

The
LIGHTHOUSE



Autumn 2001, Volume 4, Number 3

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

Reflections

Why are Thanksgiving and Christmas so difficult for those who have lost a child? Because these gatherings are family times, and that empty place hurts. Memories come flooding back.

One Christmas Eve Davey hid with big sister Mim behind the loveseat in the living room. At age 8 he still believed in Santa Claus. Batten Disease had taken most of his sight, but those keen ears were listening. Sure enough, jingle bells, tread of boots, and a hearty “Ho - Ho” fired his excitement.

“Hey, Santa !”, Dave called out. St. Nick (alias Pete Stickney in red suite and beard, Mim’s boyfriend) left presents, shared a cookie and clomped off into the snowy night. “Wow ! I saw Santa !”, Dave exclaimed. We cherish the memory.

It’s important to talk about these precious moments when you celebrated holidays with your child/ren. In this Autumn edition of The Lighthouse there will be suggestions for making your own memorial. On white styrofoam circles I have glued photos of Karen, Jon and David with touches of sparkly sequins and pearls. They decorate my Christmas in a small tree of angels and holy symbols. Candles, green and pictures can also create a special place to meditate and be thankful for your dear one/s.

For you who are recently bereaved, the pressures of the holidays may feel unbearable. You’ll find guidelines for easing up on “shoulds” and being kind to yourself in the midst of mourning.

Some of you have written poignant poems and stories about your brother, daughter or son. Your word pictures remind us of dear ones who’ll never be forgotten.

As we enter the holidays, may God’s peace be with you.

Connie Jackson

Raindrops from Heaven

Raindrops from Heaven - Tears of an angel you see.
To drench your souls, flood your heart, her love pure and free.
Little sprinkles of her heart’s light, refreshing and now new.
to glisten on your soul like fresh morning dew.
Let her wash over you from the heavens above, to soak into
your heart and fill you with love.
A love that is soothing as warm summer showers.
A love filled with strong emotions and healing powers.
Please cherish this love given straight from her heart.
It comes from her inner being - her soul’s deepest part.
Raindrops sent from the heavens above, are the tears of an
angel longing for her true love
Puddles are pools that she’s cried. She dreams of being with
you, being close by your side.
When heavenly skies open, the rains pouring free,
an angel is near you,
In your heart - she longs to be.....

Dedicated to: My Angel Girl Savannah B. Meras
From: Momma Melissa Meras

A word from Melissa.....

My name is Melissa Meras, I am 31 years old and my daughter, Savannah, passed away from Late Infantile Batten Disease three years ago. She was seven years old and was diagnosed with it less than a year and a half before she died.

Its been three years now since she went to Heaven and I am finally finding peace and a way to express what she meant to me. It would mean a lot to me for you to print my poem dedicated to her. I have been alone in this struggle to go on without the human presence of my daughter, Savannah. I would like to continue to send poems to be printed. It’s the best way for me to express myself and the feeling I have or am going through. This is a way to express how I feel when there’s no one to talk to.... Enclosed is my home phone number, address and email address.....

Melissa Meras
1059 W. 7th. St. Upland, CA 91786-6302
909-946-6764
Abgelicskysz@yahoo.com

Editor’s note: Melissa puts into words how so many of us feel. Words like “struggle” and “alone”. We parents, who have lost a child/ren to Batten Disease can certainly empathize. Just as we reached out to each other for information and support when our children were alive, let’s continue to reach out to each other now.

Thanksgiving for the Memories

My dad died over twenty years ago at a time when I was out of the country and unable to return for his funeral. I thought I had done all the grieving I needed to do, including the guilt I felt for not being there for my mother and sister. A number of years after my father's death, I was working as a hospital chaplain. I had a patient who was very much like my dad: Irish, grumpy, talkative, rough in manner but with a heart as big as all outdoors. I enjoyed my interaction with him and was rather surprised that when he died my feelings of loss were out of proportion to my relationship with him, which was, after all professional, not personal. A friend of mine was wise enough to point out to me that I was still grieving for my father. The likeness of the patient to my father triggered emotions that I thought were long settled. I learned through that experience that grief does not just finish and go away. The place in my heart that belongs to my dad can never be filled.

That experience also helped me to begin to reflect on my father. I admired him very much and think I am probably like him. I, too, have become a grumpy Irishman who loves to talk and tell stories, who is often not easy to get along with but whose bark is worse than his bite, whose heart manages to find room for whoever crosses his path.

This Thanksgiving I will spend time reflecting on my dad and on the many other friends and relatives who were a joyful part of my life and who have died. I am grateful for the memories.

Jim Mulcahy

My Memoir About Kristopher

I remember the night before it happened, the feeling that something was wrong and the panic that went around in the room. I've felt this way before but it was never this intense. While sitting there watching my parents work on him, I thought about how delicate and fragile Kristopher was that night, but he was everything but fragile. He was actually fighting the end of his fight. Finally after what seemed like hours of sitting there worrying about him, my mom said it was ok and I went to bed. As I walk out of Kristopher's room I really did think that now everything is ok because I have had this happen to me many times before and everything usually turned out to be ok. But this time it was going to be different.

I look back on it now and really do wish I would have stayed in his room a little longer and really thought about how much I loved him and just say good night a little longer. But I didn't know at the time that this would be the last time I would be able to say good-night to him. So I walk into my room and the minute my head hit the pillow I was asleep. The next morning I was awoken by my cousin Tay-Tay who was staying at my house for the summer and I got angry. I got angry because I never wake up that early during the summer. It was 8:05 and

she told me she had heard my mother screaming and crying and this sent me into full panic, and right as I opened the door there she was tear stained cheeks, coming to wake me.

As soon as she saw me she took me into her arms and told me he was gone. That was the end of his life and the end of his fight. A fight that was well fought and one that he would have won if Batten Disease wasn't such a powerful thing. I remember myself running to his room, seeing him lie there, no longer with us. My knees shook and all my sadness just burst out. I didn't think twice about him passing the night before and then there I stood, the next morning, seeing him, saying good-bye one last time, with my heart in pieces. Kristopher was only eight and was sick five years of his life but even if this was so, I still had many memories made that I will always cherish. Even if I will not get as much memories and as others will get in the years to come, they still mean the world to me and nothing can make me forget them.

The next few days passed in a blur the sadness that was felt by everyone in the family, his stuff, the thought of his not being there, never seeing him again and then his funeral. The funeral was beautiful, everything was perfect. It was honestly like nothing I have ever seen before, but the strength that it took to get through it was incredible and something that wasn't in me. The minute the funeral started I felt a tear welling up in my eye. A single tear ran down my cheek and wet the tissue that had rested in the palm of my hand. Before my brother got sick, his life was race cars, his pacifier, and a fire truck just like any average 2 year old. But since he will never again get to enjoy a passing fire truck, the silence that took place in the church right after I finished my speech was broken by a siren of a fire truck. Then eight honks in honor of the eight years of Kristopher's life. After hearing that, I cried, and I didn't stop. I couldn't and I didn't want to either. I hurt too much to stop myself.

Till this day I still feel the hurt that I felt that day but I know that I can't stop everything that goes on in world. Losing Kristopher was the last thing that I wanted to happen to him or me but there's nothing that I could have done to stop it and now he's definitely in a better place. Now that I have had time to cope with being without him I have started to realize that everything happens for a reason and I will never EVER stop loving him.

By Ashley Killebrew - Ross, Kristopher's sister

It feels good to feel merry as well as teary on Christmas Day.

You may want to do most of your Christmas grief work a day or two before Christmas or early on Christmas morning so you can have merry thoughts through the day.

Yes, you may want to check into a motel and not come out until Christmas is over, forget all *old* Christmas habits. If that's what will best get you through the day, do that.

But don't close your mind to creating new rituals to spark your *young* Christmas joy. One couple I know went on a Caribbean cruise the Christmas after a drunk driver killed their daughter.

Or you may want to change just one or two traditions, like the room where you put the Christmas tree -- fix things so the big difference isn't so stark.

Is putting up the tree or sending out cards more painful than helpful? Who else can do these things? What will happen if they don't get done? You don't have your usual energy; if you exhaust yourself physically, you'll deplete your emotional reserves just when you need them most.

Decide ahead of time what Christmas parties you will pass by this year, and build supports ahead of time for those you will join in. Prepare your hostess for your early departure. Order the gifts you bring from a catalog.

Your worst Christmas may not be your first Christmas, so don't be surprised if the pain hits you harder in later years. Be thoughtful of yourself on all the Christmases of your grief.

It feels good to give purpose to your pain on Christmas Day.

Joe and I will put a poinsettia in church this Christmas, let its bright red reflection gladden the lives of our church family. And we'll make a donation to the Cystic Fibrosis Foundation, too, in hope that children with C.F. in our world family will celebrate more Christmases than did our children.

Perhaps you'll want to invite each member of your family to choose one of their prized possessions, wrap it, and give it to someone in need. Or you may want to pick a neighbor who's out of a job and leave a box of foodstuffs at his door, quiet as a Christmas mouse.

The last suggestion calls back Christmases of my childhood when my father was out of work and our church brought baskets of canned goods, each can wrapped in white tissue paper, to our house on Christmas Eve.

I puzzled over why mother cried at such a marvel. I tore the paper of those cans in a frenzy of glee. I didn't cry -- till now.

Most of us grievors have a history of loss in addition to our current loss. We know what it's like *to be without*. Who is better prepared for a season of giving than we? Of all people, we grievors know what it means to have someone touch our pain with their love,

One thing we grievors grieve for on Christmas Day is that our *love* is missing Christmas. One thing we grieve for on New Year's Day is that our *love* has no new year ahead. No new dreams for him, or so we think. No new growth to strive for.

God gave His child to us as a gift on the very first Christmas because we are His *loves*. Nothing feels as good when we're bereaved of love as breathing in new love. God coming to me is about me since my children went away from me-- to Him.



***Anniversaries and holidays -
Times that used to mean joy and celebration -
can be among the toughest now.***

***Observe them with care and simple ceremony to
ease the pain***

COPING WITH HOLIDAYS AND SPECIAL DAYS

Holidays and special days present challenges even when our lives are running smoothly. These days bring us together to celebrate traditions or honor an individual and the absence of a loved one is deeply felt. Our first family gathering without a loved one can seem overwhelming. Often we aren't just dealing

with one day to get through, but a whole season and all the anticipation that goes with it. Other difficult days include birthdays, anniversaries, reunions and graduations. We do have some control over what happens on these days, if we choose to take it. Let's look at the four "C's" of coping with the holidays and special days.

COMMUNICATE YOUR NEEDS:

Communicate your needs and concerns to those around you. Families that sit down together and discuss the holiday ahead of time do much better and avoid some of the fatigue, resentment and disappointment that can surface. What does each family member need to make it a special day? What can comfortably be put on hold? What changes will make things more bearable? Can the responsibility for the holiday be shared among several family members?

CHANGE YOUR ROUTINES:

A few families stick exactly to traditions, but most families find it helpful to make minor, or very major changes. Having a meal at a different location or different time of day can help. Going out to eat can ease some stress. Opening gifts at a different time or location might work. Families who find worship routines too full of memories have attended a different service with a friend or neighbor. If you find yourself dreading a certain part of the holiday rituals, use your creativity to find an alternative. Sometimes, we worry that if we change or drop a tradition, we will lose it forever. It might help to be clear that we are just putting that particular piece of the holiday on hold until some time has helped with the healing.

CUT BACK ON YOUR ACTIVITIES:

Grief is physically and mentally fatiguing. You may also be experiencing some disorientation or lack of motivation and disorganization. Streamlining commitments during holidays is an important selfcare activity. You probably won't lose friends if you skip cards or send them more selectively the first year. Gift certificates, catalogs and checks can help you avoid distressing shopping trips. Limiting the time you spend at family and social gatherings can conserve precious energy. While it's important to touch base with family members and special friends, setting realistic limits is essential. If you find yourself involved in an activity that just doesn't feel good, give yourself permission to withdraw.

CELEBRATE THE MEMORY OF YOUR LOVED ONE

The word "celebrate" can also mean "to honor". Many families chose to set aside a special time or create a special way in which to honor the memory of those who are no longer there to share the special day. Some make a gift or donation in their loved ones name. Others light a candle or put out a picture or photo album. A time to share favorite stories or memories can be very valuable. Everyone will be thinking of the person who is gone away, and having a constructive way to acknowledge the loss together is helpful. Each family members presence becomes especially important after there has been a loss. You may not feel like the best company, but your loved ones still need some time with you on special days. And remember that it's all right to have some good times.

Laughter and enjoyment are still important parts of living.



Celebrate your loved one with your own memories and the memories that others share with you

This celebration will keep your loved one with you and a part of you.

CREATING YOUR OWN MEMORIALS

We now invite you to enjoy your own creativity. You may wish to adopt part of the traditions we have told you about, tailoring them to your family's tastes and needs. You may wish to venture on your own. The important thing is that rituals are part of learning to cope. We follow with a few suggestions for the thanksgiving feast, Yuletide or the New Year. Most of these suggestions are adaptable for any of the holidays or throughout the entire season. Developing a new ritual takes planning, care and love. The thought you put into it will reap you many benefits in the days to come.

1. **The Living Christmas Tree.**

Most nurseries and Christmas tree vendors now sell live evergreens that are ready to be planted in the yard after the holiday season. Planting new life to commemorate the meaning of love in your life can be shared with family and friends, who may also be invited for refreshments or a meal after the planting ceremony.

1. **Toast your loved one.**

Create a special toast to your loved one, using your favorite wine or beverage. This can be done on any of the holidays when the family is gathered together, or even when you are alone.

2. **Purchase or make a memorial candle.**

Which will be lit each morning or evening and extinguished only before bedtime throughout the holiday season.

4. **Place a single flower on the table.**

In honor of the "presence" of your loved one.

5. **Observe a moment of silence**

or prayer before the meal or another time you deem appropriate.

6. **Spend some time together as a family with the family album.**

Make it a special celebration when the past is discussed, reviewed, and re-lived.

7. **Reserve some time to tell a favorite story**

at the table about your loved one. This could accompany the special toast to your memories.

8. **Buy a Christmas present for your loved one.**

In the form of a gift for the home which will have a special place or take on a special meaning for the holiday season.

9. **Buy or create you own Advent calendar.**

You may wish to place a photograph of members of the family or close friends behind each window from December 1st to December 25th. This tradition anticipates coping slowing, day by day as the season passes.

10. **Garnish your tree.**

This year with fresh flowers, berries or other products of nature.

11. **Create Lumieres.**

to line your sidewalk or driveway. These are a Mexican tradition and are simple to make, yet lovely as they light up the night in a soft glow. All you need are brown paper sandwich bags, small candles and sand. They signify a warm welcome.

12. You may want to **decorate the altar at church** in memory of your loved one.

13. **Make a donation to charity**

in the name of your loved one or help a family in need by providing Christmas dinner for them.

Taking the Time You Need to Grieve Your Loss

I remember the dark night I was driving 55 miles an hour on the interstate and hit a patch of ice.

My reflex action was to turn the steering wheel away from the direction in which my car was sliding. As a result, I veered across the median strip, narrowly escapes hitting an oncoming semi-trailer, and finally to a stop after glancing off the back bumper of another car. Since that incident, I've learned that when driving on ice, it's a life-giving decision to turn into the slide rather than away from it.

This lesson also applies to dealing with grief. Our reflex action is to turn away from this painful process. But the life-giving decision is to meet grief head on - to turn into it, rather than away from it. As William Bridges, author of *Transitions: Making sense of life's changes*, expresses it, "The way out is the way in."

Bereaved people who believe the half truth that "time heals all wounds" often find themselves with unresolved grief years after a loss. It interferes with their ability to function productively, to engage in meaningful relationships, to live happily. It's not enough to simply let time pass.

Finding meaning in life after loss depends on what you do during your time of grief.

You need to give yourself permission to grieve for as long as you need - even in the midst of family, friends, and coworkers who may not understand, especially if they haven't "been there."

This CareNote offers some reflections about grief and practical suggestions of activities you might find helpful during your time of bereavement. It discusses internal challenges you may face as you struggle to heal the deep wound your heart has sustained. Meeting these challenges is a vital part of your "grief work".

Much important grief work is done not in activities, however, but in the inactivity of what William Bridges calls the "Neutral Zone." This is the time between endings and new beginnings - a valuable dormant time that is as necessary in our lives as rests in a score of music. This time of internal reorientation allows us to begin to shape a new identity and a perspective for how we will live our life after such a major change.

Carve out time to do your grief work.

One of the first questions most bereaved people ask is "How long does grief last?". There is no universal timetable for bereavement. Grief does not come in nice neat stages that you complete in a certain amount of time. Each person's grief process is unique because his or her relationship with the deceased was unique.

The length of the grief process depends largely on the survivor's willingness to do his or her grief work. Set aside time daily or several times a week for intentional grief work. Consider using this time to look at pictures or to put together a photo album of your loved one. Play music that reminds you of the one you are missing. Watch family videotapes. Keep a journal about your feelings. Visit the gravesite and talk to your loved one. Write a Series of letters to him or her or to God expressing your thoughts.

These activities may bring tears. Tears are the body's release valve for the emotions of grief, which can be physically destructive if "stuffed" inside. Tears are one of God's healing balms.

LEARN ABOUT THE NORMAL GRIEF PROCESS.

" I feel like I'm going crazy" is one of the most common statements made by people in the midst of grief. It is vital to your psychological, physical, and spiritual health to understand what the "normal" grief process is since it can seem so abnormal. You may experience a roller coaster of emotions, including sadness, emptiness, relief, regret, loneliness, and anxiety. You may not be able to sleep or have much of an appetite. You may feel abandoned by God. These - and many other feelings and behaviors - are common responses to loss. Spend time reading books and articles about the grief process. This can give you much needed reassurance, especially in the early days when you may feel like a traveler in a foreign land.

Attending a support group with a fellow traveler on the journey through grief can also help. Sharing your story of loss is a necessary part of the healing process, and hearing others' stories will help you realize that you are not the only one experiencing such a mixture of thoughts and feelings. Hospice programs and many religious congregations sponsor such groups.

If you are feeling "stuck" in your grief, seek out a mental

health professional or clergyperson with knowledge of grief and loss issues. Reaching out for help is a sign of strength, not weakness.



***Be with those who also grieving.
As you tell your stories, you will share
an understanding of the heart that is
deeper than words.***

CREATE A NEW RELATIONSHIP WITH YOUR LOVED ONE.

"Letting go" of a deceased loved one is a scary thought to most people. Doing grief work does not wipe out the memory of a loved one. On the contrary, one of the real challenges of this time of bereavement is to create a new relationship with your loved one without a physical presence. As Robert Anderson, playwright of *I Never Sang for My Father*, beautifully states, "Death ends a life, not a relationship."

You face the task of creating that new relationship - one of heart, mind, and spirit. Incorporating your loved one's values and passions into your own life and passing them onto others will create a living memorial that will keep alive the essence of your loved one and bring you comfort.

Allow the bittersweet memories to carve a holy place deep in your soul where you know your loved one will always be. Once that love is secure, you will find renewed energy for creating your new life. As one of my young widowed friends described it , "I know Charlie will always be a golden thread in my heart."

TAKE A CLOSER LOOK AT YOUR BELIEFS.

It is virtually impossible to experience the death of a significant person in our lives without stirring up spiritual struggles. Those struggles may involve not only our beliefs about the afterlife but also our beliefs about life in the present.

We can choose to believe, for example, that "nothing good can come from this terrible loss" or that "something positive can still come out of this." We can believe that " I will never love or be happy again" or that "it's possible I will find love and happiness in the future." Whatever beliefs we create for ourselves, we will set about gathering evidence to support them.

Therein lies the challenge for rebuilding your life. What do you choose to believe about your life and the future? Author Henri Nouwen offers this thought: "Those who expect joy to come out of sadness can discover the beginnings of a new life in the center of the old."

LOOK FOR A TURNING POINT.

"Why did this happen to my loved one and me?" is the question that reverberates endlessly in the mind of someone suffering a loss. For most people, this question has no satisfactory answer in this life.

Some people get stuck in their feeling of anger - at God, at the loved one for leaving, at medical personnel, or at themselves for not having done enough. Indulging the feeling of being treated unfairly avoids the hard but healing work of the grief process.

It's a true turning point in your grief when you are able to give up asking, "why?" and instead ask "Now that this has happened, what shall I do?" This new question acknowledges that your life has been forever changed, but that you are open to what is yet to be. Perhaps the words of Helen Keller express it best: "When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us."

Take Heart

As you journey down the path of grief, you may feel your'e wandering in a dense fog - uncertain of what lies ahead or which way to turn. You may wonder if you'll ever see the sun again.

There are signposts along grief's path, however, that will help

you to know your headed in the right direction. Days will come when your not totally consumed with thoughts of your loved one- which will create space and time for new thoughts, activities, and people. Your energy level and ability to concentrate will begin to improve. You'll be able to laugh once again without feeling guilty. Memories of your loved one will no longer double you over in pain, but instead bring warmth to your heart. You'll be able to invest yourself in new relationships and endeavors.

And then one morning you'll realize that the fog has finally lifted and you'll see the sun shining brightly once again. May God be with you on your healing journey!

Used by permission from Abby Press.

In Closing:

Just a gentle reminder that The Lighthouse would be blessed by a story or poem from you. Actually, it's you the readers, who help each other as you share your experiences with your children who had Batten Disease. That indomitable spirit shines through and we want to hear about it!

Send your contribution to: Connie Jackson
6571 Mossy Bank Rd
Bath, NY 14810



To everyone.....

Wishing you peace and joy
this Christmas season.

Connie, Debbie, Nancy and Lance