

The

LIGHTHOUSE

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Batten Disease Support and Research Association

Reflections

Outside on Mossy Bank the “big one” has arrived, sleet and snow are driven by gusts from the southwest. I have been house-bound for two days, blocked in by four-foot drifts. Now I hear the growl of my neighbor’s monster tractor burrowing its way through the snow. Sandy plows me out while Elizabeth, her daughter, shovels the porch. They refuse pay “Just want to help you,” Sandy explains.

This kindness that makes a rough winter bearable reminds me of “earth angels”. These were unexpected people who gave special care to Karen, Jon, and David as Batten disease took its toll. A “foster grandmother” visited Karen weekly those last months in the hospital. Stripped of speech, unable to eat much, my daughter surprised me one afternoon. “One, two, three, four, five, six, seven, eight, nine, ten, eleven, twelve, thirteen, fourteen...” Karen counted. “I’m going to be fifteen, she clearly announced. Wow! While I saw only the devastation of the disease, her adopted Grammy worked with her potential for learning, My daughter’s last birthday was extra special.

With Jon it was Gerald, his big black roommate at school for the Blind. Every night he taught my son wrestling moves, state heavyweight champion, patiently working with his weaker friend. Once Jon came home, almost pinning his opponent. “He was like spaghetti in my hands,” he gloated. Gerald was cheering from the sidelines as his friend had his best match ever.

David’s earth angel, David Gray, his one to one aide at School for the Blind, took him motorcycling, dancing, and bowling. When agitation mounted, his aide knew how to calm him. The antidote? Listening to Bible tapes and later a bubble bath. “I liked that dude’s spunky spirit,” David Gray recalls.

You too over the years have written moving tributes to the people who cared for you and your child(ren) when you needed it most. You and I in turn have opportunities to reach out to others who are trying to keep their heads above water in the wake of Batten disease.

In this winter issue of “The Lighthouse”, you’ll find a thank you sonnet to a listening friend; a sister’s beautiful poem of appreciation in memory of her brother; and a tribute of thanksgiving to Jordan Anderson which captures his spirit and the gift of those who helped care for him. Other poems and articles will help you face the loss and understand the feelings of you unaffected children. My prayer is that you will find light for your journey.

Peace and joy.
Connie Jackson, editor

A Thank-You Sonnet for a Listening Friend

By Claire Matlock McLean

On October eighth, nineteen-ninety-four,
Our beautiful daughter, Emily, died
Like her older sister five years before;
While silent tears rolled down our cheeks, we cried.

November thirteenth in eight-nine,
Erica had quietly slipped away,
Body emaciated- no life signs...
Yet for her, it was a Glorious Day.

Our two sweet daughters and our infant son
At times don't seem so very far away.
We miss them terribly- they died so young,
And I thank you for listening today.

To parents whose grief never seems to end,
How priceless is an understanding friend!

-January 19, 2004

OUR TRIBUTE TO JORDAN...

As we think of Jordan, many words come to mind... brave, trusting, a real character, undemanding and a love so pure. He truly is an inspiration. It is unbearable to imagine all these beautiful qualities denied to us but then he has left us with a lot to be grateful for.

In Jord's 9 years, has taught Vanessa and me so much about parenting and life. Cody too, has been touched by a special brother and in time will learn more of its meaning.

We know that he gave us the strength to give him all we could and that every day, with one's child, is so precious. It is little things that come to mind like the time Jordan was found to be smothering himself with blockout, so priceless, his once contagious laugh captured in our memory.

He showed us how priceless life is when I think of him playing, uninhibited of clothes, sitting in the garden, pretending to talk to me when he thought I was flying. The stories he could tell.

So much has happened in 6 years of his struggle. Endurance of many things proved his courage and determination to stay with his family. It has been a privilege and honour to bring Jordan into this world and to be there as he departed it. A million photos and videos will always keep our Jordan with us. Words are not enough to capture Jordan's life, even for the short period of time that we had him.

We were able to give Jordan the care that he so needed and deserved, through the support of family, close friends and all the care-providers that have been a part of every day during Jord's life. To each of you, we thank you from our heart.

Jordan, now that you are free of your battle, watch over us and do all the things that you were unable to do. We'll always love you. Now you are at peace.

Graeme, Vanessa and Cody Anderson.

The Face of Grief-Death by John Dreshcher

"What man is he that liveth, and shall not see death? Shall he deliver his soul from the hand of the grave?" Psalm 89.48

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

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

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

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

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

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

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

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

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

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

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

From "Grief's Lone Hour"

A Tribute to Logan

from his sister Tabatha

No one knew the pain you felt,
No one was faced with the hand you were dealt.
In your bed you were confined,
As the hours you lived were to be timed.
Playing was something you couldn't do,
Warming a person's heart, that was for you.
With your long eyelashes and a smile on your face,
No one on earth could ever take your place.
Your life was too short and this we know,
No one could imagine that you would have to go.
In our hearts you will stay,
In our words as we pray.
In our thought, our pictures we find,
There you'll be, on our mind.
All the pain has left you now,
Someday ours will too, some way, somehow.
I hope you're better being up there,
I know there's so many people who already care.
Look for your brother, he'll be right there,
He'll also agree it just wasn't fair.
At least you're together and waiting for us all,
To you guys we'll come, when we get our call.
Just have fun and live your life,
Now that it's not filled with strife.
We love you still,
And we always will.

Love, Tabatha "2003"

The Horse on the Dining Room Table

A colleague of mine, the late Dr. Richard Kalish, was one of the pioneers in the field of grief counseling. He used to tell a parable of the horse on the dining room table. He would ask his listeners to imagine a dining room table elaborately prepared for an exquisite holiday dinner. It would be beautifully set with the best china and the finest crystal. The meal would be lovingly prepared, each dish a joy to see and taste. Only the finest wines would be offered. The decorations would be carefully chosen, every one carefully selected to reflect the theme.

But in the midst of his fabulous feast right on the table, was a horse. He would lie on the table, present but so out of place. The guests all realized he was there but no one would say anything lest they would break the mood. People would pass dishes over and around him; they would talk about every other subject. Yet, no one would ask the obvious, troubling question, "What should we do with this horse?"

Kalish's story was meant to be a parable about death. We all know it is there, but we refuse to talk about it. I often think of this story around the holidays. We experience grief keenly during the holidays, yet we are reluctant to talk about the person who died, to handle our memories and our grief. Like the horse, it just lies there. We need to name that horse.

Grief can be thought of as a roller coaster of reactions. We have good times and bad times- highs and lows. For many of us, the holidays are a predictable low point.

There are many reasons for that. The holidays are centering moments in our life-full of memories. We remember the Thanksgiving when the turkey was under-cooked, the Christmas we received the bike, or Grandma's special Hanukkah treats. It is natural that at these times, memories flood our mind.

There may be other reminders as well. We see gifts that seem perfect or recall a gift given or received by the person we still mourn. Cards may still come addressed to that person.

It is so easy to feel so different. In the midst of a joyous season, our own grief seems out of place. And our mood is further darkened by the shorter days and isolation that cold and night bring.

The grief is ever present.

We need to acknowledge our grief. We also need to ask how we will handle our grief.

We cannot run from, avoid, or deny our grief. It helps to invite our grief into our holiday. It will be there anyway. We have a ritual in our house. Each year, when we decorate the tree, the first ornaments we put on are memorial ornaments to three people we so miss: my parents and my godson's father. It offers opportunities to share memories and to tell stories. In the early years, we may even have cried as we did it. It gave us that moment to do so-to mourn our loss together, talk about our grief, and share our memories. It gave us permission to name the horse.

By Kenneth J. Doka

The Faith of a Child

I'm sitting down to write on a Sunday evening, having just returned home from our church service. When we got home, there was a mess awaiting us. A new member was added to our family over the Christmas season. A puppy named Simon. And as anyone who has ever had a puppy knows, the idea of owning a puppy is far more romantic than in reality of it. I find I must remind myself that it really did seem like a good idea at the time we got him.

Mid November, Justin's braille teacher wanted him to start working on his Christmas list. We did not realize that Justin had included a dog on his list until his class interview the first week of December. We had already got him a cat about a year ago. He kept telling us that Alvin was lonely and needed another cat. I assured him that Alvin was fine, and there would be no more cats in the house. Being the persistent child that he is, he then decided that if there was not to be any more cats, then a dog would do just fine!

On December 1st, Scott's grandfather passed away. Grandpa loved dogs. In fact he raised beagles, and had six at the time of his death. That Sunday night, as we sat down to tell the children that Grandpa had gone to heaven that night, Justin could only think of one thing. "Who's going to look after Grandpa's dogs? What's going to happen to the puppy?" In fact, Justin was so focused on the dogs, that Jennifer was more than a little annoyed that he didn't seem to be at all concerned that grandpa had died.

The next day at work, a peculiar thing happened to Scott. A lady came to him and asked, "Do you have any dogs?" Scott replied that no he didn't, but that his grandfather had just passed away, and that the family had six beagles to disperse.

The lady told Scott that her husband worked for the company that made milk bones for dogs, and through a mix up on an order, they ended up with six extra skids that they were giving out to the public. She asked Scott if he would like some, and proceeded to load two cases (24 boxes) of milk bones into the car.

The next morning we told the kids what had happened. Justin of course was very interested in this. "Jesus is going to give me a dog, isn't He?" From that moment there was no question in his mind. As we proceeded through the funeral, and all the events surrounding it, it became more and more apparent that we would be getting grandpa's only puppy. Justin became more confident that it would happen, and mom became more aware that her desires to remain a one pet family were being "submerged." She finally gave in with an, "If your can't beat'em, join'em" approach.

The faith of a child can be so simple. Justin was so optimistic that the milk bones meant that a puppy was on the way. Jesus says that for us to enter into the Kingdom of God, we must become as a little child. A child is so trusting in his parents. As adults, we can complicate the issues of faith, especially when trying to understand the 'whys' of our circumstances.

None of us are looking for the milk bones of life. According to Justin, they don't taste very good. But Justin was able to see that something greater was yet to come. Justin reminds us of the little boy, digging around in a pile of manure, believing there must be a pony there somewhere.

As we all struggle through our "whys", let us trust our Heavenly Father that somewhere beyond where we are now, that He has a greater reward awaiting.

The Faith of a Child; Scott and Faith Cross, parents of 2 children with Batten disease, Justin and Sara-Dyan.

Watch For Internalized Anger

There is anger in grief. It is there because anger is the natural response to hurt. We may not recognize it as anger because it feels more like hurt, frustration or just being upset. Anger is actually helpful in the grief process. It becomes the motivator that pushes us toward coping. We hit bottom, get mad, and fight our way back.

Grief also causes anger in children. Just like adults, children need a way to vent off some of this anger. Sometimes we need some physical way to “let off the steam.” I am including some pictures of a place called “The Kids’ Place” in Edmond, Oklahoma. This center for children in grief started as an outgrowth of the Oklahoma City bombing. Two of the pictures are of their “Emotion Commotion Room”. This is a small basement room that is padded and soundproofed. They have a punching bag there and several other tools for physical outbursts. When a young person feels the need, he or she can go to the room and cry, scream, or punch the bag in peace. I call this the scream room.

I have two friends whose sons died in car wrecks. They put Easter eggs on golf tees and blasted them with golf clubs. Sometimes we just need to let it out.

The problem with anger is it needs a place to focus. It is not enough to be angry, we need to be angry at something or someone. The anger will find a place to focus. When a child acts out in school or starts having fights they are just finding a place for the anger. The person on the other end of the fight did not have anything to do with the cause of the anger, but they are handy. When I found out my brother was dying of cancer, I cried for two days and woke up the third day mad at my wife. That is normal and it needs to happen.

The focus of anger I worry about is when we turn it inward and start focusing on ourselves. When a person starts doing this they will begin to obsessively play the game of “If Only.” Notice I said obsessive. We all play some “if only”. When a person is internalizing anger they will build elaborate scenarios to prove it was their fault. One lady thought her daughter-in-laws murder was her fault because she accompanied the couple on the trip to look for an apartment and had been the one to find the apartment where the murder happened. She would say, “If I hadn’t found that apartment, they would not have been in that apartment, so it is my fault.” That is internalized anger. A lot of the guilt we feel in grief is really not guilt, it is internalized anger making us feel guilty.

Children also internalize their anger. I talked with a nine-year-old girl whose father had been killed in a car wreck a few weeks earlier. She said, “I should have been with him. I should have been there.” Now what is a nine-year-old girl able to do about a car wreck? She was turning all the hurt feelings in on herself.

The strange thing is we do not change the focus of anger by changing the focus of anger. That is another way of saying we cannot change the way people feel by changing the way they think. If we can help people realize that anger is what they are feeling, and let them express it without a lecture on how they should feel, the anger will change focus on its own. I could have said to the girl, “Now you know your father would not have wanted you there, you might have been hurt and he would not want that to happen.” Instead I said, “You seem to have some bad feelings about your daddy’s death.” In nine-year-old language and for a nine-year-old length of time she told me how angry she was even though she did not know it was anger and did not use the word.

When we allow our children the right to be angry, and when we give them the chance to talk out the feelings instead of trying to force the feelings to change, the anger is lessened.

From “Lean on Me Gently” by Doug Manning

The Seasons of Grief

All Winter we looked forward to Summer. It arrived and now is rapidly moving towards Fall. It becomes difficult sometimes to remember what day it is as the tasks pile up and our duties and family responsibilities carry us forward.

Grief has seasons too. The seasons of grieving don't move as orderly as Summer, Fall, Winter, Spring but they too have their characteristics.

In the Spring of our grief, it is all new and grows faster than we can comprehend. Everything and everywhere reminds us of our pain which seems to fill every corner of our being. The rains of grief's Spring are the tears.

In the Summer of our grief, we are surrounded by the fruits of our pain. We have days that are comfortable and seem manageable and days when our discomfort seems to take away the very air we need to breathe. But there are also good and comfortable days.

In the Fall of our grief, we begin to shed some of the defenses we have placed around us. Just as the trees shed their leaves, we begin to shed isolation and loneliness as we join little by little in social, community and family events and manage to look forward to them sometimes.

And in the Winter of our grief, we rest, just as the earth rests from its season of growth and harvest. We take comfort in our memories and in our love and look forward to the next spring when we will grow once again, this time as a new person having realized what it means to go on.

And in each season come the unexpected storms that take us by surprise and cause us to run inward to escape the turmoil. But after the storm, the sun shines once again.

Jim Mulchahy from "Help Along The Way: Living With Grief"

Three Doors

The first door was the death. It slammed shut, was locked and sealed. It separated me from my loved one. It was a heavy, cold steel door. I can never open it. It leaves me alone outside.

The second door swings open and beckons me to come inside. It leads to all my memories of our life together. At first, the door is wide open as I spend most of my time back inside reliving every precious moment-the sad memories, the bad memories, and thank goodness, the very special good memories. Gradually, I spend less time there, but often I return to the second door.

Sometimes I find myself spending a lot of time there. Sometimes I chuckle and leave appreciative and happy for the experiences we shared. The second door welcoming me back in time. The more I heal, the more I walk away from the second door and toward the third door.

The third door is stiff. It is hard to open. It opens slowly. It is scary inside when I first open it, but each time I try to open this door, it becomes easier to open. Inside, I find rays of hope. Beyond are many paths, many choices. As time passes, I feel more comfortable entering.

Gradually, the third door opens wider and I find myself able to explore all that is within. Soon the paths take me in many directions. The door opens up my new life.

by Pat Dickerman, Hacienda Heights, Ca.

Sweet Memories, Sweet Pain

Have you ever kept pain so deep inside
that you thought it was gone, thought it had died?

“Til one day you find the pain you’ve been keeping
had not really died, it only was sleeping?

And when it awakens, you find that the pain
hurts in a way you cannot explain.

It still makes you weep and cry tears like a flood
But this time it’s different, and it almost feels good

You’re not so afraid to let yourself feel
the sadness and heartache that may never all heal.

It comes now to caress you and lets your heart know,
it need hide no longer from the pain that won’t go.

by Maureen Cummings
Orlando, Florida

**Sympathy sees and
says “I’m sorry.”
Compassion feels and
whispers “I will help you.”**



**Remind yourself of your reasons for living. You have a future worth
enduring for, and you deserve a renewed sense of purpose and
pleasure in your life.**

A Safe Place

**To the family facing grief,
the home must become
the safe place to be
For no place on earth feels as
safe to us
as home.**

Special thanks to: Kim Chance, Mother of Allie, 1998-2002, For her help with this issue of The Lighthouse.

In Closing...

I invite you to send your story about your child's own special "earth angel", someone who came to help and care just when you needed it most. It will be and inspiration for each of us to other who need reassurance and a listening ear. You are in my thoughts and prayers.

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