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# *LIGHTHOUSE*

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**Batten Disease Support and Research Association**

## ***Reflections***

April was a bittersweet month, full of reminders of Jonathon (1958-1984) whose birthday was April 1<sup>st</sup>. In church, a hymn sung at his memorial service brought sudden tears. An album full of camping pictures revealed his impish grin and fuzzy crew cut. Oh, how I missed him! What would Jon be like at age 46 had the genes been right?

Sometimes comfort comes in unexpected ways. With my daughters and grandkids I was spending spring break at Litchfield, SC. It was 6:30 Easter Sunday morning as condo dwellers gathered on the beach for the sunrise service. Rhythmic crash of breakers and cry of seagull mingled with our singing, "Christ the Lord Has Risen Today." Then the pastor preached a powerful message of hope.

There had been no sign of the sun. Now just before the final hymn, a sliver of orange beamed above a bank of grayness. "Let us be silent as we watch the dawn," the pastor advised. All eyes watched expectantly as a bright ball of fire rose from behind the clouds. Bathed in light, we all joined in singing.

" Because He lives, I can face tomorrow.  
Because He lives, all fear is gone.  
Because I know He holds the future  
Life is worth the living just because He lives."

I sensed that Karen, Jon, and David were singing with us in the glory of eternal morning. With the rising sun, hope was reborn in me.

That's the focus of this spring edition of "The Lighthouse" HOPE REBORN. You'll find down to earth stories by other mothers and dads, made available through the kindness of Donna Corrigan, editor the "Bereaved Parents Newsletter." Also included are poems, a touching personal story, information about what grief feels like, and a recent article about the Castor/Jackson family. For those with unaffected children, Manning's and Rosof's contributions will help you understand how young ones deal with loss. May this "Lighthouse" be a beacon of light to bring you hope on your journey.

Peace and joy,  
Connie Jackson, editor

## **Spring is a Time for Starting Over**

As parents how many times have we told our children to try, try again? Your can do it, just start over,” we’d say, be it a coloring book not kept within the lines, learning to tie shoes, school assignments, or later, other difficulties that life brings.

Little did we think that this well-meaning advice we gave out of love and concern for our children’s well being would be the words that we must follow. Hang on. Don’t give up. Try again, and start over. All this now applies to us. Had the situation been reversed, we would not have wanted our children to live out the rest of their lives in pain and unable to go on. We would have wanted them to continue, not in constant sorrow, but with hope for renewal, and better days ahead.

As we have said to them, they would be throwing it right back to us. It is a hard road that you must travel, but you can do it. What you wanted for me, I want for you. Do what you have to, to find your way out of the dark tunnel, and when you fall, pick yourself up and start over again. You can do it.

What we wanted for our children is not less than they would want for us. If we could hear them, right now, they would be saying:

LIVE, for life is but a moment.

LOVE, for that is what really matters.

GO ON, for we shall be together again, someday.

By Mary Ann Lambden, Gloucester County, New Jersey

## **Spring Cleaning**

As the seasons change and we become aware of the stirrings of nature, our thoughts turn to “Spring Cleaning.” It prepares for the new season by getting our “house” in order.

Let’s dust off our memory chests, shake out and examine each item we’ve folded away in our heart and our mind. Dig into the corners and bring light and air into the darkness. Deep in the closet we have accumulated all the things we couldn’t face or needed time to think about. We must go through these. As we sort through we will discard some unnecessary, unwanted feelings, hurts, anger and other emotions. Now we can count our treasures and carefully fold and put them back in fresh containers, smaller, easier to find, more in time with now and in good order.

**A day spent doing these tasks will no doubt leave you exhausted, but the effort will bring a deep sense of contentment.**

By Betty Stiegelmeier, TCF, Pikes Peak, Colorado

## **Bereaved Birthdays**

When it comes to celebrating the birthday of a lost child, what on earth do we have to celebrate? The fact that our son/daughter is no longer with us makes the day one we should rather hope to forget about. REALLY?

I defy any bereaved parent in our group to tell me that they don't remember when their child's birthday was!

In our house, we choose to celebrate that in October. We gather friends and family together, perhaps lunch out, or if nice weather, perhaps a picnic. We spend the time in happy conversation speaking of our girl with love and fond memories. After we are all full from our meal, we take a trip over to the grave where we hang personal little messages onto balloons and let them loose. It has proven to be a very moving but happy time. It's always good to know that people remember!

The death anniversary is totally a different story! This date we choose to keep just between mom and dad. No celebration, no fun. We spend the day doing things to help us remember the good times, and try not to focus on the bad event day! Then, hand in hand, we visit the grave to quietly tell our girl just how much she is still loved. Fresh flowers at the grave and a few tears, and the day has, once again, passed us by for another year.

From Bereaved Parents Newsletter

### **Silent Tears** By Paul Costello

On a lonely night a mother weeps,  
For the soul of a child she could not keep.  
She knew his smile, she knew his touch,  
He knew she loved him very much.  
Now she is empty, with a void so large,  
The child is now in angels' charge.  
A young spirit oars, as free as a dove,  
No bell shall toll the death of love.

Submitted by Steve Thompson

Reprinted from March 8, 2004 Democrat and Chronicle - Rochester, NY.

**Stalking a 'predator' - UR scientists zero in on mystery of Batten disease, which has devastated a Steuben County family** By Jim Memmott

Batten disease, so rare in the United States that few people know its name, follows an awful course. First the blindness comes. Then slowly, inexorably, the child's mind and body break down. Eventually, death comes, often before the victim turns 20.

"It was like a predator, a cloud over the family," says Connie Jackson of Bath, Steuben County, who lost three of their six children to the genetically inherited disease.

Batten takes about 1,000 lives a year in the United States, striking most often in children, who will be healthy until age 5 or so before the disease strikes.

The disease has proven a difficult mystery, but Dr. David Pearce of the Center of Aging and Developmental Biology at the University of Rochester and his team of researchers have made significant breakthroughs toward understanding the process.

And given that understanding, Pearce says the next step is to consider the possibility of moving forward with a clinical trial for a treatment of the disease.

Pearce stresses that should a clinical trial be held, he will not be testing a cure. "But we will be looking to slow the progress of the disease," he said.

In researching the disease, Pearce has come to know the young people struck by it. This has made him even more committed to his research.

"As far as I'm concerned, we're on a mission here," he said.

Stepping out of the laboratory, Pearce has also stepped into the hearts of the families who deal with Batten disease firsthand.

"He's a person who is not just a scientist," Jackson said. "He's a person who is a very caring, compassionate friend."

Like Pearce, Jackson has written about Batten. But while Pearce has reported on the impact of the disease on the body, Jackson has looked at the impact of the disease upon the family.

In her book, *Nothing Can Separate Us* (Green Key Books, 2002), she tells the story of her family's unimaginable losses, how they shook her faith, though she emerged from this struggle still believing in a benevolent God.

Jackson's former husband, Steve Castor, a retired teacher and school administrator, lives in Nunda, Livingston County.

Their three surviving children are now adults with children of their own. They talk of their lingering sense of loss, a loss balanced by memories of their siblings' courage in the face of death.

"I almost had my quota of grief when I was 16 or 17," said Rick Castor, 44 of Nunda. "I thought, 'I'm not going to think about it anymore.'" But it would come back. Like a wave, it would wash over you. Now, I grieve the amount of love in my life that's gone."

### **Striking the brain**

Batten disease was first identified in the early 1900's by Frederick Batten, a British ophthalmologist.

The disease comes from a genetic defect that leads to neurological dysfunction. It can occur only when a child received a defective gene from each parent. The chances of this happening are slim, Pearce says.

There are an estimated 400,000 people in the United States who carry the defective gene. The odds are against any two of these people marrying. When they do there is only a 1-in-4 chance that their children will inherit two defective genes.

The disease first manifests itself when a seemingly healthy child starts having vision problems. Other neurological problems then set in, including loss of motor control, dementia and behavioral changes, much as if the aging process horribly accelerated.

Though rare everywhere, the disease is most common in Scandinavian countries and in Newfoundland.

The disease result from a buildup of protein waste in brain cells. Unable to break down the waste, the cells eventually die. This, in turn, affects the brain's ability to send signals to the rest of the body.

## **Pearce's mission**

Pearce, 38 a native of England, began work on the disease at the University of Rochester in 1996 about the same time his son, Matthew, was born.

“I had never heard of Batten disease,” he said. “I became more involved in it as I became a parent...though I'll never pretend to know what Batten parents are going through.”

Pearce's lab has recently focused on determining the reasons why the cells lose the ability to get rid of the waste material.

In a paper published December in *Proceedings of the National Academy of Sciences*, Pearce and his colleagues Yoojin Kim and Denia Ramirez-Montealegre show that the affected cells have below-normal levels of arginine, and amino acid.

“It's not being moved around into the cells correctly,” Pearce said. “And that creates an imbalance like a short circuit. Because you don't have enough electrons accumulating, the cell doesn't send enough messages.”

Pearce said that he is careful not to raise false hopes with the Batten families.

“I'm completely honest with them, he says. “It could be this is the major defect, or it could be the cells are tricking us.”

Pearce and his colleagues have not yet linked this finding with their earlier determination that children with Batten disease have elevated levels of autoantibodies, indication that their immune system might be attacking the body's proteins.

## **Intense grief**

Much less was known about Batten when Karen Castor was diagnosed with the disease in 1962, four years after she had begun to go blind. She was 10 years old. At the time of her diagnosis, the family was living in Webster, where Steve Castor taught high school English.

By this time, her mother, the daughter of a Baptist minister, struggled with depression.

“There were a couple of years when I doubted my simple childhood faith,” Jackson says. “I came to the end of my rope.”

When she was diagnosed, Karen had four younger siblings, Miriam, Jonathan, Rick and Catherine. A sixth child, David, was born in 1967. J

Jonathan was almost 5 when he was diagnosed with Batten in 1963. David was found to have Batten disease in 1973 when he was 5 and the family was living in Elba, Genesee County.

“A Batten family’s grief is most intense at diagnosis,” Jackson said. It begins the long, long process of letting the child go.”

Karen died in 1968 at age 15. Jonathan was 25 when he died in 1983. David was 28 when he died in 1996.

“It’s terrible, terrible, to watch your kids lose the capabilities they have as youngsters,” said Steve Castor. “With each one, we thought they were perfect. They seemed to be models of good health.”

As she looks back, Jackson finds herself focusing on her deceased children’s lives. “There thing that happened to all of my Batten children was they had deep abiding faith,” she said. “I took strength from them.”

We continue to grieve,” said Steve Castor, “but I wouldn’t have it any other way. They were an important part of my life. I learned a lot from those children.”

As remembered by their surviving sibling, each child with the disease had special graces.

“Karen was Miss Manners,” Rick said. “Jon and I were buddies, and so were David and I. But David could see his future. He could look at Jon, who was stumbling, and see his own future.”

Sitting in the kitchen of his sister Miriam’s farmhouse outside Geneseo, Livingston County, Rick, a building contractor, also recalled his own efforts to dull the pain of loss. For years, he used marijuana. Now he draws support from Narcotics Anonymous and from his faith. He also attends, with his mother, the annual meetings of the national Batten Disease Support & Research Association, telling his story in an effort to help siblings of children with the disease.

Miriam, now Miriam DaBramo, is a special education teacher in Perry, Wyoming County. She remembers growing up well amidst illness, trying to make better something that couldn’t ultimately be fixed. Always, too, there is the sense of what was and what might have been.

## **A lingering regret**

Feelings of regret and loss never seem that far beneath the surface, she said. A lyric from a song, a simple phrase, can bring it all back.

“You grieve the futures, the futures that were lost,” she said.

Dabramo has put together photo collages of each of her lost siblings. They are haunting in part because the children seem typically young, Healthy in appearance but already blind, they face the camera, smiling, happy, doomed.

At age 41, she is the youngest surviving child.

When she was very young, Collier didn't comprehend what exactly was going on in her family, but slowly she came to understand the implications of Jon and David having the same illness that killed Karen.

“I just remember it was so heavy, all these little puzzle pieces came together,” she said, looking back, she has the strongest memories of her older brother Jon.

“I had thought he was a pest, though I shouldn't say that,” she said.

“But he was sort of grumpy, and then with his illness, he started to soften up and let people love him. ...

“Dave was less likely to take love from us. It was hard to see him so depressed, so sad, so angry.”

The experience of seeing her siblings die shook, but did not destroy, Collier's beliefs. Collier does not recall worrying about getting the illness herself or about passing it on. But she finds that memories of the difficult days endure.

“I think it's always tucked away inside, very easily brought to the surface,” she said, “I used to not be able to talk about it at all.”

## **Journey's Companion** - Characteristics of the Grieving Process

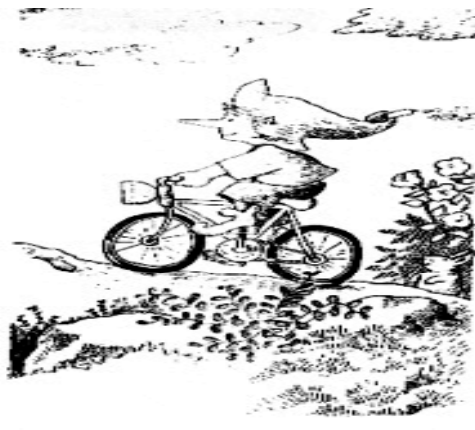
Grief. It is one of life's most difficult and painful experiences. Yet grief is also a natural and important process—one where we display countless, often conflicting emotions and actions that, over time, aid in healing our sense of loss.

Grieving is a necessary part of life. Whether our loss happens suddenly, comes unexpectedly or takes place over time, experiencing the death of someone we love is never easy. Grieving hurts. Grieving takes time.

It is common to experience a wide variety of reactions during the grief process—from sadness to anger, from numbness to pain, from guilt to fear. And since grief surfaces differently, we don't react to it in the same manner. Although it is a process that has been experienced by many people, there is no "best way" to manage our grief. There is no step-by-step manual, no written directions. Grieving is an individual, unique experience.

No matter how we manage or work through our own grief, it helps to know that intense feelings and reactions are commonplace. Everyone mourns the loss of a loved one. Everyone reacts emotionally to grief.

It often has been said that life is a journey. When the journey of a loved one comes to an end, our grief becomes its companion. Grieving the loss of a loved one is one of the most emotional and traumatic events we experience in life. By finding healthy ways to manage and face our grief, overtime, we can accept the loss of our loved ones and continue on with living.



*Make small beginnings toward reshaping your life without the one you loved. Your efforts are seeds of hope that you can cultivate into a fruitful new existence.*

## **Five stages of grief**

Many people credit psychiatrist Elisabeth Kubler-Ross, who is best known for her work in bereavement, for defining the stages of grief. Although her stages were originally defined to address the experiences of people coping with terminal illness they also worked well in defining the reactions of people experiencing grief. Today, these five stages are commonly referred to as the stages of grief.

### **Denial:**

The initial reaction to the loss of a loved one is a feeling of shock and disbelief. This isn't happening, we may tell ourselves. We are sure this has to be a mistake. This stage offers a temporary way to cope, through denial, with the news of the death.

### **Anger:**

This intense reaction surfaces in many ways-through emotional outbursts, or by placing blame on others or holding resentment toward others. Anger at God is common during this stage, as are feelings that the death is unfair. We may question why it was our loved one that died.

### **Bargaining:**

Referred to as a temporary truce, this stage is marked with "if only..." statements. We want to make a "bargain" to have life return to the way it used to be.

### **Depression:**

Following the reality that a loved one has died, this is the stage where public grieving begins. It surfaces a s intense sadness and withdrawal from others. It's hard to get out of bed, hard to get through the day. We may fee alone and may be unsure of how to carry on.

### **Acceptance:**

This final stage is marked by accepting the reality of the death and the change it has created in our lives. In this stage, we are able to let go of our loved one and move on. Our intense grief lessons and our lives slowly begin the return to some resemblance of normal.

## **Other common reactions to grief**

Because the grief process is an individual process, its reactions and its stages are different for everyone. Nothing is set in stone. Some people may experience all five stages of grief while others may experience none of them.

There are many ways to grieve. In addition to the five stages of grief, many other reactions are common.

### **Pain:**

It is not uncommon to experience physical pain during the grief process. An upset stomach, body aches and pains, shortness of breath, lack of appetite and inability to sleep are all common physical reactions and may be present during our grief process.

### **Stress:**

In the days immediately following the death, there are many activities that require our attention: planning memorial and funeral services, attending to family members and visiting friends, handling legal issues, taking care of the deceased's belongings, sending thank-you notes and acknowledgments. Juggling these responsibilities with emotional reactions to the loss can lead to high stress levels. We need to be aware of our stress and its affects on our physical and mental health. We need to allow ourselves the time and the resources need to manage our stress. And we need to seek help if necessary.

### **Forgetfulness:**

During times of grief, it is common to become disorganized in our thoughts or forgetful in our conversations. This especially can be frustrating when making important decisions, which often follow the death of a loved one. Lapses in our memory are normal during grief. As time passes, our memory improves.

### **Anxiety:**

Anxiety often accompanies our grief, surfacing as a feeling of fearfulness or a sense that we have lost control. Change is always difficult and brings with it a fear of the unknown. Change resulting from the death of a loved one is perhaps the most difficult-and most fearful-change we experience in life.

## **Guilt:**

In some instances, such as a death following a long illness or a painful physical condition, we may feel relieved that our loved one has died. These feelings, in turn, may cause us to feel guilty. These emotions are common and natural and in no way diminish our love for the person who has died. We may also may experience feelings of guilt for being alive. These too may be normal feelings during our grief.

### **From “Journey’s Companion”**

***I believe that laughter is the only cure for grief. And I believe that love is stronger than death. Robert Fulghum***

## **Healing Affirmations**

An important method for keeping the mind healthy and which will have residual healthy effects upon the body is the practice of affirmation. That which is affirmed continuously and with faith tends to be accepted in consciousness first by the conscious mind. If the affirmation is persistent the idea will pass by a process of intellectual osmosis to the unconscious, where it will give direction to the entire personality, including the body. As Dr. Smiley Blanton, the famous psychiatrist, used to say, “God presides in the subconscious.” Therefore, an affirmation, being a positive form of prayer to God, stimulates power in the inward state, which is manifested in the outward state to produce well being.

An impressive example of the health and healing power of affirmation was that of Lawrence Townsend, who lived a vigorous, healthy and happy life to age 94. He had a distinguished career in the foreign diplomatic service of the United States. The last post he held was Ambassador to Austria. And he *really* looked like an ambassador. Townsend was an ambassador in the grand manner. He and his wife were intimate friends of the late King George and Queen Mary. He often came to my church: stately, erect, vigorous, healthy.

He had a home in Florida, and I went to see him there one time and had lunch with him. I asked, "Lawrence, how come at your age you are so healthy and vital and your mind is keen and your eyes are alight and you are happy? You are a wonderful man. What makes you this way?"

"I am in constant contact with the life force", he replied.

"Like what", I asked.

"Every day of my life," he explained, "I renew the life force within me. I turn to the great God who created me and I ask Him to recreate me. And then I go out and I commune with the sun and the sea and with the rain and the snow and the wind. I am a child of earth and I am a child of God. Come out back with me."

That day the sun was intermittent and it was rather cold. He took me to a shelter he had built in his garden. It had no top but was closed on all four sides. He took me inside and said, "Strip to the waist." I did as directed, and he did likewise. Then he said, "Stand tall. Stand as though you were against a wall trying to touch it at as many points as possible." I discovered that by doing every organ seems to fall into place.

So standing tall, he said aloud, "Heavenly Father, we are now dropping from our minds every unworthy thought, every sinful idea, every dark and unlovely thing. We are now filling our minds with the glory of God, with the love of Jesus, with the love of man, with the faith and hope and courage. We are filling our minds now with every wonderful thing. The life force is now coursing through body, mind and soul. And we are strong, happy, healthy sons of God!"

It is the truth, a great truth-that the life force is within you, and it can cleanse and heal you. As I saw Lawrence standing there that day in positive affirmation I said, "I feel great!"

**By Norman Vincent Peale**

**Cry Not for Me**  
**By Joan B. Danziger**

When I shall die and  
Leave behind this earth  
I love,  
These trees,  
This sky,  
The everpounding sea,  
The yearly hop of spring.  
Cry not for me.  
Rejoice!  
My soul has wing and in its  
Freedom  
Sings.

**THE LIFTED CURTAIN**  
**BY Edward K. Leaton**

*For many years my wife and I waged a life-and-death battle for our two sons, both of whom had muscular dystrophy. Only when the long, long struggle was over did we realize that God had revealed Himself to us. Yet we would have missed His visit had it not been for a good friend, Edwin Feree and for our church.*

*Ed and Henrietta Ferree, and my family belong to St. Paul's in Darien, Connecticut, and when I say "belong" I mean just that. It is part of us and we are part of it, part of the Body of Christ on earth, and as the Bible says, "we bear one another's burden."*

*My son Ken, was three years old when doctors diagnosed his slowness in walking as muscular dystrophy, Duchenne-type. Prognosis was for progressive deterioration of his muscles until, sometime in his teens, those muscles necessary to life itself would be affected.*

*A few weeks after we received this verdict, Ken's younger brother Billy was born, suffering from the same condition.*

*Several years later, Jan and I, knowing we would have Ken and Billy so short a time, determined to enjoy every day together to the utmost. And there was much to enjoy as the boys walked and talked and explored their world. But with this disease every gain is temporary. Ken, being older, was the first to move into a wheelchair. Some days I would come home to find Jan shut in an upstairs bedroom, tears streaming down her face, while downstairs the therapist painfully straightened bent legs and uncurled clenched fingers.*

*The strain on Jan as they grew older was enormous: toileting the two large boys, dressing them, feeding them. As Ken's circulation slowed he had to be turned in bed throughout the night. One morning I came downstairs to find Jan, head down, asleep at the dining room table; she'd been catching naps between trips to the downstairs room where the boys slept.*

*At last in June, 1968, when Ken was 14, Billy, 11, we entered them both in New Britain Memorial, a hospital specializing in long-term and terminal cases. We could probably have managed Billy at home for another year, but it seemed to us that hospitalization would be traumatic enough without separating the boys as well. Billy, with his mop of straight black hair and huge hazel eyes, had never had the muscle control of lips and tongue to speak clearly. Only Ken seemed to have no trouble in understanding him. They would talk by the hour, Ken's blond head bent close to Billy's dark one, the older boy interpreting the younger one's thoughts for the rest of us. We knew they must stay together.*

*Having turned our precious sons over to the care of others, and finding that their world did not collapse, Jan and I began to wonder whether in other ways we were relying too much on ourselves alone. It was at this point in our lives that we began the great experiment at St. Paul's, turning ourselves, our family, every detail of living over to the Lordship of Jesus.*

*It was the beginning of a whole new way of perceiving reality. Not us and our problems in a box over here, others in their separate boxes over there, but all of us at St. Paul's sharing our heartaches, our defeats and victories, together. And one of the parishioners whom we drew especially close to was Edwin Ferree. When Jan and I didn't understand some spiritual concept, when something was too hard for us, we could use Ed's understanding, Ed's strength.*

Nearly four years after the boys entered New Britian, Billy caught pneumonia. The doctors saved him, but he could no longer breathe without machinery. He was moved to the Intensive Care Unit on the floor below where his older brother could be wheeled to visit him each day.

For four months, while Ed Ferree and the others at St. Paul's supported us in prayer, Jan and I made the 130 mile round trip to New Britain almost every evening. Our invariable routine was to visit Billy first, then go up and be with Ken,

On August 30, 1972, however, for no reason we could have explained, we went first to Ken. He was full of the visit he'd had with Billy. "They let me stay twice as long as usual because Billy's feeling so good. He wasn't even stuttering much."

Down in Intensive Care we found Billy just as Ken had said, hazel eyes shining as he watched television through the tubes and wires linking him to his life-support system. The TV was tuned to the Munich Olympics: Olga Korbut. Like many handicapped youngsters Billy was fascinated by physical perfection. Olga was his heroine.

Her flawless routine ended, he turned to us. "I'm going to do all those things!" he said pronouncing each word distinctly. "Just like she did."

It wasn't a question or a wish, it was a statement of fact.

Billy!" cried Jan, leaning over him. "What's the matter?" His color so ruddy a moment ago, had turned a sickly blue.

In an instant a nurse was at the bedside, then the doctor. But in spite of all they could do, Billy slipped gradually into a deep coma. Through the evening I kept thinking about the tenderness of God. If Ken had died first as in the normal course of the disease he would, being three years older, stammering Billy would have been left without his link to his world. And so in spite of all medical probability the Lord was taking the younger boy first.

Peggy, the night-duty nurse came on. The clock crept to midnight...one a.m....two a.m. And at that moment Billy's eyelids fluttered open. His eyes found Jan.

*“Thank you, Mom”. Then me: “Thank you, Dad.” Then they opened wider still, looking not at us, but beyond at something we could not see. “Oh!” he cried out. Then with a joyous shout: “God!”*

*His eyelids closed; he was again in a deep, unreachable coma. Peggy and I bent over the bed; Jan closed her eyes, praying. After about 20 minutes something like a warm breeze blew past me in the still air. The same instant Jan opened her eyes.*

*“Billy’s gone,” she said  
“I know.”*

*At three o’clock we went upstairs and woke Ken. He made us tell over and over again about the look on Billy’s face as the curtain between earth and Heaven drew aside. When the day nurse came on Ken asked her, “Can I be the one to tell the kids about Billy?” I want to tell them he wasn’t afraid and I’m not going to be, either.”*

*Before leaving the hospital we telephoned Ed Ferree who had given us so much support. How glorious to tell him that we knew Billy was with Jesus.*

*I kept wondering if Billy were already swinging from the high bars in some heavenly arena. Back flips, somersaults, handstands...just like Olga.*

*And then a year and a half later, we were driving home from New Britain one final time. Nineteen months had passed since Billy’s death. Time for Ken to graduate from New Britian High, to cast his vote by absentee ballot, to handle his lonesomeness by befriending new youngsters entering Memorial, especially those with speech defects: “I can understand him, nurse. You see, he talks a lot like my little brother did.”*

*That afternoon, March 23, 1974, Ken had died. Only-this time-Jan and I had not been there. We had arrived at the hospital around 3:30 on a perfectly routine visit, to be told that Ken had passed away very unexpectedly an hour before.*

*Why? I wondered, all the long drive home. Why couldn’t we have got there one little hour sooner? I turned off the parkway at our home exit. I’d been so sure that the Lord would give us some new reassurance, some fresh glimpse of His Presence, when Ken had to leave us, too.*

*I pulled into our driveway. What were we going to tell the people at church, this time? I'd phone Ed Ferree: he'd help us think of what to say. Inside the house I dialed the number as slowly as I could. This would be as big a shock to Es as to us.*

*"Ed Ferree speaking." There was his voice on the line.*

*"We're just back from New Brit..."*

*"Ken's with Jesus," said Ed.*

*It was a moment before I could find my voice, "Yes, Ed. But how could you..."*

*"It happened at 2:30", said Ed. He hadn't been thinking about Ken especially, in fact he was down in his study digging some papers out of a drawer, when all of a sudden it was as though a movie were unrolling on a screen in front of his eyes. There before him was Ken, tall and straight, striding like a long-distance hiker up a grassy hillside, his blond hair glowing like gold in the bright air.*

*Then, as Ed watched, Ken came to a swift-flowing stream and stopped, apparently uncertain how to get across. At that moment Ed saw coming down the hill a shining figure that he knew to be Jesus. The radiant Being came to the edge of the stream and stretched His hand across to Ken. Ken reached out, clasped it, stepped easily across. The next moment both had turned and were climbing the hill together, hand in hand.*

*"That's what you called to tell me, wasn't it?" said Ed. "Ken is with Jesus."*

*The unfinished feeling disappeared. God had lifted the curtain once again. For a moment I had simply forgotten that Jan and I no longer had to depend on our own sight alone, that we had many eyes and hearts with which to know Him.*

*"Yes, Ed," I said. "That's what I called to say."*

**From "Life After Loss"**

## ***The Open Door by Grace Coolidge***

*Grace Goodhue (Mrs. Calvin) Coolidge, widow of the 30<sup>th</sup> President of the United States, wrote the following poem after the death of her son, Calvin Jr., in 1924*

*You, my son,  
Have shown me God.  
Your kiss upon my cheek  
Has made me feel the gentle touch  
Of Him who leads us on.  
The memory of your smile, when young,  
Reveals His face,  
As mellowing years come on apace.  
And when you went before,  
You left the gate of Heaven ajar  
That I might glimpse,  
Approaching from afar,  
The glories of His grace.*

*Hold, son, my hand,  
Guide me along the path  
That, coming,  
I may stumble not,  
Nor roam,  
Nor fail to show the way  
Which leads us-Home.*

### ***“So, how are you doing?”***

*Something that bothers grieving people very much is the seeming insensitivity of friends and casual acquaintances who, in the days and weeks following the death, either don't mention the loved one's name at all or casually ask “So, how are you doing?” One of my grieving friends has come to dread going to church because she is afraid that one of these Sundays she will lose her composure and shout: “How do you THINK I'm doing? I'm doing LOUSY!” At the same time, she realizes that they are well-intentioned. Support group members believe that unless someone has been through it, there is no basis for understanding the degree of distress experienced by the griever. There is little comprehension of the pain such remarks cause.*

*As time goes on, our grieving friends learn techniques to deal with this insensitivity. One method is to quickly assess who is asking thoughtlessly or without really wanting a truthful answer. In that case, a proper response is a quick “Thank you for asking.” When someone seems genuinely compassionate and caring, it is fine to tell that person exactly how you are doing.*

*Another evidence of insensitivity is the void that can develop in the weeks after the death. Just when a grieving person most needs a friendly call or visit, people have disappeared. One explanation is that others don’t recognize the pain. Another is that the grieving person’s pain is very uncomfortable for friends and relatives to witness. Absence is their way of sparing themselves the discomfort. As wonderful as it would be if the community recognized signs of normal pain and grief and loneliness, the fact is they don’t. What is more, the grieving person is responsible for creating and using a support system.*

*If I am lonely and sit around waiting for someone to call me, I will become more lonely, then self-pitying, then angry at those who don’t come or call. If I am lonely and pick up the telephone to ask for support, then I am taking in hand the tools that are available to me. If I am aching from the loss and feel that my expressions of grief are a burden to my family, I have the choice to suffer alone and in silence or to reach out by finding a support group or calling an understanding friend or minister or rabbi for a visit.*

*What it comes down to is that I own my grief and I own the choices I make about it. Sitting and waiting for someone to take care of me doesn’t work. Waiting for people to become sensitive is unrealistic. Assessing what I need and then asking for it may be the harder choice but it also is a choice that takes responsibility for my own feelings and my own needs. I would love it if others would change but I don’t have the power to cause their change. I do have the power to take care of myself and find the supports I need to get through my rough times.*

*Jim Mulcahy*

**From “Help Along the Way”**

**A small tear relieves great sorrow. -Proverb**

## **A Climate for Children to Grieve**

*As a parent, you want to help your children deal with the loss they have suffered. The last thing you want is to compound the loss. Yet three factors conspire to make it possible for parents not to see the extent of their children's grief. One powerful factor is our adult reluctance to know that our children feel terrible pain. To know how much our children are suffering brings with it the obligation to help. If you know that your children are hurting as badly as you are, then you must do something. When you are immobilized by your own pain, you simply may not have the strength to help anyone else. It may be easier to believe that the children are too young or don't understand.*

*Children's more limited capacity for verbal expression is a second factor that makes it easier not to see their grief. Children are simply not as articulate as adults; the younger the children, the less capable they will be of putting their feelings into words. Young children may feel their loss as intensely as their parents do, yet never speak of it. If you do not speak of the dead child, the events surrounding the death, or of your own feelings, surviving children may feel forbidden to speak. Or they may simply be unable to find words for what they feel.*

*Children also take breaks from grieving; they can play with their friends or become absorbed in a television show, or beg to go to the circus even in the midst of their own intense grief. What for children is necessary respite from overwhelming sadness may look to their parents as evidence that they simply do not feel the loss.*

*A third factor that tends to obscure children's grief from their parents is children's exquisite sensitivity to their parents' tolerance for painful feelings. If children sense that a parent cannot bear to hear their feelings, then that parent will not hear them. The children will suppress their feelings, even at considerable cost to their own well-being.*

*Children can begin to deal with their own loss when you, as parents, grieve, allow your children to know of your grieving, and can hear your children's feelings. In chapter 8 we look more closely at how children experience grief at various ages and how you can help your child.*

*It is essential that grieving children maintain their connection with their parents. In her essay "Loss and the Family: A Systemic Perspective," family therapist Monica McGoldrick speaks to the healing potential of connectedness: "When families come together and share the grief experience, quite positive changes are likely to accompany the distress, strengthening the family unit and all members...Families can develop a clearer sense of life priorities, and increased valuing of relationships, and a heightened capacity for intimacy and empathy."*

*Achieving these positive changes requires time and hard work; grieving is indeed a long haul.*

**From "The Worst Loss" - Barbara Rosof**

## **Tools and Resources for helping children grieve**

### **Preschool to Early Elementary**

#### **Make A Feelings Activity Bag**

*Find a canvas tote bag or shopping bag with handles. Let the child decorate the bag with pictures of family and/or the loved one and assure the child that this is her/her special "feelings" bag to be used and played with whenever needed. Take the child shopping (or find around the house) some of the following items:*

***play-dough-for banging when needed or shaping into interesting forms when talking or thinking***

***pad of paper and special crayons/markers-for drawing pictures, writing expressions of feelings or writing notes to the loved one***

***picture frame-for choosing a special picture of the loved one that is the child's to keep***

***flower seeds or tree seedling for planting in a special place so that every year the loved one's memory can bloom again***

***stuffed animal-whether it be a teddy bear, a rabbit, a dog or a penguin, make it a special animal that is reserved for hugs, whispers, tears and smiles, songs and memories of the loved one***

***a stress ball-balloon filled with cornstarch and flower that can be squeezed to relieve tension***

***a “mood” chart-you can buy a commercially ready one(see bibliography)or make one on a large piece of paper or construction paper let the child draw faces that express different emotions (e.g. happy, sad, afraid, angry, confused, ect.) and use this as a conversation starter to let the child show what he/she is feeling at the time***

***a “nerf” ball-safe to throw, hit, bang or squeeze***

***Other handy items to have:***

***a rice box - fill a large box with rice for expressive and creative play. (It is easier to keep and easier to clean than a sand box)***

***family dolls - find some dolls that represent members of the family through which a child can play act some of their feeling, fears and hopes***

***dress-up clothes-for playacting and expressing feelings through play***

***age-appropriate books on the subject of feelings and/or loss***

***Late Elementary Through Teen-Age***

***Mood Chart***

***As mentioned on the early years page, whether you purchase a commercially prepared one from “How Do You Feel Today?” Company or make one on poster board at your house, this is an excellent way to begin a conversationalist like a teen.***

***Memory Box***

***Find or buy a box that can be used specifically for keeping memories of the person. Pictures, letter, a piece of jewelry, the funeral service program, a flower, a letter that the child writes to the loved one might be things with which to start the box.***

## ***Memory Book***

***There are commercial versions of this on the market, or your child may just want to get a blank book to have a place to put memories, express their feelings or tape important mementos. Or use a cassette recorder and let your teen record feelings, emotions or thoughts as they come. They could also record favorite songs that remind them of happy or sad times.***

## ***Planting***

***As mentioned above in the early years list, children of all ages appreciate the opportunity to plant something to memorialize the person. After the Oklahoma City bombing, almost every school in Oklahoma City planted a tree in memory of the victims.***

## ***A Safe Place for Feelings***

***As mentioned in the book, a scam pillow, a special stuffed animal or a punching bag are all ways to communicate to the child that emotions are all right and there are safe ways to handle them.***

## ***The Cemetery***

***If the loved one is buried in a location where you have access to visiting, let the young person help plan what to take to place on the site a various times during the year. Many families try to keep flowers or decorations on a burial site current with the seasons and your child might enjoy picking out some of the items and themes that will be used.***

## ***Pictures***

***Some people feel that they must remove pictures so that they won't be seen and remind the family that someone is gone. Whether pictures are out or not, no one is going to forget that the loved one is no longer there. Most experts agree that leaving pictures out that were normally in the house is the best approach. Even choosing one special one that a child can keep in their own space helps the young person know that when someone dies, everyone else doesn't rush to erase the image.***

## **Conclusions**

***No one is dead until they are forgotten. It is never too early to learn the importance of keeping another person alive through memories, stories, pictures and the impact that person had on many lives.***

***Cherishing memories can often teach volumes about treasuring the joys and opportunities of every day living - a vital lesson to learn as children walk through those difficult adolescent and young adult years.***

***As the child progresses through these activities, their questions, fears, anger and anxiety, which we call grief, will have an opportunity to have a voice and find a resolution.***

***from "Lean on me Gently" - Doug Manning***



***When you find yourself doubting your capacity to recover, be patient and realize that the grief process, though lengthy, ultimately does bring healing.***

## **A Bereaved Parent's Wish List**

*Reprinted with permission, Compassionate Friends, Oakbrook Illinois*

- *I wish my child hadn't died. I wish I had him back.*
- *I wish you wouldn't be afraid to speak my child's name. My child lived and was very important to you also.*
- *If I cry and get emotional when you talk about my child I wish you knew that it isn't because you have hurt me. My child's death is the cause of my tears.*
- *You have talked about my child, and you have allowed me to share my grief. I thank you for both.*
- *I wish you wouldn't "kill" my child again by removing his pictures, artwork, or other remembrances from your home.*
- *Being a bereaved parent is not contagious, so I wish you wouldn't shy away from me. I need you now more than ever.*
- *I need diversions, so I do want to hear about you: but I also want you to hear about me.*
- *I might be sad and I might cry, but I wish you would let me talk about my child, my favorite topic of the day.*
- *I know you think of and pray for me often. I also know that my child's death pains you, too.*
- *I wish you would let me know those things through a phone call, a card, note or a real big hug.*
- *I wish you wouldn't expect my grief to be over in a short period of time. I wish you could understand that my grief will never be over.*
- *I will suffer the death of my child until the day I die. Grief is a life long process.*
- *I am working very hard in my recovery, but I wish you could understand that I will never fully recover.*
- *I will always miss my child, and I will always grieve that he is dead.*
- *I wish you wouldn't expect me "not to think about it" or "be happy".*
- *Neither will happen for a very long time, so don't frustrate yourself.*
- *I don't want to have a "pity party", but I do wish you would let me grieve. I must hurt before I can heal.*
- *I wish you understood how my life has shattered. I know it is miserable for you to be around me when I'm feeling miserable. Please be as patient with me as I am with you.*

- *When I say, “I’m doing okay”, I wish you could understand that I don’t “feel” okay and that I struggle daily.*
- *I wish you knew that all of the grief reactions I’m having are very normal.*
- *Depression, anger, hopelessness and overwhelming sadness are all to be expected.*
- *So please excuse me when I’m quiet and withdrawn or irritable and cranky.*
- *Your advice to “take one day at a time” is excellent advice. However, a day is too much and to fast for me right now. I wish you could understand that I’m doing good to handle an hour at a time.*
- *Please excuse me if I seem rude, certainly not my intent. Sometimes the world around me goes too fast and I need to get off. When I walk away, I wish you would let me find a quiet place to spend time alone.*
- *I wish you understood that grief changes people. When my child died, a big part of me died with him. I am not the same person I was before my child died, and I will never be the same person again.*
- *I wish very much that you could understand my loss and grief, my silence and my tears, my void and my pain, BUT...I pray daily that you will never understand.*

From the Compassionate Friends

**Happiness is...**

- **Closing my eyes and seeing my child, smiling.**
- **Finding a box full of school papers saved since kindergarten and reading how my child thought back then.**
- **Having a friend who will cry for you before you even start. Friends like that are hard to find.**
- **Sitting in the yard on a warm summer afternoon and seeing a beautiful butterfly moving between the flowers in the garden.**
- **Having a father’s day card hiding away in a place where only you can find it and read it...often!**

**Build a living memorial this spring**

After our children, what could be more beautiful than the colorful petals of a flower, more delicate than the wings of a butterfly or more heart lifting than the song of a bird ? Please see next page.....

Connie Jackson has spoken briefly before of her memorial garden to her children and the story below, from Paula Pohren, tells of her special garden in memory of her daughter, Laura.

Laura was diagnosed as 'legally' blind on the first day of school her second grade year. She came home from school, after a few days, and was all excited because the teacher told them they were to put together a butterfly collection. Steve and I just looked at each other. How could she collect butterflies when she couldn't see them? So, over the Labor Day week-end, Steve and I chased butterflies so she could have her collection. Each year, during the Labor Day weekend, when I see the monarch butterflies, I remember.

It was the next summer when the doctors gave us the diagnosis of Batten's Disease.

During the previous winter, I remodeled Laura's old bedroom. I felt kind of guilty for getting rid of the pink carpeting that she had wanted so much back 20 years ago. However, I did replace the pink carpet with a light yellow carpet. I painted the walls yellow and added a wall paper border that has a picket fence, flowers and butterflies. I kept going back to the butterflies in decorating the room and I couldn't understand why I was so drawn to butterflies.

One of Laura's second grade teachers came to her funeral visitation and told me that she would always think of Laura when she saw a butterfly. Then, everything kind of came together for a time. I had forgotten about the butterfly collection. But the teacher's words reminded me and made me realize that we still have Laura's room in our home.

We were given a beautiful little cherub statue in memory of Laura from my aunt and uncle and families. After the funeral, Steve and I created Laura's flower garden around our front porch with the beautiful outside flowers that were given in her memory. The cherub sits in the middle of the flowers.

About two weeks after her death, I was thinking about all the stories that you read where someone receives a sign from God after the death of a loved one. I was wishing I could have some kind of a sign that was Laura saying, "I'm OK, Mom, don't worry about me." That evening when I got home from work, I walked up to the front porch and there were butterflies fluttering around the flowers. I had my sign from God!

by Paula Pohren

**In Closing... How has hope been reborn in you? What or who has brought you comfort? Your story is unique and valuable, healing to others. I'd love to hear from you.**

**Connie Jackson**

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