

The Lighthouse



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Reflections

I'm sitting by the woodstove, sipping a mug of hot cocoa and absorbing the warmth. It's that bittersweet time of year when dates remind me of loss. It's Jon I'm thinking about tonight. Once every four years the anniversary of his death is on the calendar, February 29th. (1959 - 1984). Etched in my heart are memories of a sturdy, courageous boy with a "can-do" spirit.

On the wrestling team at the N. Y. State School for the Blind, body limited by Batten Disease and seizure meds, Jon gave each match his all. Once he was winning by points and almost pinned his opponent. "Mom, he was like spaghetti in my hands", he told me later. At graduation family and friends cheered when Jon received the Sportsmanship Award.

March 3rd is coming soon, the anniversary of Karen's death (1952-1968). At age 15 she left this life to meet her friend Jesus. During her short time on earth she blessed us with her strong faith and giving spirit.

In the dayroom at Newark Developmental School, Karen and her friend Joyce wove an amazing potholder rug of many squares sewn together with love. How proud she was to bring this gift home to her family!

You are remembering the precious dear one(s) no longer with you. Perhaps the loss is fresh and the wounds are deep. The ravages of Batten Disease leave scars. As time passes, however, the pure brave essence of your child/ren shine through. You know that the hours of loving care was worth every minute. This edition of the Spring Lighthouse is offered to you as a guide and comfort on your journey through grief.

Peace and Joy, Connie Jackson, editor

Heartache

Our little girl has left us
And now her spirit's free
Just like a little butterfly
She's flown away from me

Just where she's gone I do not know
But what she's left behind
I'll treasure 'til my final days
In archives in my mind

Her contribution touched the hearts
Of many whom she met
In a special unique way
A way they can't forget

Our dear Michelle, who came to us
To teach us how to love
Has done her task so off she's gone
Back to her place above

I feel so sad that she has gone
But feel relieved as well
She's free from her helpless cocoon
As far as I can tell

I give my thanks for what she brought
I've grown a lot since then
And may this heartache slowly die
And let me live again.

BASIC TRUTHS ABOUT LOSS AND CHANGE

Loss and change happen to all of us.

Every change involves some loss.

Loss, though painful, can be a great opportunity for change.

Loss and death are a natural part of the life cycle.

Grief over loss is normal, acceptable, and healthy.

Grief is different for every person.

Loss is painful in proportion to the thing/person lost.

Grief over loss has no time limit; it may take longer than is usually recognized.

Mourning is a time for restoring balance.

Physical reactions to loss are real.

Dreams about the person lost are normal occurrences.

Feelings of guilt and regret are normal.

The pain of grief does ease; you won't always feel like this.

Grief is hard work; most people need to slow down and be kind to themselves for a time.

In times of change the opportunity exists for creating something new and better.

Into New Life

This is a paraphrase of an illustration that Norman Vincent Peale used in a message to speak about the Christian view of death. He said that when we are conceived, and still in our mother's womb, we feel very comfortable with our world as know it. We feel no reason to leave the warmth and security of our home to venture out into the unknown. And so the actual time of birth feels like a death to us. We no longer have our arms and legs held closely to our body. We no longer have the umbilical cord providing us all the food and liquids we need. We no longer have sounds from the outside softened by our mother's body. We are vulnerable and afraid. But we do not stay that way. We find after awhile, that all our needs are still met, although in quite different ways, and we able to find warmth and security in increased measure. At that point, we would never want to return to the home we lived in before our birth.

Perhaps our life here on earth is like that. Even though we say we can't wait to get to heaven, we fear leaving the comfort and security of our home as we know it. We are not really sure in our heart of hearts that heaven will be so much better than the support and love and comfort we now enjoy, or that we are deserving of such a place as is promised in the bible. But, like our birth, our death is also inevitable. We cannot stay here forever. I believe that "when the roll is called up yonder," and we who believe go to be with God, we will again find security and warmth and peace in a measure those on earth cannot begin to understand. We will laugh at our previous fears and worries. And we will know that once and for all, our joys and sorrows along the way were not in vain.



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

SIX HELPFUL THINGS TO DO WHEN YOU'VE HAD A LOSS

Think about you loss. Relive experiences in your thoughts. Allow the details and the emotions that come with them to be fully expressed. Explore memories as they come up. Trust that your system is bringing up these thoughts as part of your healing process. The repetition of painful memories helps flush out the strong emotions attached to them.

Talk about your loss. There is much release in talking about your losses. You may need to tell the same stories over and over as part of your healing. You may need to talk about your losses for a long time but wonder if anyone wants to hear about it anymore. Support groups are a place where you will always have the opportunity to be heard.

Write about your loss. Keeping a journal isn't for everyone, but it can be a powerful tool for healing. Writing about feelings and events can help you to focus and identify emotions. Words can constructively channel fear and pain and can create a record of your progress. There are some good books available on keeping a journal if you are unsure of how to start.

Cry about your loss. Tears can relieve a lot of pressure. Learn to trust your body's needs to cry or not to cry. There will be both wet spells and dry spells while you are grieving. Individuals use tears differently so respect your own relationship to tears. Be sure you aren't telling yourself that tears mean that you are weak or out of control.

Make space for your loss. Sometimes people lose their routines when someone dies and may feel that they have too much unstructured time in which to grieve. Others are so busy that they need to create quiet moments in which to work with their feelings. Sometimes you need a down day just to sit with your loss. Other days, you may feel the need to be as busy as possible. Respecting your needs for healing time and creating opportunities to grieve is important.

Take care of your health after your loss. Do your best to get adequate food and rest. If you're due for a physical or have put off some health screening or follow up, make an appointment. Exercise can release a surprising amount of tension, anger and frustration. Try to get out of doors in the fresh air.

Understanding grief

Grief, with its many ups and downs, lasts far longer than society in general recognizes. Be patient with yourself.

Each person's grief is individual. You and your family will experience it and cope with it differently.

Crying is an acceptable and healthy expression of grief and releases built-up tension for the bereaved person. Cry freely as you feel the need.

Physical reactions to the death of a loved one may include loss of appetite or over-eating, sleeplessness or sexual difficulties. The bereaved may find that he/she has very little energy and cannot concentrate. A balanced diet, rest and moderate exercise are especially important for you at this time.

Avoid the use of drugs and alcohol. Medication should be taken sparingly and only under the supervision of your physician. Many substances are addictive and can lead to a chemical dependence. In addition, they may stop or delay the necessary grieving process.

Friends and relatives may be uncomfortable around you. They want to ease your pain, but do not know how. Take the initiative and help them learn how to be supportive of you. Talk about your loved one so they know this is appropriate.

Whenever possible, put off making major decisions (changing residence, changing jobs, etc) for at least a year.

Avoid making hasty decisions about your loved one's belongings. Do not allow others to take over or to rush you. You can do it little by little whenever you feel ready.

The bereaved may feel he/she has nothing to live for and may think about a release from this intense pain. Be assured that many bereaved persons feel this way, but that a sense of purpose and meaning does return. The pain does lessen.

Guilt, real or imagined, is a normal part of grief. It surfaces in thoughts and feelings of "if only". In order to resolve this guilt, learn to express and share these feelings, and learn to forgive yourself.

Anger is another common reaction to loss. Anger, like guilt, needs expression and sharing in a healthy and acceptable manner.

Children are often forgotten grievers within a family. They are experiencing many of the same emotions you are, so share thoughts and tears with them. Though it is a painful time, be sure they feel loved and included.

Holidays and the anniversaries of your loved one's birth and death can be stressful times. Consider the feelings of the entire family in planning how to spend that day. Allow time and space for your own emotional needs.

A loved one's death often causes the bereaved to challenge and examine his faith or philosophy of life. Don't be disturbed if you are questioning old beliefs. Talk about it. For many, faith offers help to accept the unacceptable.

JOURNEY THROUGH GRIEF

At unexpected moments you may find yourself bathed in tears for no obvious reason. Concentration may seem impossible. At times, you may be overcome by exhaustion. Getting out of bed may seem very difficult. It is not unusual for bereaved people to hear familiar sounds associated with the deceased such as footsteps, laughter or a child's cry. People have reported smelling aftershave or perfume associated with the deceased or feeling his or her presence. For many these sensations are comforting. It is important to realize that these and other experiences are perfectly natural grief reactions. They will eventually fade.

An increasing awareness of the loss brings a welling-up of feelings that may be difficult to understand. You may feel helpless, angry, guilt, lonely or relieved. You need time to cry and talk. It takes great courage to risk feeling the depth of loss.

Loss intensifies feelings of helplessness. You cannot bring the person back and you feel powerless to relieve your pain. Being left by someone close to you is a form of abandonment. Even when death is the cause, anger at that person is a perfectly natural response. It is important to allow yourself to feel honest, painful emotions. Acceptance and expression of your feelings are two of the keys to healing.

Death many times brings a feeling of relief. Although it is a natural reaction, relief may be difficult to admit. It is important to realize that it does not mean a lack of love for the person who has died. You may feel relieved that the deceased is no longer suffering. Also, many times death frees us from demands, responsibilities and pressures. This is true especially after a long and painful illness.

The passage of time helps to ease the pain of grief. However, time alone is not enough. Expressing your feelings through sound and motion helps mourning. Crying is a healthy emotional outlet; tears are a natural release of tension. You may need to talk endlessly about your loss. Support groups for the bereaved provide a place where you can share your feelings and experiences. You need not be ashamed or your reactions and needs.

FIVE THINGS TO HELP YOU WHEN GRIEF IS NEW

by Robert Zucker

Everybody seems to think they know what grievers are supposed to think or feel or do - and when they're supposed to be done with it. I've been working with people facing profound losses for over 20 years now, and I've experienced my share of grief as well. Something I've learned again and again is that while some things may be predictable about our grieving, there are still many different and equally valid paths for each of us to discover. So as you read this care note, please

remember to trust yourself and to take time to find your own way.

Working your way through - In the first hours, days and even months following your loss, everything may seem surreal, beyond belief. You may find yourself denying what seems to be going on around you. As you face the unthinkable, you may find yourself saying, "This can't really be happening. I don't believe this!" In the midst of your struggle to come to grips with the impossible, take time to consider this critically important question: "Who do I need to gather around me, right now, for support?"

Seek out your family and friends. Over the years, I've worked with people facing terribly difficult news, and I've seen them reach out for support in different ways. Some tend to carefully select a few special people to share their profoundly difficult and sacred time, while others gather all of their immediate and extended family as well as their larger spiritual community. Look inside your heart and choose what form of support feels right for you.

If you don't have a community or family to turn to during this painful time, remember that you deserve the same love and support as everyone else does. Perhaps there is a support group, a person in ministry, or a counselor who would be honored to walk with you on part of your grief journey.

Give yourself permission to change. Our deepest losses change us forever. Sometimes this feels unbearable. When she was 11 years old, Alicia Sims faced the death of her brother. As she pondered the meaning of this tragedy for herself and her family, she began to write letters to her brother, which later were published in a little book, *Am I Still a Sister?* In her letters, Alicia asked her brother many poignant and seemingly unanswerable questions: *Are you still my brother now that you are dead? Must I let go of my role as your sister? Now that everything has changed, do I have a chance in determining who I am becoming?*

May Alicia's courage inspire you to face what is truly lost for you, and to discover who you are becoming. What parts of yourself have you already left behind? Who are you now?

Find you safe haven. A safe haven is a place where it is Okay to be yourself, where you don't have to put on a happy face, where any feeling you have is acceptable, and where your unique style of grieving is appreciated. For some, a safe haven offers a place to cry or rage or to simply talk out loud with another caring person. For others, a safe have is completely solitary. Look into your heart and find what you need to feel safe enough to grieve well.

“Where there is sorrow there is holy ground” - Oscar Wilde

Linda told me about her mother’s death, she was worried about her father because he never talked about his grief or shared memories with her or even cried. He spent every spare moment working alone in his backyard garden. As she thought about her Dad, Linda realized that while he was never much of a talker - and certainly never shared his feelings - he always took pride in his green thumb, and has always loved to garden alongside his wife. Perhaps now, after her death, their special garden had become his sacred ground to commemorate, and re-invest in new beauty, new life and hope. Perhaps he had found his own way to mourn his loss.

Show your loved ones what you need. In September, Will and Jan’s little boy Ian died in a car accident. As winter approached, they began to think about the holidays, and wondered how they could possibly face a celebration in the midst of their agony. Will pictured their Christmas tree, and told Jan that the only way he could ever survive the challenge of Christmas would be in knowing that he could take comfort in seeing Ian’s special Christmas angel hanging on their tree. Jan bristled at the idea. For her, it would be unbearably painful to have Ian’s Christmas angel on the tree.

Will and Jan began to argue bitterly about their opposing needs, disappointing and hurting one another in the process. The more they fought, the more they resorted to blame and recrimination. It seemed as if they would never come to any resolution.

Many families discover that members have seriously opposing needs - especially following a shared loss. If this happens to you, try organizing a family meeting for the purpose of teaching one another what you need. Listen to one another with an open heart, and support and encourage one another to get what each of you needs - even when your needs seem to be incompatible.

Jan and Will finally tried this strategy. They sat down to talk. Will recalled how Ian loved Christmas. The pain Will felt now was incompatible with any sort of joyful holiday. Their son’s angel, he explained, could possibly provide him some small amount of comfort that would help him get through the season. Without the angel hanging on the tree, he explained, he worried that he might die of sadness.

Jan told Will that her suffering would not be lessened by seeing the angel, and that for her, it would actually be seriously worsened. Seeing Ian’s angel would take her breath away, and she knew in her heart that she could not live with it in their home.

Jan and Will sat together for a moment, in a sort of loving dissonance. They told one another that they appreciated each other’s needs, and wondered together whether they would find any compromise. Then Jan brightened as she said to Will,

“Maybe you can take Ian’s angel to work this year, and hang it on the tree in your office.” A magical compromise had emerged out of their hard work of teaching one another of their needs, truly listening, and remembering their love for one another.

Cultivate your strengths. So often we ask ourselves whether we have the inner strength to handle what seems to be happening to us. For many, this question is answered in subtle, incremental stages.

After a long vigil in the hospital June was faced with the horrific news of her daughter’s death from a brain tumor. When I asked her if she would like to spend some time with her little girl in a private room, she seemed startled by the suggestion - sitting beside her daughter’s lifeless body was inconceivable to her.

But about half an hour later, June came up to me and asked if she could still have time with her daughter. Somehow, now it felt right. As she walked towards her daughter, it was as if the cold hospital room was transformed into a sanctuary. June sat with her child and held her and began to understand some of the harsh reality before her. She also began to discover her own inner strength, which would become more and more available to her in the months and years to come.

Grief tends to disarm us; we may minimize or even forget about the strengths and coping skills that we’ve counted on in the past. But this painful experience offers an opportunity to take stock of who you are and what special qualities you bring to this very difficult challenge.

Take heart - As you face this difficult time in your life, many new strengths emerge for you out of your despair and helplessness. and may these strengths contribute to your healing and growth. With time, may you look back on this defining moment as a period that also brought insights and a deep appreciation for the gift your loved one has been in your life.

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Respect the power of grief. Know that it can affect you psychologically, physically, and spiritually in intense and sometimes surprising ways. Stay gentle with yourself.

Telling Your Story

Only in the telling of your story can you recover the most important thing in your life - your basic life orientation. This is more important than your feelings about the person you lost, your concerns about what others think, or your business affairs.

That which is most important is what I call *orientation*. When we experience a loss, particularly through death, it is natural to become disoriented. From a medical perspective, mourners become *dysfunctional*, which means that day-to-day health needs are handled as completely as before the loss. From a psychological perspective, mourners become confused, distracted, and preoccupied, so that decision making is difficult. From a theological perspective, mourners become distrustful because they must rethink not only who or what can be trusted, but whether one can trust at all.

To be disoriented is to be lost. Everyone becomes disoriented momentarily every time something unexpected is encountered. Orientation is recovered quickly as individuals refer to a familiar person, place or time. It is normal to measure what is new against what is known. Mental adjustments are made so quickly that people frequently fail to realize how often they go through the processes of reorientation. That is, they fail to realize this until they encounter an experience to which they cannot readily adapt. For some people, the disorientation may be so profound that they feel - or are seen by others as - crazy. The disorientation most people feel after the loss of someone they love is frustrating. They find it difficult to think clearly, and often they feel a general malaise. From this perspective the world is in disarray. Subsequent disorientation becomes even more frightening as they struggle to maintain normalcy. To be orientated once again becomes their most important goal in life.

Telling your story will be the most important thing you do as a mourner, because in the very act of telling it you are putting your life back together. By telling your story you will discover it you will discover that your facts change, not because the facts themselves are changed but because your choice of what is important changes. You may discover that your initial impressions of what happened were incomplete or even inaccurate. The more unexpected the death, the more likely it is that initial impressions were wrong.

As you first tell your story, you will probably not be able to provide an ending. Some people try. They say things like, "This is God's will," or "It was meant to be." More unfortunate are those mourners who, in trying to tell their story, are given ending by other people who share "words of advise," give "testimony," or respond with cliches. Linda, for example, was told that she ought not mourn because she was young and could have another baby. Marge was told that she was old and had lived a full life. Erica and Warren were told that they should find comfort in the fact that their son had brought them so much pride. All these ending simply did not fit. Rather than helping these mourners become reoriented, such cliches only further disoriented them.

You will need to tell your story of loss and change, again and again in order to get your facts straight, clarify how you are part of the facts, and finally to determine how you fit into the arrangement of the universe.

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 ?

Connie Jackson has spoken briefly 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 weekend, 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

You, too, can have a lovely memorial garden. It need not be large or spectacular. Just a few particular flowers and plants can attract a myriad of colorful, delicate butterflies that can fill your heart with happiness. Here are a few of the flowers/plants butterflies like most. Many can be purchased at any nursery or store and many are wild, depending on the area of the country where you reside.

Butterfly bush, Goldenrod, Joe-Pye weed, New England Aster, Dianthus, Verbena, Lavender, Lantana, Cosmos, Zinnia, Milkweed, Buttercup, Yarrow, Sheep Sorrell, Azalea, Honeysuckle, Impatiens, Marigold, Mint, Hibiscus, Bougainvillea, Shepherd's Needle, Clover, Gloriosa daisy, Fleabane, Knapsweed, Buttonbush, Statice and Ironweed.

You can attract birds to your home/yard by hanging a couple of feeders. Thistle seed will attract Goldfinches and Purple House Finches. Red and white millet, black oilers and sunflowers will attract a large variety of different birds including Cardinals, Blue Jays, Chickadees, Titmouse, Nuthatches, and others. Hummingbirds can also be attracted to feeders. Providing bird houses can bring one a great deal of joy in watching the parents build, nest and raise their young. We have had a pair of House Wrens coming back to the same house for five years.

There are many sites on the World Wide Web that can provide additional information and pictures to help you identify the variety of butterflies and birds that will come to your memorial garden.
LWJ

In Closing: As you remember a birthday and date of passing, the story of your dear child has a special meaning to you. Please share it with us.

Speaking of stories, my book, "**Nothing Can Separate Us,**" is noted on the internet: www.greenkeybooks.com - home page, new releases.

I'd love to hear from you !

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