



# A JOURNEY TOGETHER

NATIONAL NEWSLETTER OF THE BEREAVED PARENTS OF THE USA

WINTER 2022

BPUSA NATIONAL GATHERING CONFERENCE ♦ July 22–24, 2022

Volume XXVII No. 1

*Helping grieving parents and their families rebuild their lives following the death of a child.*

## ***THE TRAUMATIC LOSS OF A LOVED ONE IS LIKE EXPERIENCING A BRAIN INJURY*** By Amy Paturel

What happens in the brain when someone you love dies — and how to overcome it with time.



It was a crisp night in June, the sky bright from the light of the full moon. I stopped at a gas station to fuel up before heading to the hospital to see my father. Three months after heart surgery, his newly replaced valve had begun driving bacteria into his brain, causing multiple strokes. He was dying.

Standing at the pump, I thought about how he would never visit our new home. How we would never dance together again. I paid for my gas, got back in the car and drove out of the gas station — with the nozzle still lodged in my tank.

When I stopped the car, an onlooker who had watched the nozzle fly out of my car's gas tank said smugly, "You're lucky it snapped off."

I was embarrassed, ashamed and, most of all, in despair — not just because my dad was dying, but also because I was losing my mind. But I know now I was not alone: Frequently, humans who have experienced grief can recall incidents in which their brains seemed to stop functioning.

"The problem isn't sorrow; it's a fog of confusion, disorientation and delusions of magical thinking," writes Lisa Shulman, a neurologist at the University of Maryland School of Medicine, in a blog post for Johns Hopkins University Press about her book *Before and After Loss: A Neurologist's Perspective on Loss, Grief and Our Brain*. "The emotional trauma of loss results in serious changes in brain function that endure."

Scientists are increasingly viewing the experience of traumatic loss as a type of brain injury. The brain rewires itself — a process called neuroplasticity — in response to emotional trauma, which has profound effects on the brain, mind and body. In her book, Shulman, whose husband died of an aggressive cancer, describes feeling like she was waking up in an unfamiliar world where all the rules were scrambled. On several occasions in the months after her husband's death, she lost track of time. Once, after running an errand, she drove to an unfamiliar place and ended up unsure of where she was or how she got there. She pulled off the highway and had to use her GPS to navigate back home.

If these things can happen to a neurologist who understands brain biochemistry, what hope was there for me?

## The Grieving Brain

After a loss, the body releases hormones and chemicals reminiscent of a “fight, flight or freeze” response. Each day, reminders of the loss trigger this stress response and ultimately remodel the brain’s circuitry. The pathways you relied on for most of your life take some massive, but mostly temporary detours and the brain shifts upside down, prioritizing the most primitive functions. The prefrontal cortex, the locus of decision-making and control, takes a backseat, and the limbic system, where our survival instincts operate, drives the car.

In an attempt to manage overwhelming thoughts and emotions while maintaining function, the brain acts as a super-filter to keep memories and emotions in a tolerable zone or obliterate them altogether. According to a 2019 study published in *Social Cognitive and Affective Neuroscience*, grievers minimize awareness of thoughts related to their loss. The result: heightened anxiety and an inability to think straight.

As I watched my dad transform from a brilliant mathematician who could calculate complex algorithms in his head into a childlike dependent searching for words he couldn’t find, I began to feel like I was the one recovering from a stroke. I fumbled to find words for common objects like lemon or cantaloupe. There were times when I blanked on my husband’s phone number and even my own.

According to Helen Marlo, professor of clinical psychology at Notre Dame de Namur University in California, that’s not unusual. People who are grieving may lose their keys several times a day, forget who they’re calling mid-dial and struggle to remember good friends’ names.

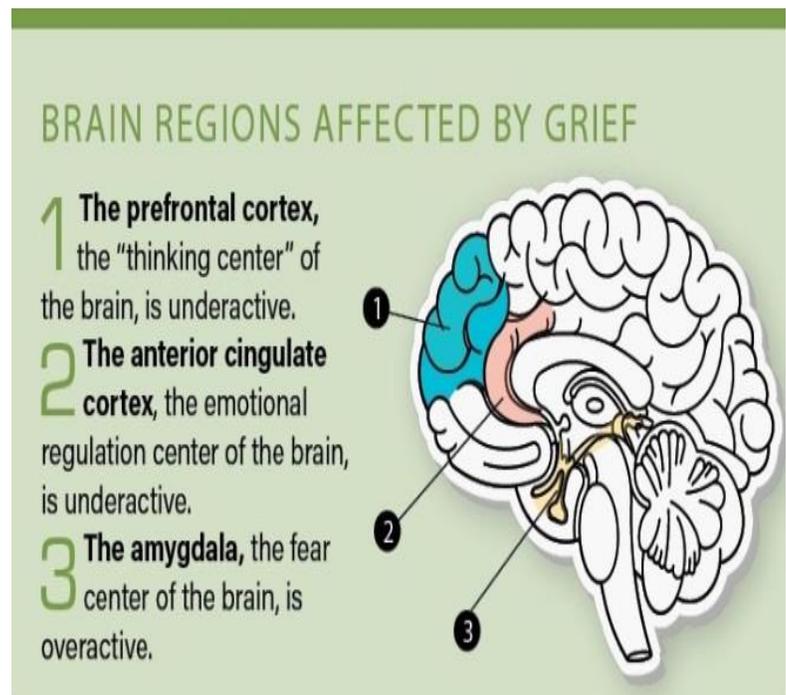
Research shows these cognitive effects are more pronounced among people who have complicated grief, a condition that strikes about 10 percent of bereaved people and is marked by an intense yearning for the deceased. People with complicated grief experienced greater cognitive decline over a seven-year study period compared with those with a less complicated grief response, according to a 2018 study published in *The American Journal of Geriatric Psychiatry*.

As Marlo explains it, our brains have trouble processing the reasons for the death of a loved one, even making up explanations for it. This can lead us down a rabbit hole of “what ifs” and “if onlys,” particularly if we’re stuck in our grief. Only over time, and with intention, can grief provide fertile soil for growth and transformation.

## The Grieving Mind

My dad always seemed to me almost superhuman — all go, no quit — and was at his best when he was making people laugh. He loved pulling a good prank, even dressing up as a waiter at my wedding rehearsal dinner. Nearly 20 minutes passed before it dawned on me that the odd server delivering wine and appetizers was actually my father. He lavished his grandchildren with tickles, belly kisses and really bad renditions of Marvin Gaye’s “I Heard It Through the Grapevine.”

Research suggests our experience of loss — whether muted or traumatic — is mediated by relationships, and the life of those relationships resides in the mind. “Each of us responds to grief differently, and that response is driven by the relational patterns that we lay down early in life, as well as the intensity of the grief,” says Marlo. “So even though regions of the brain might be firing and wiring the same way after loss, the way the mind reacts — the ‘feeling’ experience of grief — is unique to the individual.”



What I hadn't fully grasped in the early days of my grieving is that the brain and the mind, while inextricably linked, are completely separate entities. Like the parts of a car engine, the two feed off of each other. That's why my amygdala (part of the primitive limbic system) sounds an alarm when I see a grandfather playing with his grandchildren at the park. It's because the brain triggers a stress response attached to my feelings of loss.

"Grieving is a protective process. It's an evolutionary adaptation to help us survive in the face of emotional trauma," Shulman writes in her book. The way grief manifests — from depression to hopelessness, from dissociative symptoms to emotional pain — is just evidence of altered brain function. So how do you heal an emotionally traumatized brain? "You have to embrace the changes that are happening in the brain instead of thinking you're losing your mind," says Marlo.

### *Finding a Way Forward*

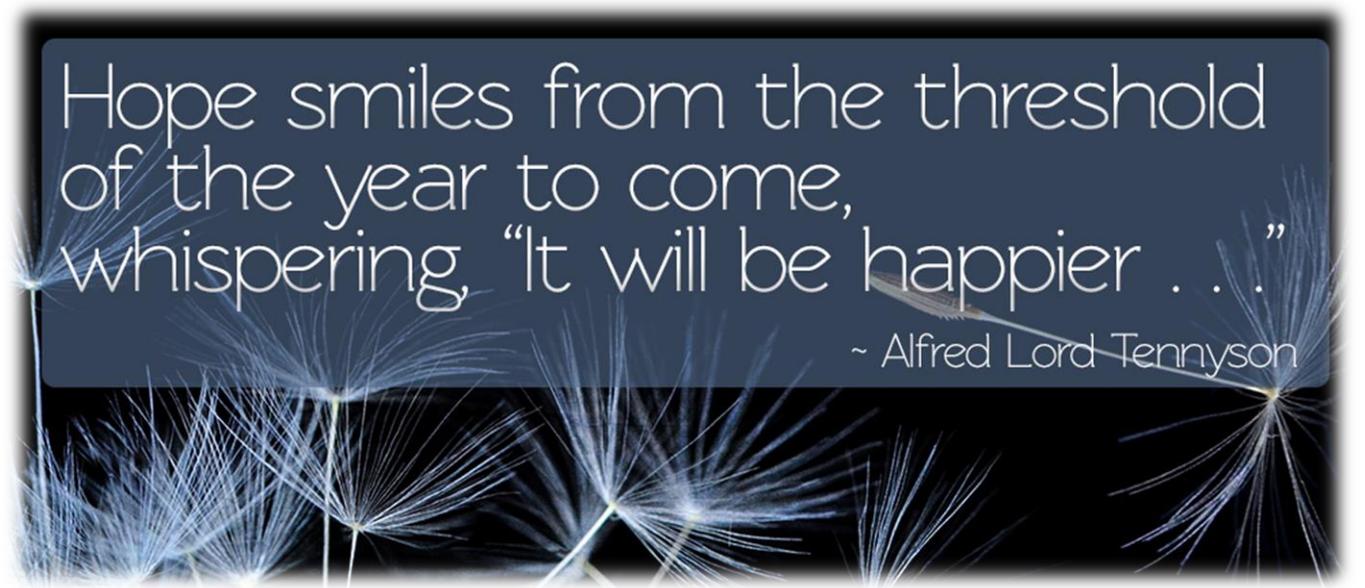
As with any injury, an emotionally traumatized mind requires a period of recovery and rehabilitation. We don't return to our usual activities immediately after heart surgery, yet somehow, we expect to bounce back after the mind scramble of losing a loved one. "With grief, the mediator between the right and left hemispheres of the brain — the thinking and feeling parts — is impaired," explains Marlo. "The task is to integrate both, so you're not drowning in the feelings without thought as a mediator or silencing feelings in favor of rational thinking."

Research suggests that you can encourage the integration of the right and left hemispheres with activities from medication to psychotherapy to massage. A 2019 study of 23 bereaved people published in *Frontiers in Human Neuroscience* found that participating in an eight-week mindfulness-based cognitive therapy improved the ability to execute complex mental processes, such as working memory and the ability to curb impulses. Other studies suggest that traditional cognitive behavioral therapy — which trains the brain to change thought patterns — helps foster personal growth among people who are grieving.

"Neuroplasticity moves in both directions, changing in response to traumatic loss, and then changing again in response to restorative experience," Shulman writes in her book. One way to heal is to reflect on the relationship with the deceased and work to hold both the love and the pain.

For some, that means wrapping themselves in a beloved T-shirt or quilt, visiting the cemetery, journaling about positive memories or creating a photo book or video of life with their loved one. For me, it meant stalking hummingbirds in my backyard; my dad loved to watch their tireless pursuit of happiness. In that respect, the birds were just like my dad. When they flutter around me, I can almost sense his presence.

"Connecting the loss with behaviors and activities helps the grieving brain integrate thoughts and feelings," says Marlo. "So, if your hummingbird-seeking behaviors elicit feel-good emotions, that can put your grieving mind on a path toward healing."



Hope smiles from the threshold  
of the year to come,  
whispering, "It will be happier . . ."

~ Alfred Lord Tennyson

# *GRIEF DURING WINTERTIME*

## **How to Cope with Grief During Another Pandemic Winter**

By Jill S. Cohen, Family Grief Counselor

It's wintertime now. The days are getting darker earlier and those who are bereaved will likely feel "darker" earlier too. It's tough to handle grief when it's dark and dreary to begin with, then add the coronavirus pandemic to the mix. Now, you have a very isolated grieving time, with less light and fewer people around to brighten your days.



### **Learning to Cope**

To cope a little bit better, try to keep some of these tips in mind:

### **This Will End**

As hard as it may be, realize that the pandemic will eventually end, and you will be reunited with the comfort of people who support you, keep you company and give you a hug when you need one.

### **Others Are Experiencing Challenges**

Be gentle with some of your supportive friends and family members who don't seem as "available" as you expected them to be. They may be experiencing their own challenges of living through the pandemic, and not intentionally ignoring your grief. Reach out to them if you need to.

### **Stay Active**

Make sure you get outside at least once a day. It's tempting to stay inside where it's warm but push yourself. You need fresh air and a change of scenery. Those are important.

### **Keep Busy**

If you're up to it and have time to fill, try handling some projects which need to be done after the death of a loved one. i.e., sorting through mail and paying bills, collecting photos and creating an album, making a "memory box" of your loved one, organizing files for insurance, banking, health records, and other important paperwork.

Tackling these projects will be helpful to you in the long run, and give you something to focus on, and give you a sense of productivity and accomplishment.

### **Keep Having Fun**

If you have children who are grieving too, play games this winter. Play games (i.e., Dollhouse, or Doctor, for example) that allow the kids to act out their feelings.

This will give their grief an outlet for expression. Also, have kids make memory boxes, dreamcatchers, keep a journal, and do artwork to encourage talking about their loved one and expressing their feelings of loss.

### **Enjoy Movies**

Watch funny movies. Finding a good comedy to watch is one of the best ways to lighten up your mind.

### **Mix Things Up**

Just for a change, try a new or different activity. Try cooking things more adventurously, try building something in the garage, try crafts, find new books to read.

# STIFLED GRIEF: HOW THE WEST HAS IT WRONG

By [Michelle Steinke-Baumgard, www.facebook.com/OneFitWidow](https://www.facebook.com/OneFitWidow)



**Editor's Note:** Although Michelle is speaking from a widow's perspective, her observations are fitting for bereaved parents and families. K.C.

*The reality is you will grieve in some capacity for the rest of your life. Once loss touches you, you are forever changed despite what society tells you. Stop looking at the expectations of an emotionally numbed society as your threshold and measuring stick for success.*

I'm here to say that the West has the concept of grieving all wrong.

I'd like to point out that we are a culture of emotionally stunted individuals who are scared of our mortality and have mastered the concept of stuffing our pain. Western society has created a neat little "grief box"

where we place the grieving and wait for them to emerge fixed and whole again. The grief box is small and compact, and it comes full of expectations that range from time frames to physical appearance. Everyone who has been pushed into the grief box understands it's confining limitations, but all of our collective voices together can't seem to change the intense indignation of a society too emotionally stifled to speak the truth. It's become easier to hide our emotional depth than to reveal our vulnerability and risk harsh judgment. When asked if we are all right, it's simpler to say yes and fake a smile than to be honest and show genuine human emotion.

Let me share below a few of the expectations and realities that surround grief for those who are open to listening. None of my concepts fit into society's grief box and despite the resounding amount of mutual support by the grieving for what I write below, many will discount my words and label us as "stuck" or "in need of good therapy." I'm here to say those who are honest with the emotions that surround loss are the ones who are the least "stuck" and have received the best therapy around. You see, getting in touch with our true feelings, embracing the honest emotions of death only serve to expand the heart and allow us to move forward in a genuine and honest way. Death happens to us all so let's turn the corner and embrace the truth behind life after loss.

**Expectation:** Grief looks a certain way in the early days. Tears, intense sadness, and hopelessness.

**Reality:** Grief looks different for every single person. Some people cry intensely, and some don't cry at all. Some people break down, and others stand firm. There is no way to label what raw grief looks like as we all handle our loss in different ways due to different circumstances and various life backgrounds that shape who we are.

**Expectation:** The grieving need about a year to heal.

**Reality:** Sometimes grief does not even get started until after the first year. I've heard countless grieving people say year two is harder than year one. There is the shock, end of life arrangements and other business matters that often consume the first year and the grieving do not have the time actually to sit back and take the time to grieve. The reality is there is no acceptable time frame associated with grief.

**Expectation:** The grieving will need you most in the first few weeks.

**Reality:** The grieving are flooded with offers of help the first few weeks. In many cases, helping the grieving six months or a year down the line can be far more helpful because everyone has returned to their lives and the grief stricken are left to figure it out alone.

**Expectation:** The grieving should bury the dead forever. After a year, it is uncomfortable for the grieving to speak of their lost loved one. If they continue to talk about them, they are stuck in their grief and need to "move on."

**Reality:** The grieving should speak of the dead forever if that's what they wish to do. When someone dies, that does not erase the memories you made, the love you shared and their place in your heart. It is not only okay to speak of the dead after they are gone, but it's also a healthy and peaceful way to move forward.

**Expectation:** For the widowed - If you remarry you shouldn't speak of your lost loved one otherwise you take away from your new spouse.

**Reality:** You never stop loving what came before, and that does not in any way lessen the love you have for what comes after. When you lose a friend - you don't stop having friends, and you love them all uniquely. If you lose a child and have another, the next child does not replace or diminish the love you had for the first. If you lose a spouse, you are capable of loving what was and loving what is....one does not cancel out or minimize the next. Love expands the heart, and it's okay to honor the past and embrace the future.

**Expectation:** Time heals all wounds.

**Reality:** Time softens the impact of the pain, but you are never completely healed. Rather than setting up false expectations of healing let's talk about realistic expectations of growth and forward movement. Grief changes who you are at the deepest levels and while you may not forever be in an active mode of grief you will forever be shaped by the loss you have endured.

**Expectation:** If you reflect on loss beyond a year, you are "stuck."

**Reality:** Not a day goes by where I am not personally affected by my loss. Seeing my children play sports, looking at my son who is the carbon copy of his Dad or hearing a song on the radio or smell in the air. Loss becomes part of who you are and even though I don't choose to dwell on grief, it has a way of sneaking in now and again even when I'm most in love with life at the current moment. It's not because we dwell or focus, and it's not because we don't make daily choices to move forward. It's because we loved and we lost, and it touches us for the remainder of our days in the most profound ways.

**Expectation:** When you speak of the dead you make the griever sad, so it's best not to bring them up.

**Reality:** When we talk about our lost loved one, we are often happy and filled with joy. My loss was six and a half years ago and to this day, my late husband is one of my favorite people to talk and hear about. Hearing his name makes me smile and floods my mind with happy memories of a life well lived. It makes the grieving sadder when everyone around them refuses to say their name. Forgetting they existed is cruel and a perfect example of our stifled need to fix the unfixable.

**Expectation:** If you move forward, you never loved them or conversely if you don't move forward, you never loved them.

**Reality:** The grieving need to do what is right for them, and nobody knows what that is except the person going through it.

**Expectation:** It's time to "move on."

**Reality:** There is no moving on - there is only moving forward. From the time death touches our lives we move forward, in fact, we are not given a choice but to move forward. However, we never get to a place where the words move on resonate. The words "move on" have a negative connotation to the grieving. They suggest a closure that is nonexistent and a fictitious door we pass through.

**Expectation:** Grief is a linear process and a series of steps to be taken. Each level is neatly defined and the order predetermined.

**Reality:** Grief is an ugly mess full of pitfalls, missteps, sinking, and swimming. Like a game of *Chutes and Ladders*, you never know when the board might pull you back and send you down the ladder screaming at the top of your lungs. Just when you think you've arrived at the finish, you draw a card that sends you back to start and just when it appears you've lost the game you jump ahead and come one step closer to the front of the line.

**Expectation:** The grieving should seek professional forms of counseling exclusively.

**Reality:** The grieving should seek professional forms of counseling but also the grieving should look strongly towards alternative modes of therapy like fitness, art, music, meditation, journaling and animal therapy. The grieving should take an "active" part in their grief process and understand that coping comes in many different forms for all the different people who walk this earth.

**Expectation:** The grieving either live in the past or the present. It is not possible to have a multitude of emotions.

**Reality:** The grieving live their lives with intense moments of duality. Moments of incredible happiness mixed with feelings of deep sadness. There is a depth of emotion that forever accompanies those who have lived with a loss. That duality can cause constant reflection, and a deeper appreciation of all life has to offer.

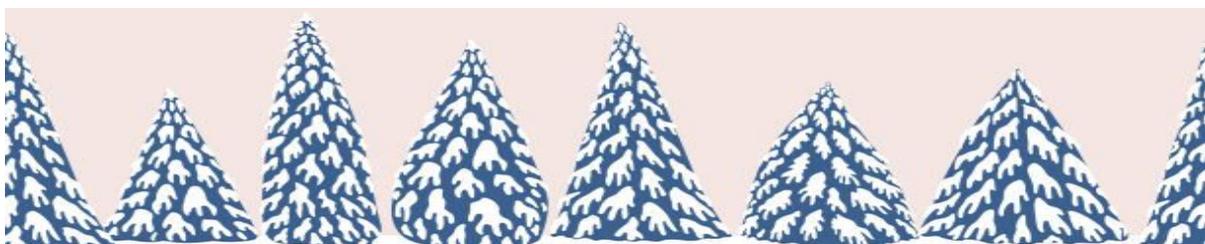
**Expectation:** The grieving should be able to handle business as usual within a few weeks.

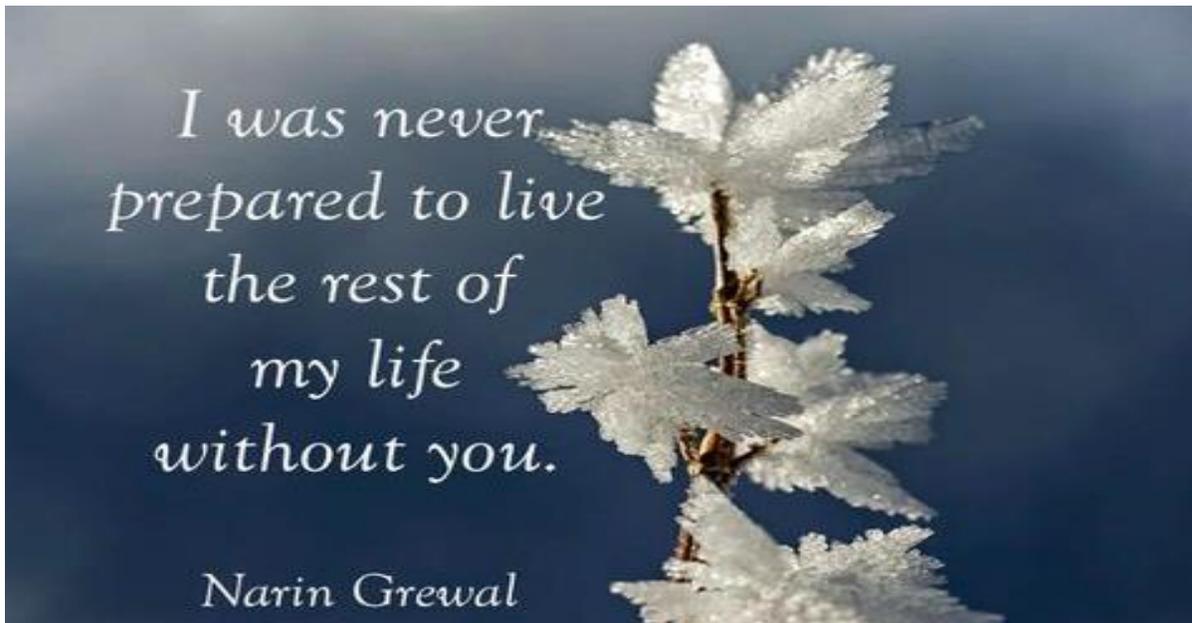
**Reality:** The brain of a grieving person can be in a thick fog, especially for those who have experienced extreme shock, for more than a year. Expect forgetfulness, a reduced ability to handle stress and grayness to be commonplace after a loss.

I've just scratched the surface above on the many areas where grief is misunderstood in our society.

One hundred percent of the people who walk this earth will deal with death. Each of us will experience the passing of someone close that we love or our personal mortality. It is about time we open up the discussion around death, dying, and grief and stop the stigma that surrounds our common bond. Judgment, time frames, and neat little grief boxes have no place in the reality that surrounds loss. Western culture asks us to suppress our pain, stuff our emotions and restrain our cries. Social media has given many who grieve the opportunity to open up dialogue, be vulnerable on a large-scale level and take the combined heat that comes with that honesty. As a whole, society does not want to hear or accept that grief stays with us in some capacity for the rest of our lives. Just like so many other aspects of our culture, we want to hear there is a quick fix, a cure-all, a pill or a healthy dose of "get over it" to be handed out discreetly and dealt with quietly.

The reality is you will grieve in some capacity for the rest of your life. Once loss touches you, you are forever changed despite what society tells you. Stop looking at the expectations of an emotionally numbed society as your threshold and measuring stick for success. Instead, turn inward and look at the vulnerable reality of a heart that knows the truth about loss. With your firsthand knowledge escape the grief box and run out screaming truth as you go. If we make enough noise, maybe someday society's warped expectation will shift to align with reality.





## NATIONAL GATHERING 2022



### Bereaved Parents USA

JULY 22-24 ♥ ST. LOUIS, MISSOURI

### **CALL FOR BPUSA WORKSHOP PRESENTERS**

*Are you a bereaved parent, sibling or grandparent? Do you have a topic, talent, or skill that you think might help someone grieving the loss of a loved one? Have you thought about being a workshop presenter at the 2022 National Gathering Conference?*

*Please submit an application to be a workshop presenter **HERE***

**Deadline for submission March 1, 2022**



“ Surround yourself with people who will make it less difficult than it is already is. ”



[www.facebook.com/BereavedParentsUSA](http://www.facebook.com/BereavedParentsUSA)