



**BEREAVED
PARENTS
of the USA**

A JOURNEY TOGETHER

NATIONAL NEWSLETTER OF THE BEREAVED PARENTS OF THE USA



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Fall 2013

We, as bereaved parents, help grieving parents and families rebuild their lives following the death of a child.

FOUR MILES TO BRIDGEVILLE

On the way to the beach we pass through a little sleepy town. Bridgeville is bejeweled with lovely tree lined streets and magnificent old homes adorned with an abundance of ornate ginger bread and super-sized porches overlooking beautiful colorful gardens. As we approach the town there is a sign that announces "Bridgeville 4 Miles." I love seeing that sign not only because it signals that I'm about to look upon an architectural feast, but also I know it is only thirty minutes more till we reach the shore. After a lengthy journey it is a welcome sign indeed.

Grief is much like that drive to the ocean. After being on the road a long time we are tired. Tired of endless tears. Tired of being sad. Tired of wishing for what can never be. Oh, how we hope for some sign that this oppressive grief will end; that we will find a way to enjoy living again

without feeling guilty should we discover even a little happiness. But the road seems to go on and on without relief, without a Bridgeville in our future.

In the early years after my son Brad died my journey revealed little that suggested I was progressing toward a happier tomorrow. Day by day, however, I was learning, adjusting, changing. I was becoming a new person who could find love and purpose while not diminishing the importance my missing child had in my life. And, while I never saw a sign that read "Happiness 4 Miles," there were clearly signs. Going to a movie and actually laughing at something funny. That was a sign. I joined a gym and found exercise to be soothing. That was a sign. When Brad's brother got married that was a sign. When my grandson was born that was a sign. When I retire and take up the projects that have been too long delayed



that will be a sign, too. I've seen Bridgeville and I look forward to reaching the shore of inner peace. If you haven't found your Bridgeville yet, don't despair. It's waiting for you just around the bend.

Editor

Lean Into Those Curves

Last week I was having lunch with a group of senior Harley Davidson riders. One of them was wearing a T-shirt emblazoned across the front: *When life throws you a curve lean into it.* All of these bikers had lived long enough to have seen a lot of curves, and not just the ones on those back country roads motorcyclists love to travel. I asked them about this and found each had a "story," but what surprised me is those who had suffered great personal loss were not adverse to talking about it.

Those who had long marriages and were now widowers found it cathartic to talk about their wives. One chap who suffered financial ruin through no fault of his own was looking forward to enjoying the rest of his life, albeit on a tight budget. And I could see the emotions still visible in the radiant blue eyes of the fellow who told me he appreciated the opportunity to talk about the little boy he and his wife lost forty years ago.

My friend, Mark Epstein, a noted psychiatrist,



in *The Trauma of Being Alive* (The New York Times August 3, 2013) says, "Grief needs to be talked about. When it is held too privately it tends to eat away at its own support." These aging bikers apparently had learned that lesson. "Trauma," he continues, "is not just the result of major disasters. There is no way to be alive without being conscious

of the potential for disaster. One way or another, death (and its cousins: old age, illness, accidents, separation and loss) hangs over all of us. Nobody is immune. Our world is unstable and unpredictable, and operates, to a great degree and despite incredible scientific advancement, outside our ability to control it."

Dr. Epstein believes, "Grief is not the same for everyone. And it does not always go away. Mourning has no timetable. The healthiest way to deal with trauma is to lean into it, rather than try to keep it at bay." Is Dr. Epstein a biker? Apparently he knows when the road suddenly banks right or left you have to lean hard into the curve or risk falling.

My biker friends ride because it's fun and they like it, fully aware that disaster could be waiting just down the road. They've learned to lean into life with all its curves.

**R & D, Maryland
BP/USA**



Things That Touch Your Soul

Release a balloon with love messages at any given time.
 Release a new butterfly into the world with love and hope, a sign of renewal.
 We smile and take a moment to watch the hawk or great blue heron soar through the air,
 glide in the wind and land on its perch.
 We walk slowly thru the garden, touching and smelling each flower, savoring in the beauty.
 Because life can be cut short and we know how precious everything around us is, we do these things.
 These things help us feel close to our child, make us feel warm and sometimes lets us shed a tear.
 They heal and they comfort.
 We pause to listen for the buzz of the honey bee.
 We stand in the middle of nature and gaze in awe at the grandness surrounding us.
 We have stood at the edge of the ocean and at the base of the mountain; both places bring comfort to our souls.
 Do things that bring you peace, visit places that bring you healing.
 Stop, close your eyes, take a deep breath, release and feel.
 Our children are a part of our hearts and souls forever.
 Smile and remember, that love will never fade.
 Gaze into the stars as they twinkle, watch a rainbow get brighter and feel the calmness of each sunset.
 Let each of these things touch your soul and feel the love that surrounds you.
 Wishing you peace.

Lee Ann Hutson
Greg's Mom
President, BP/USA



When we honestly ask ourselves which people in our lives mean the most to us, we often find that it is those who, instead of giving advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a warm and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is a friend who cares. **Henri Nouwen**

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BEREAVED PARENTS OF THE USA

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The Gathering

My wife, Jean, and I attended our seventh Bereaved Parents of the USA Gathering in Sacramento. Almost as we walked in the hotel lobby we met Becky who greeted us with a big smile, open arms, and a warm "Welcome Home." Seven years ago we felt we needed to go to the Gathering because we were lost and in pain. Today we still explore workshops, raptly listen to speakers, anticipate the candle lighting; but today we attend the Gathering for the big smiles, open arms, invitations to return home. At the Gathering friends step towards you when you tell stories about dead children. Too often the world steps away, seeking to escape and to forget that their perfect world is only a breath away from ours.

The staff at the hotel was incredible. As with all large groups there were mistakes, confusion, frustrations, but the hotel staff set everything right with a big smile and an offer of additional assistance. They were empathetic and eager to please. During the emotional roller coaster of a gathering, helpful staff is better than cold lemonade on a hot day.

I still deal with anger over Matt's death. So



I attended Anger: Dr. Bob Baugher. Obviously many of us deal with anger. Dr. Baugher did a great job. I'm still angry but I have a set of tools to deal with my anger. Jean really liked Grief and Internet Resources by Glen Lord. Jean likes quiet reflection and moving at her own pace. The workshops available dealt with many of the problems we all face and offered a variety of styles to meet individual needs. There really was something for everyone.

We always find the keynote speakers helpful, sincere and often entertaining. This year the hosts offered brief five minute presentations as a message of hope. We liked the variety. Both of us really enjoyed Love in Motion signing

choir. We also liked the first attempt we've seen at a question session with a panel of experts.

The best and worst part of the weekend is the candle lighting and slide show of our kids. It is inspiring to feel the love in the room as our children pass before us as their parents light a candle, but seven years ago we knew four or five kids. Today we've met so many of them through their parents. After all, isn't that why we come? We want to share our children with others. Now pictures are real people filled with both joy and pain. We've heard about dance, football, cars, fishing and oh so much more. We promise to return to Seymour carrying pictures of life and seas of love with us.

Then it is time to say good bye. Returning to the outside world is always hard but we have St. Louis to look forward to on July 25-27 next year. Come home to those who will help you celebrate life rather than curse death. You owe yourself the Bereaved Parents of the USA National Gathering. "Meet me in St. Louie."

Keith Swett
Seymour, WI

Life Goes On and Death Goes On

Recently, my son got married. It was a joyful occasion and, at the end of the night, my cheeks were aching from smiling. However, always, under it all, there was the fact that we were desperately missing my daughter, his sister, Maggie. We did not hear her roast her brother at the rehearsal dinner. We did not see her, standing beside the bride with the other beautiful girls, in purple dresses, her favorite color. And she was not the one to close down the party, dancing her heart out. Though we felt her spirit, of course, powerfully, it was very hard work not to wish it could be otherwise.

When I arrived home again, I went into an emotional tailspin. I had held myself together, admirably, through all the wedding events, and then, in the comfort of my own home, I fell apart. I ate chocolate. I refused invitations. I read three books in a week. I was snippy and impatient with my partner. I was a mess, and, eventually, it passed. The fact is: Life goes on and death goes on, and those of us who are still alive get both.

Meg Tipper
Catonsville, MD

Meg Tipper is a frequent contributor to A Journey Together. Her book Standing at the Edge chronicles the first year after her daughter, Maggie, died.

Grieving is a journey that teaches us how to love in a new way now that our loved one is no longer with us. Consciously remembering those who have died is the key that opens the hearts, that allows us to love them in new ways. **Tom Attig, The Heart of Grief**



BOOK REVIEWS

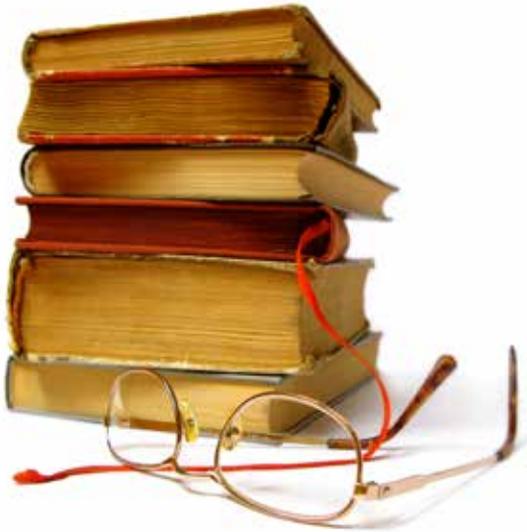


The Disappearance
Geneviève Jurgensen
W. W. Norton & Co. 1999

Twelve years out Geneviève Jurgensen writes a series of letters in which she recalls the shock and sadness surrounding the death of her two young daughters as a result of an auto accident. The letters written over several months recount not only the tragedy, but also the raw emotions that followed and the “new” life that emerged including the birth of additional children who are now older than their older siblings were when they died. It is amazing how vividly Ms. Jurgensen remembers every detail, but that should be no surprise to any bereaved parent. The author is Parisian and writes with a French eloquence. Although the translation by Adriana Hunter is admirable,

There are no Miracles. There is just this. The love that nourished your happiness will nourish your pain.

I wish my French was good enough to read this effort in the original. In The Disappearance, Geneviève Jurgensen both teaches and shares. That’s what we do for each other.



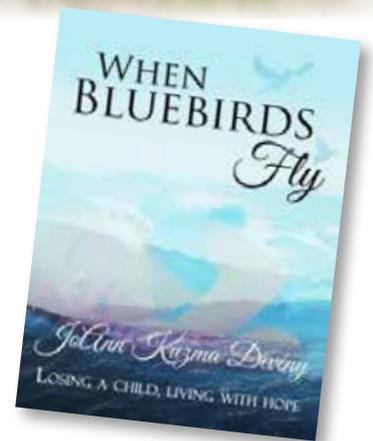
When Bluebirds Fly
JoAnn Kuzma Deveny
Radiant Heart Press, 2013

When Bluebirds Fly is a detailed letter, of sorts, written in alternating remembrances by Dick and JoAnn Deveny to their son, Billy, who drowned prior to his second birthday. They have also included the recollections of some of the people involved in the unfortunate circumstances surrounding the baby’s death. Half the book is spent telling us about the family, the tragic events and aspects about the funeral. The reader is drawn into the torturous emotions by the voluminous particulars so deftly described.

Coldness permeated through the blanket, gradually chilling your mother’s thighs and arms as though she was holding a wrapped block of ice. The weight of you in her arms and the curvature of your body in her lap felt so natural that she had been fooled. It took her cloudy mind a few minutes to accept that her once warm, soft child was the source of this unnatural, chilling sensation.

The rest of the book deals with the emotional roller coaster so familiar to all bereaved parents, holidays, returning to work, marital issues and other life struggles. Much is written about their efforts to help Billy’s three year old brother deal with the loss. In one place Dick writes that 75 percent of bereaved parents divorce within two years. That, of course, is complete nonsense. He offers no citation to back up that statistic and his editor should have insisted that kind of information, in a book designed to help others, be supported or removed otherwise it is dangerous mis-information.

If you want to immerse yourself in the minds, hearts, and souls of a bereaved family then When Bluebirds Fly should be on your reading list. Keep the Kleenex handy.



The reality is that we don't forget, move on, and have closure, but rather we honor, we remember, and incorporate our deceased children and siblings into our lives in a new way. In fact, keeping memories of your loved one alive in your mind and heart is an important part of your healing journey. **Harriet Schiff**



Practical Advice from Jeremy Shatan

A High-Functioning Bereaved Parent

So where am I now, 13 years after my 2½-year-old son, Jacob, died because of a brain tumor? One thing I can say is that my junk mail has no idea where I am. The other day I threw out yet another letter offering to give us advice on Jacob's college career, as well as a solicitation to re-subscribe to Highlights magazine. Obviously, Jacob is not going to college. And my surviving children are 11 and 13, a bit out of the Highlights demographic.

One construct I use to help myself understand where I am now is a term my wife and I came up with: High-Functioning Bereaved Parent. As is often remarked, someone who has lost a spouse is handily defined by the word "widow" or "widower." But there is no shorthand to describe a parent who has lost a child. Language is a reflection of culture. The great majority of people will never experience the loss of a child and would prefer not to think about it all that much. Raising children is fraught enough without having to dwell on their mortality. So for now, H.F.B.P. will have to do. I'll certainly take it over "every parent's worst nightmare."

So how exactly does being a High-Functioning Bereaved Parent manifest itself? I get out of bed, I help raise our kids and run our household, I laugh, tell jokes, watch violent movies, listen to music and go to concerts. So it all looks pretty good from the outside, and it usually feels...not bad, which is how I prefer to answer when someone asks me how I'm doing. I have no doubt that much of this equilibrium comes from the fact that my wife and I have been together through all of this and still find a lot of joy in our marriage and our surviving children. I also have the privilege of being the executive director of Hope & Heroes Children's Cancer Fund and working every day to improve the lives of children with cancer alongside the staff of the Herbert Irving Child & Adolescent Oncology Center. Among bereaved parents, I consider myself very lucky that I get to work for Jacob every day.

But I knew from the moment Jacob died that we would never get over his loss; we would only learn to live with it. At the risk of torturing grammar, perhaps I should revise that mantra to be "we would only be learning to live with it," because it's a process that never stops.

One way I know that is from the physically jarring sensation I feel when the huge chasm in my life abuts the solid ground I usually walk



on. It could be at a high school information seminar for my daughter, for example. There's just this moment of wrongness. Somewhere in my soul there's a trajectory for Jacob's life that is still going on, a part of me that wonders why we haven't already hit these milestones with him first. The natural order of things has been disturbed, but that hasn't entirely stopped me from attempting to hew to that order. Or it could happen with a change in the weather, which can trigger a sense memory sending me back to the time when Jacob was being treated.

That aspect of things is a form of post-traumatic stress disorder, I suppose, which feels like unprocessed experiences that my brain is constantly working on behind the scenes. A hint of fall in the air, and the curtain is momentarily yanked open, exposing the churning attempt at understanding what happened.

For reasons like those, some days are more effort than others. Also, occasionally my status as an H.F.B.P. can lead to a balancing act in relation to my work. Naturally, I can empathize with the parents I meet at the clinic — I have walked in their shoes. But since Jacob did not survive, I don't want to shake their carefully constructed hope that their child will. One thing I always make sure to convey is that each diagnosis is unique and that treatments have continued to improve. My perspective still allows me to have hope for others, and if things do take a turn for the worse, I can offer the powerful example of my own survival after the loss of my son.

But it hasn't always been that way. In the emotional chaos shortly after Jacob died, my wife and I took our infant daughter to a retreat for bereaved families provided by Chai Lifeline. We were already wrung out, but this was a new form of wringer: story after story of gut-wrenching, unimaginable loss. My wife got a migraine so intense that the rattle of a newspaper caused her pain; we considered leaving after the first night.

We stuck it out, and through the haze it dawned on us: you can live on after the loss of a child, it's not impossible. After the retreat, when the sadness would threaten to become overwhelming, I would think of these other bereaved parents and take strength from their behavior. Regular conference calls with a group of dads also helped a great deal.

So my path has not been through completely uncharted territory. I have had mentors to follow, whether or not they would have called themselves High-Functioning Bereaved Parents. In the end, I'm not sure if being an H.F.B.P. is a choice, exactly, but I believe that putting a name to our "condition" has helped us not just survive, but to thrive and engage with life more fully.

Jeremy Shatan lives in Inwood, Manhattan, with his wife and two surviving children, is proud to serve as Executive Director of Hope & Heroes Children's Cancer Fund, and writes about music at [LINK 3 AnEarful](#) and [@AnEarful](#).

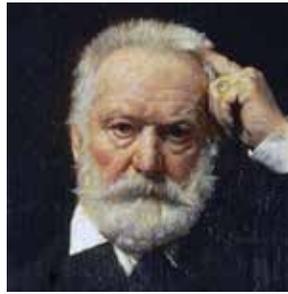


Did You Know They Were Bereaved Parents?

Les *Misérables*, Victor Hugo's condemnation of the social injustices of his time, was written shortly after his nineteen year old daughter, Leopoldine and her husband drowned in a boating accident at Villequier on the Seine. This was not his first experience with loss of a child. Years before the Hugo's first born son died in infancy. Was Hugo's railing in *Les Misérables* against the political and legal establishment actually his expression of the unfairness of life?

Victor Hugo had already made a name for himself with the publication of *Notre-Dame de Paris* (known in English as *The Hunchback of Notre-Dame*). With the earnings from that success and others he was traveling and learned of his daughter's death in a newspaper story he was reading while sitting at a café in the south of France. It is not hard to imagine the depth of shock and sadness that over came him to learn such horrific news in such an unexpected manner.

After Leopoldine's death Hugo wrote many poems about her life and death. These include *A Villequier* and, perhaps most famous, *Demain, des l'aube* (*Tomorrow, the Dawn*), in which he describes



visiting her grave. It is believed he never completely recovered. (Do any bereaved parents ever "completely" recover?)

After these writings, Hugo needed to find other outlets for his unrelenting grief. He turned to music and art. He befriended Franz Liszt, who helped him perfect his piano playing and Louise Bertin, with whom he worked on *La Esmeralda*, an opera based on a character from *The Hunchback of Notre Dame*. In addition over one hundred operas are based on Hugo's works including Verdi's *Rigoletto*.

Hugo used art as a private form of creativity and expression. He produced in excess of 4,000 drawings done in dark brown or black pen, rarely with color. For the most part these, usually small drawings, were kept out of the public eye, but some were given as gifts or calling cards. Artists of his time such as Van Gogh and Delacroix believed if he had become an artist instead of

a writer, his work would have been among the best in Europe.

Victor Hugo refused to allow the grief to swallow him up, but instead found ways to express his grief in literature, music and art. The world is richer because he did.

The Shirt in the Clothes Hamper

The shirt was at the bottom of the dirty clothes hamper when he died. I found it there when I got around to doing wash sometime after the funeral. Life must go on in spite of what happens to us, and the wash is part of ordinary day-to-day life.

It was natural for the shirt to be there; I'd done his wash since he was born twenty-one years before. I stood and looked at it and decided to leave it there.

Year after year, wash after wash, I left it there. This was a symbol of normal life. My life wasn't normal any more, and I left it there to sort of hang on to the past, I guess. It gave me comfort to see such an ordinary, normal thing as one of his shirts in the dirty clothes when my life was so extraordinary now.

One by one such "hangings on" are done away with as we slowly reenter life's mainstream again. We know the time is right for these habits to go, when we don't grieve for them when they happen. And they must happen, just as we must move on eventually.

One day in a fit of neatness my daughter did the wash, and she washed the shirt. It must have been five years after her brother died. I felt a tiny surprise when I saw the shirt hanging clean in the closet, but I didn't feel the sorrow or even disappointment. The time seemed to be right for the shirt to leave the dirty clothes hamper. A simple thing, but this was a symbol of progress of sorts. I'm glad no one rushed me – I would have resented it. I was allowed this simple idiosyncrasy until it was natural to give it up. Left alone I probably never would have removed the shirt, just left it there, never really knowing why. But when this happened, I knew I was getting better. Finally, I was letting go, and that was okay.

Faye Harden
TCF Tuscaloosa, AL





POETRY PAGE

Lessons Learned

They'll come to the door in make-up and masks.
 Trick or Treat, they will say.
 I'll smile and give them candy
 On this joyous, sorrowful day.
 I'll celebrate this day with joy
 In my heart and a tear in my eye.
 It is the day my Johnny was born.
 With joy and sorrow I'll cry.
 I'll remember the first time I held
 Him, my sweet baby boy.
 I'll think about our four years
 Together with all the love and joy.
 I'll think about what was lost,
 The future that might have been,
 But then I'll remember what we had
 And I'll smile once again.
 The sorrow I can't deny,
 The pain his death has brought,
 But on this day I choose to remember
 The lessons of love he taught.

By Tom Wyatt
 BP/USA St. Louis



Thanksgiving Prayer

I'm thankful this Thanksgiving that my grief is not so new.
 Last year it was so painful to think of losing you.
 Death can't claim my love for you though we are far apart,
 Sweet memories will always be engraved upon my heart.
 Time can never bring you back but it can help me be
 Thankful for the years of joy you brought our family.
 To all the parents with grief so new I share your loss and sorrow.
 I pray you find with faith and time the blessings of tomorrow.

Charlotte Irick
 BP/USA Tampa, FL

Wish by Sascha

I wish you gentle days and quiet nights.
 I wish you memories to keep you strong.
 I wish you time to smile and time for song...
 And then I wish you friends to give you love,
 When you are hurt
 and lost and life
 is blind.
 I wish you friends
 and love and
 peace of mind.



Awkward Silence

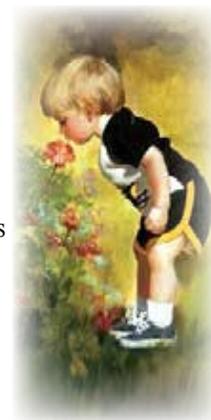
I wish that someone would say his name.
 I know my feelings they're trying to spare,
 And so we go through the charade, the game,
 Of dancing around the ghost that is there,
 Trying to avoid evoking a tear,
 Or stirring emotions too painful to bear.
 That he be forgotten is what I fear,
 That no one will even his presence miss,
 As if there were no trace that he was here.
 By referring to him, my purpose is
 Not to stir pity or keep things the same,
 But my heart will simply break if his
 Memory will die like a flickering flame.
 I just wish someone would say his name.

Richard Dew, M.D.
 Knoxville, TN

Excerpt from A Villequier

You see, we really need our children,
 Lord; when one has seen in one's life, some morning,
 in the midst of cares, hardships, miseries,
 and of the shadow our fate casts over us,
 how a child appears, a dear sacred head,
 a small joyful creature,
 so beautiful one thinks a door to
 heaven has opened when it arrives;
 when for sixteen years one has watched
 this other self grow in loveable grace and
 sweet reason,
 when one has realized that this child one loves
 makes daylight in our soul and in our home,
 that it is the only joy that remains
 here below of all that one has dreamed of;
 consider that it is a very sad thing
 to watch it going away!

Victor Hugo





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BEREAVED PARENTS OF THE USA

CREDO

We are the parents whose children have died. We are the grandparents who have buried grandchildren. We are the siblings whose brothers and sisters no longer walk with us through life. We come together as Bereaved Parents of the USA to provide a haven where all bereaved families can meet and share our long and arduous grief journeys. We attend monthly gatherings whenever we can and for as long as we believe necessary. We share our fears, confusion, anger, guilt, frustrations, emptiness and feelings of hopelessness so that hope can be found anew. As we accept, support, comfort and encourage each other, we demonstrate to each other that survival is possible. Together we celebrate the lives of our children, share the joys and triumphs as well as the love that will never fade. Together we learn how little it matters where we live, what our color or our affluence is or what faith we uphold as we confront the tragedies of our children's deaths. Together, strengthened by the bonds we forge at our gatherings, we offer what we have learned to each other and to every more recently bereaved family. We are the Bereaved Parents of the USA. We welcome you.