it. The fear of being caught in the undertow was a big reason pot was such a comfort.

It's only in the past 5 years that I've realized heart pain has become part of the spectrum. "I have come that you might have life and have it abundantly," Jesus said. "Here, Rocky, check this out. Feel the experience, the abundance of deep loss, and know that you are alive."

I have learned that heart pain will not kill me. I had become so good at keeping it away that in the rare times my grief came down, I would be so overwhelmed by "the wave", I thought my heart would literally break. It's not "the wave" that kills but death can come by running from it, numbing myself from it, deny this is part of who I am.

Losing two precious children will forever be a part of who you are. Your story of that treasured time, the four hours you spent with Emanuel and Caleb, was a brief interlude of joy-and then grief. I pray that you will have the courage to hold your grief close, to remember, to share. If you do, your children will continue to live in your hearts and to give life in ways right now you can't imagine. I see my own mother's courage as a real life example.

I spent 2 days skiing in Vermont earlier this winter. On December 21st, the darkest day of the year, I ended up skiing alone in the snow covered woods late in the day. "Darkness and snow and mystery surrounded me. The woods seemed to be saying, We could swallow you up without a thought."

I said, "I know you could, and I'm OK with it. I am small, nobody, yet I'm so alive and king of the world!"
My brother Jon said, "Rejoice in these words." See the mystery of life right here! Be grateful and know we are always part of who you are. We won't leave you; please don't leave us."

In love and in a small sense of knowing,
Rock

I want to thank Rick, Joslyn and Brian for sharing and giving us permission to publish this letter. In doing so may some of you feel comfort in knowing that others have interest in your pain. --
Editor.



In a letter, a poem, a drawing, a journal entry, or an imaginary conversation with the one you have lost, pour out the feelings you have never had a chance to express. This will foster healing.

TIME TO LET GO -By: Lurlene McDaniels

Lurlene McDaniels, who lives in Chattanooga, TN, has written several series of books suitable for young people 12 and up. One book, *Six Months to Live*, was included in a literary time capsule at the Library of Congress in Washington, D. C. Her subjects are involved in many situations, including the deaths of siblings, peers and other children with whom their lives have interacted. Her novels are realistic, but offer readers hope and inspiration in the message.

Ms. McDaniels writes from her experience as the mother of a son facing a chronic life-threatening illness: "I want kids to know that while people don't get to choose what life gives to them, they *do* get to choose how they respond".

Time to Let Go is the story of Erin Bennett as she struggles to find a physical cause for her throbbing, painful headaches. Her older sister, Amy, died from injuries received in an auto accident a year before.

The guilt that Erin silently feels and her headaches do not subside even after she gets the lead in the senior musical opposite a popular, good-looking guy. Although David is attracted to her she often finds his attention and happy, clowning personality to be annoying but can't figure out why. Her headaches sometimes even get worse. She recognizes him as the hospital clown with whom she worked once when she filled in for Amy.

David, and his younger sister, Jody, who is deaf, begin to make an imprint on Erin. After she watches David's interaction with Jody and her special- school friends Erin gradually allows herself to spontaneously confide some of her feelings with David the night of their prom. Erin regrets this when she realizes that David's support and caring for her will not go away in spite of her efforts to push him away.

Erin becomes more aware of David's intuition in helping others when he comes to the hospital to help her and her friend, Beth, look after Beth's younger sibling. Their mother is undergoing a second kidney transplant. David's clowning and tricks provide welcome relief as it takes their minds off of their worries for awhile. David has said he wants to be a clown for this reason.

Erin finds irony in the fact that Beth is an anchor for her family. She feels more like a burden to hers since she has felt that Amy was the talented, favored child in the family and the accident was her fault. Erin begins to accept the facts and reason that her parents approved an organ donation, although she found it hard to admit that Amy was dead and for her parents to agree to the donation. Now she can appreciate that Beth's mother is still alive and how a transplant will impact the entire family and their lives.

Eventually Erin reluctantly begins to attend the grief support group for teens recommended by her therapist and meeting her scheduled appointments. Her parents, who have grown apart since Amy's death, become involved with family counseling with Erin and the therapist as well as attending a Compassionate Friends support group for parents who have lost a child.

Erin and David each had dreams for college, but with their parents' opposition. As the new school year approaches, plans for college are happily finalized, Erin's headaches have pretty much gone away and they look forward to seeing each other on campus by the second semester.

Readers can get online with this author at www.lurlenemcdaniel.com and locate her books in the Young Adult section of the local library in either paperback or hardcover.

Barbara Coloroso suggests the TAO of MOURNING in her book PARENTING THROUGH CRISIS as a method for adults, specifically parents, to use in helping children mourn. I covered Chapter I, DEATH; HELPING KIDS MOURN in the November 2007 LIGHTHOUSE. This described three passages that are experienced over and over in our journey through the losses in life. Ms. Coloroso refers to TAO as the Zen Buddhist word for “way” or “path”. She has used the word as an acronym for the three things we need when we face the many chaotic changes and losses of life. T is for Time, A for Affection and O is Optimism. At this time I will review her list of six critical life messages which are: 1. I believe in you 2. I trust in you. 3. I know you can handle this. 4. You are listened to. 5. You are cared for and 6. You are very important to me.

Families are comprised of members of a variety of ages, physical, emotional and intellectual development. Many varieties of relationships have been created within each family. When a family member dies the effect of the loss will influence each individual member differently. According to Ms. Coloroso there are 5 factors that have the most influence on children’s grieving.

1. Who died and the relationship of that person to the child.

For our purpose we will discuss the relationship to be that of a sibling. Frequently a child will feel anger towards the parents for not preventing the death. Sometimes blame the parent for not being honest about how ill the sibling was. They may feel guilt at surviving, or have negative thoughts towards him/her, or fear of saying things to upset their parent. There is the memory of the dead sibling that might be difficult to compete with, awareness of their own mortality and of course the feelings of being alone, isolated, afraid and ignored.

With two siblings at the death of one the remaining child becomes an “only” child, and often the silent mourner as the parents are being consoled and comforted. The child knows that the parents have each other, however there is no longer his/her brother or sister.

2. The manner or cause of death

Although any death brings suffering some deaths bring compounded suffering (such as suicide, murder or accident). At times the five S’s are attached to other deaths: stigma, shame,

secrets, silence and sin and cause the whole family to feel isolated and unable to grieve openly. This is usually not the case in the anticipated death of a very ill child.

3. The communication skills of the family

Children need honest, truthful explanations. The opportunity to cry and see others cry openly helps the child to express anger, hurt, disbelief, and fears. They need to know there is someone to listen and provide the support and appropriate boundaries needed for these expressions. And they, as the adults need to be able to tell their own story of loss, maybe over and over. Then they can begin to accept what has happened and to heal. If a child represses feelings or indulges in inappropriate acting-out the ability of other family members to support one another is inhibited.

4. The history of loss and death.

Mourning can be compounded by the factors of whether a death is the first experience or in a sequence of simultaneous multiple deaths. The first experience brings shock, sorrow and grief without knowing what it is like to heal and find joy and hope again. With multiple deaths often come details that recall earlier deaths.

5. The developmental level of the child.

Children of all ages express grief and loss; however the ability to do so largely depends on the developmental level of each child. It is natural to want to protect children from chaos and loss. Even small children are able to perceive and be aware of the adult's feelings of sadness, anger and hurt. They hear quiet conversations, see crying and know intuitively something has happened, however are unable to fit the puzzle pieces together. In fact, they might use imaginary pieces if real ones are kept from them.

If caring adults are able to offer time, affection and sense of optimism in allowing and encouraging children of any age to mourn and grieve, the children will acquire the ability to learn how to work through their grief. Frequently then it will be the children who reach out to comfort and reassure others in their own ways. When a child is included in mourning it allows the child to understand the grief around her and the reassurance that she is an important member of the family. If she is included in the family mourning circle she will be able to experience the healing as well.

Ages and Stages of Developmental Level and Suggestions for Appropriate TAO of Mourning:

INFANTS:

Function in the present

Tuned into environment and aware of presence, sudden change in physical and emotional climate and absence.

Death of mother greatest loss producing marked changes.

When mother grieves a loved one the infant senses the grief and responds with agitation, possible changes in bowel activity and spitting up.

TAO of Mourning: Provide loving, consistent care, gentle touching, talking and singing. Try to avoid any agitated responses and know that I believe and trust in you and know that you can handle this is mostly for you. You are listened to, cared for and very important to me are beneficial for your child. The little things you do for her affirms her importance in your life.

TODDLERS:

Active involved in doing

Learning that they can explore in safety, yet want to get parents' attention at will.

Curious

Testing all the senses

Experience wide range of emotions-tuned in to "read" wide range of emotions.

Language better understood than expressed.

Cannot conceptualize death but express sadness even at pet's death.

Need explanation of bodily function cessation, will not work again.

Grieve in short spans of 5-10 minutes, throw temper tantrums, rocking self for comfort, refer to early behaviors possibly thumb-sucking.

TAO of Mourning:

Provide loving, consistent care. Respond to needs as to infants.

Talk about what makes you sad, cry in front of them. Assure them that although you are sad right now because of---- you will make them (food) and do some usual activities. Take time to do the ordinary everyday activities in your grief and you help the children know that life goes on with you being there for them even in your own grief.

PRESCHOOLERS

Busy establishing individual identity, learning new motor and linguistic skills and figuring out roles and power relationships.

Adults and siblings are models for expression of emotions.
Curious about their bodies and the surrounding world. May ask why people die.
Attempting to separate fantasy from reality.
See death as temporary and a journey from which they can return or a sleep from which they awaken.
Can feel loss, experience wide range of strongly felt emotions and grieve.
Ability to put tumultuous feelings into verbal expression and words lags behind the body's experience and expression of those emotions.
When told about a death, they might appear sad, bewildered, ambivalent or act out feeling through play. May speak their feelings to imaginary friend, or imitate role of grief seen in movies such as The Lion King.
May use bullying and aggression to cover fear, anxiety and sadness.
Cling to parent for security.
Often attach themselves to a person who looks or acts like the person who died and call that person by deceased's name.

TAO of Mourning

Provide same loving care, affection and attention needed as with the younger children. Keep routine and daily activities as close as possible, but don't add new activities.

You should now discuss death in more detail and add headlines and facts about the death as well as the four attributes of death:

1. It has a specific cause. (Grandpa was very, very ill.)
2. It involves cessation of body functions. (He can't move, feel, breathe, grow and is NOT JUST ASLEEP)
3. It is irreversible. (We can do nothing to make him live again.)
4. It is universal. (Leaves die and fall off the tree, plants and animals die, Grandpa is dead.)

Preschoolers need to be reassured again and again that anything they did or said caused the death and nothing anyone says or does will bring the person back to life. They will ask the same questions repeatedly and use "magical thinking"-they believe their thoughts, words and actions have great power thus need the constant reassurance above.

FIVE-TO NINE-YEAR- OLDS

They tend to listen to collect information: compare; test; disagree with adults and peers; set, break and change rules.

They challenge parents' values, argue and hassle.

Can be openly affectionate sometimes, self-contained other times.

Separate reality from fantasy and use intuition to help decide what to do.

This group now understands the reality of death.
Fear of abandonment is expressed verbally.
They have concern for survival of self (how death will affect them personally) and worry about their own health and health of surviving relatives.
When feeling vulnerable they may deny the death happened or they are hurt in any way-act tough and hide the pain.
Possibly will search the house, in the yard and other locations for the deceased. Often will idealize the deceased and get attached to certain articles of clothing or objects that belonged to him or her.

TAO of Mourning:

There will be specific questions about the death, circumstances surrounding it and biological aspects of it.
Go over the 4 attributes of death to help ease fears. Use drawing, painting, or molding clay to help express their feelings difficult to share.
Talk with them about the passages of grief and what they can expect. They may be helped by helping other. Don't overwhelm them with all of your grief and knowledge.
Answer questions honestly.

PRETEENS

In between adults and children, but wanting to be both preteens are shier about crying or comforting although they may desperately need it.
Yearning for independence they want to be left alone to put the puzzle of grief together by themselves.
They know death is permanent and might come earlier than expected.
They want details and facts and to know how the death will affect their everyday life.
At times they will often deny that it affects them at all, sulk, say they don't feel anything, don't care, all is in an attempt to bury their intense grief and fears of their own morality.
May complain about illness, inability to sleep; may experience nightmares.
May express anger at the deceased for dying, or guilt about what they would have, could have, might have done to prevent the death.
Will often replay events leading up to the death to construct another ending.
May wear clothing, listen to music or make a montage of photos all related to the deceased.

TAO of Mourning:

Give your time, affection and expressions of optimism.
Be a mentor, show them that you express your feelings and that you are doing everything possible to get things back to normal.
Reassure them life will go on, you all will make it through this, and eventually the piercing grief and intense suffering will give way to sadness, peace, and enthusiasm for life.
Give them opportunities to spend time with peers to mourn, laugh and have fun. Peers can help them move through the passages of grief and offer respite from the pain.
Believe in your optimism that they are doing the best they can even when they revert to younger behavior or express their grief inappropriately.
Be consistent going over the six critical life messages to yourself and express them in small ways to the preteen.
Confront attempts to idealize the deceased yet help them remember the deceased as they really were and looked.
Encourage and let them help with the rituals of mourning to help them make the death a reality they can face with courage.

ADOLESCENTS

Magnify the possible responses of the preteen with the reasoning ability of an adult and erratic emotional states of a teenager.
They are also in transition on the cusp of being adults emerging as an independent individual.
They want all of the immediate answers (including financial ones) of a particular death in their own lives.
Be aware that understanding does not mean accepting.
Emotions are in turmoil, moods change abruptly, sadness to anger, giddiness to anguish.
They will often share thoughts and feeling with close friends.
Some might retreat into depression, use drugs, alcohol or food to drown the pain.
Some might question life's purpose and meaning, rage against inequities and unfairness in life and swear to never get close to anyone again.

TAO of Mourning:

In addition to the needs of preteens adolescents need opportunities to help in the decision-making and planning for ceremonies, rituals, meals and activities associated with the burial and memorial services. They may speak at the service which allows

them opportunity to put their grief into context of the relationship they had with the deceased.

They feel a need to be “strong” for family members they see falling apart. This will only delay and perhaps prolong their grieving.

Help them name their grief and respect their emotions.

There are no SHOULD and OUGHTS in grieving.

They will express desire to “wish I could be with him”. Don’t be alarmed, just listen and be understanding.

Be alarmed and seek help for the teen if he is preoccupied with the wish to be with the person who has died and talks about WHEN and HOW he intends to carry out this wish.

Take any talk of suicide seriously and be alert to signs of deep depression, severe fatigue, alcohol or drug use, over- or under eating. It is far better to look foolish than to have lasting regret.

WHEN GRIEVING IS NO LONGER GOOD MOURNING

Sometimes grief is blocked, diverted, or buried. All children will exhibit some signs as they grieve. The frequency, intensity and persistence of the following behaviors would indicate a need for concern that a child is stuck in grief and you should consult professional help to get them through mourning.

1. Acting much younger for an extended period of time.
2. Excessive, prolonged crying bouts.
3. Inability to sleep or need for excessive sleep.
4. Nightmares
5. Loss of appetite.
6. Extended period of depression when child loses interest in friends, daily activities, etc.
7. Truancy; drop in school performance or grades.
8. Prolonged fear of being alone
9. Persistent idealization of the dead person
10. Excessively imitating the dead person.
11. Repeatedly stating the wish to be with that person.
12. Clinging to the past, refusal to think positively about the future.
13. Talking about the deceased in the present tense.
14. Overvaluing, clinging to possessions of the deceased.
15. Frequent physical complaints, illness, headaches, stomachaches.
16. Detachment, pulling away from efforts at consolation.
17. Avoidance of any activities that are reminders of the dead person.

“Sadness can coexist with peace, hope, and joy. Depression cannot.”—Andrea Gambill

Although many of us are of the Christian faith, belonging to a large variety of denominations, holding as many variations of beliefs, customs and traditions as there are places of worship, there are families who are hurting who are of other religions, some having none at all. Some families and individuals are searching, confused, and in need of a belief to hold on to, for hope and comfort at the loss of a loved one. The beliefs that they have, doubt, or question may not present just not enough to help. I came across a book written by a psychic medium that I would like to present for those who might be interested in the lives and work of psychics. This is not to persuade anyone to delve into something they don't believe in, or to cause others to question what they feel, it is just to put information out for those who may have interest or curiosity as they ponder and confront new feelings which occur at the death of their loved one. Personally it has not changed my life and beliefs, however I hope that the information may be useful to someone and bring them help at this time in their grief journey.

In Loving Memory

Denver Ray Casto, son of Pansy Casto, Charleston, WV
Born: 02/11/69 – Died: 11/29/07 – CLN5

Cristopher Andre Waters, Jr., son of Lesley Bolton & Cristopher Waters, Sr., Manassas, VA Born: 5/30/97 –
Died: 12/23/07 – Late Infantile

Ali Mohammed, Columbus, OH Died: 12/23/07 – Late Infantile

Cassandra Mortell, daughter of Sandra & Darrel Thomas, Gardner, KS and Cheryl Mortell, Kansas City, KS Born: 7/7/91 –
Died: 12/24/07 – Juvenile

Garrett Campbell, son of Scott & Renee Campbell, Charlotte, NC
Born: 7/19/05 – Died: 12/30/07 – Infantile

Brooke Mulvaney, daughter of Onour Mulvaney, Highlands Ranch, CO Born: 10/13/98 – Died: 1/15/08 – Infantile

Andrea Sparks, daughter of Annette Sparks, Conception Bay North, Newfoundland, Canada Born: 8/24/01 – Died: 1/18/08 –
Infantile

Travis Witt, son of James & Sandy Bagby, Concord, VA
Born: 8/24/01 – Died: 1/19/08 – Juvenile

Joseph Gutierrez, son of Jose & Josefa Gutierrez, Belle Gardens, CA Born: 12/28/96 – Died: 1/29/08 – Late Infantile