

# THE PARENT

# Journey

january - march 2013

a *grief Haven* newsletter for grieving parents and those who support them

## "i just want to be happy"

by augusten burroughs

In our super-positive society, we have a zero-tolerance policy for negativity. But who feels 'Great!' all the time?

Yet, at first glance, it seems so guileless. Children just want to be happy. So do puppies. Happy seems like a healthy, normal desire. Like wanting to breathe fresh air or shop only at Whole Foods.

But "I just want to be happy" is a hole cut out of the floor and covered with a rug. Because once you say it, the implication is that you're not.

The "I just want to be happy" bear trap is that until you

define precisely just exactly what "happy" is, you will never feel it. Whatever being happy means to you, it needs to be specific and also possible. When you have a blueprint for what happiness is, lay it over your life and see what you need to change so the images are more aligned.

Still, this recipe of defining happiness and fiddling with your life to get it will work for some people, but not for others. I am one of the others. I am not a happy person. There are things that do make me experience joy. But joy is a fleeting emotion, like a very long sneeze. A lot of the time what I feel is... interested. Or I feel melancholy. And I also frequently feel tenderness, annoyance, confusion, fear, and hopelessness. It doesn't all add up to anything I would call happiness.

But what I'm thinking is—is that so terrible?

I know a physicist who loves his work. Yet, people mistake his constant focus and thought with unhappiness. But he's not unhappy. He's busy. I bet when he dies there will be a book on his chest. Happiness is a treadmill of a goal for people who are not happy by nature. Being an unhappy person does not mean you must be sad or dark. You can be interested instead of happy. You can be fascinated instead of happy.

### what is happiness really?

First off, Happy New Year to everyone. Whenever I use that phrase I can hear in my head some parents' responses: "What's happy about it?" That is a very legitimate question, especially in light of all that we find ourselves dealing with. So we decided to share Augusten Burroughs' thought-provoking and interesting article with you on happiness. I personally found myself pondering the issue of happiness a lot after reading his article, and I hope it will provoke interesting thoughts for you, too.



**About Newtown:** It has become clear from my discussions with various leaders that they have been besieged by so many offers that they are trying to decide what their next steps should be. We at griefHaven have decided to wait a little while before making plans to visit and provide talks and grief support. As you know, the more time that passes from that moment that changes our lives forever, the greater the need for support. So I continue to work with leaders in Newtown to prepare for our arrival at a time that will be the most beneficial overall. Thank you to those who have donated to our travel. We will only use those donations in conjunction with Newtown support, and we will keep you all posted.

Love,

~ Susan Whitmore  
founder & president



where hope resides

The barrier to this, of course, is that in our super-positive society, we have an unspoken zero-tolerance policy for negativity. Beneath the catchall umbrella of negativity is basically everything that isn't super-positive. Seriously, who among us is having a "Great!" day every day? Who feels "Terrific, thanks!" all the time?

Anger and negativity have their uses, too. Instead of trying to alleviate some of the uncomfortable and unpleasant emotions you feel by "trying to be positive," try being negative instead. Seriously, try it sometime. This will help you get in touch with how you actually feel: "I feel hopeless and fat and stupid. And like a failure for feeling this way. And trying to be positive and upbeat makes me feel angry, and feeling angry makes me feel like I am broken."

If that's how you feel—however you feel—then you have a base line, you have established a real solid floor of reference. Sometimes just giving yourself permission to feel any emotion without judgment or censorship can lessen the intensity of those negative emotions. Almost like you're letting them out into the backyard to run around and get rid of some of that energy.

A corollary to the idea that we must all be happy and positive all the time is that we must all be "healed." When I was 32, somebody I loved died on a plastic-covered twin mattress at a Manhattan hospital. His death was not unexpected and I had prepared myself years in advance, as though studying for a degree. When he died, I was as stunned as if he had been killed by a grand piano falling from the top of a building. I was fully unprepared.

I did not know what to do with my physical self. It took me about a year to stop thinking madly that I might somehow meet him in my sleep. Once I finally believed he was gone, I began the next stage: waiting. Waiting to heal. This lasted several years.

The truth about *healing* is that healing is a television word. Someone close to you dies? You will never heal. What will happen is, for the first few days, the people around you will touch your shoulder and this will startle you and remind you to breathe. You will feel as though you will soon be dead from natural causes; the weight of the grief will be physical and very nearly unbearable.

Eventually, you will shower and leave the house. Maybe in a year you will see a movie. And one day somebody will say something and it will cause you to laugh. And you will clamp your hand over your mouth because you laughed and that laugh will break your heart, it

will feel like a betrayal. How can you laugh?

In time, to your friends, you will appear to have recovered from your loss. All that really happened, you'll think, is that the hole in the center of your life has narrowed just enough to be concealed by a laugh. And yet, you might feel a pressure for it to be true. You might feel that "enough" time has passed now that the hole at the center of you should not be there at all.

But holes are interesting things. As it happens, we human beings are able to live just fine with many holes of many sizes and shapes. Pleasure, love, compassion, fulfillment; these things do not leak out of holes of any size. So we can be filled with holes and loss and wide expanses of unhealed geography—and we can also be excited by life and in love and content at the exact same moment.

This is among the oldest, deepest, most primal truths: The facts of life may be, at times, unbearably painful. But the core, the bones of life are generous beyond all reason or belief. Those things which ought to kill us do not. This should be taken as encouragement to continue.

The truth about healing is that you don't need to heal to be whole. And by whole, I mean damaged, missing pieces of who you were, your heart—missing what feels like some of your most important parts. And yet, not missing any part of you at all. Being, in truth, larger than you were before.

Human experience weighs more than human tissue.



Augusten Burroughs is the author of numerous best-selling books and lives in New York.

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# rebuilding life from my *ground zero*

by dr. gloria horsley

Every year I like to take a survey of where I stand on my love meter. Am I on the high or low side this year? How is my relationship with my husband, Phil? With my daughters and their families? Is there any misunderstanding or disagreement with a dear friend or colleague that still needs some attention? I take a quick inventory.

Inevitably, thinking about the people I love takes me hurtling back in time to what I call my "Ground Zero." For me, that was in April 1983, when my 17-year-old son, Scott, was killed in an automobile accident. That boy was the love of my life. After his death I wondered if I would ever be happy again.

Your "Ground Zero" may not be the loss of a loved one, but the loss of a relationship, a job, or even a dream. Dealing with any big loss takes time. Afterwards, you may find, as so many of us have, that doing even the most routine chore the first, second, third, or even fourth time can utterly besiege your heart.

Let me illustrate this point with a story about...banana yogurt.

After Scott's death, I remember one of the activities that I found most painful was going to the grocery store. The first time I went shopping, I just tossed things into the grocery cart without much thought, avoiding people who I knew as they avoided me. (Most people still don't have a clue about what to say to a bereaved mother.) "The task to be done today," I told myself, "is to push cart, lift items, place in cart, and get out as soon as possible."



Gloria and Scott

I was confident that, by sheer force, I could get this job done. When I got to the dairy counter, I selected eggs and milk, and then tossed in 10 cartons of banana yogurt. I trudged to the checkout counter, happy to have another task under my belt.

Several days later, I opened the refrigerator and my eyes locked on those 10 cartons of banana yogurt. I was stunned into utter silence. Tears welled up and trickled down my face as the reality hit. Scott was the only one in the family who ate banana yogurt! I quickly tossed the cartons into the garbage and made a note to cross it off my grocery list.

On my second trip, I again labored through the supermarket aisles in a fog. When I noticed a vaguely familiar face staring at me across the produce counter, I quickly turned and pushed my cart to a distant corner of the store. After collecting myself, I began shopping again. As I selected some cottage cheese in the dairy section, I looked sadly at the banana yogurt and felt a wave of grief. My eyes began to tear up. I longed to put just one or two cartons in my cart.

For weeks, whenever I opened the

*“Your ‘Ground Zero’ may not be the loss of a loved one, but the loss of a relationship, a job, or even a dream. Dealing with any big loss takes time.”*

refrigerator, I felt an empty pit in my stomach as I looked at the second shelf, which no longer had those little containers displaying a jolly little yellow banana. I still felt a huge lump in my throat, but I didn't cry.

On my third trip to the grocery store, parking and shopping seemed to be a bit easier. I even managed to pick up a couple of strawberry yogurts, which I knew Heather, Scott's 14-year-old sister, loved. By the fourth trip, I found that food shopping had become another routine that I had again mastered as a part of my changed life. With time, I passed the dairy counter with little thought.

Now, two decades later, I smile just thinking about my boy and how he lived, not how he died. He was amazing—so smart, so easygoing, and so fun-loving, and so strong. I remember how he used to carry four grocery bags at a time for me from the car into the house. Now I have to make four trips.

So like my experience with banana yogurt, some of your firsts will become routine during the first year. But many others, including the

first day of school, the first holidays, the first spring, the first birthday, and the first death day can take years. Some events only happen once in a lifetime, like a wedding or a graduation.

Facing these events and milestones takes persistence and courage, but eventually they



Scott at age 16

will begin to feel more routine. By “routine,” I mean that we develop new brain patterns so we don’t have to think so much about a task or action that

had previously been second nature. After a major loss, we are again like newborns. We have to learn to crawl before we can walk. In fact, researchers have found that it takes 35 exposures to learn a new field of study, as we must assimilate and then accommodate the new information. Thus, the first year is a time of learning and retraining.

“Give yourself a boost and look for areas where you can bring more love and joy into your life. Start with taking care of yourself.”

Where am I today on my love meter? I am pleased to say that I am on the high side this year. Take a look at your life and relationships and ask yourself, “Where do I stand?” Also, assess where you are in relation to your “Ground Zero.”

Give yourself a boost and look for areas where you can bring more love and joy into your life. Start with taking care of yourself.



Rebecca Horsley Bara, Gloria Horsley, Heidi Horsley, Phil Horsley and Heather Horsley

### here’s some thoughts:

- Kindness begins by being kind to you. Metaphorically, it is sometimes best to give yourself that rose first and then give one to another.
- Give yourself a treat that you might not normally give yourself, such as taking a bubble bath with candles glowing and soft music playing, changing your hairstyle to something you have always wanted but were afraid to try, taking a trip to a place that is different than your usual trips, or joining that gym that you have been wanting to join.
- Reach out and make a new friend or get in touch with an old one.
- Be a mentor to someone else in need.
- Write a loving note on someone else’s blog, Facebook or Twitter.
- Be the friend to yourself that you have always wanted to have.



# if tomorrow never comes

norma cornett marek ©1989

If I knew it would be the last time that I'd see you fall asleep,  
I would tuck you in more tightly, and pray the Lord your soul to keep.  
If I knew it would be the last time that I'd see you walk out the door,  
I would give you a hug and kiss, and call you back for just one more.

If I knew it would be the last time I'd hear your voice lifted up in praise,  
I would tape each word and action, and play them back throughout my days.  
If I knew it would be the last time, I would spare an extra minute or two,  
To stop and say, "I love you," instead of assuming you know I do.

So just in case tomorrow never comes, and today is all I get,  
I'd like to say how much I love you, and I hope we never forget,  
That tomorrow is not promised to anyone, young or old alike,  
And today may be the last chance we get to hold our loved ones tight.

So if you're waiting for tomorrow, why not do it now—today?  
For if tomorrow doesn't make it, you'll surely regret the way  
That you didn't take that extra time for a smile, a hug, or a kiss,  
That in your rush of living life you made that one final miss.

So hold your loved ones close today, and whisper in their ear,  
That you love them very much, and you'll always hold them dear.  
Take time to say, "I love you," "I'm sorry," or "It's okay,"  
And if tomorrow never comes, you'll have no regrets from today.

# because of katie

by karen gerstenberger

My name is Karen Gerstenberger, and I learned about griefHaven nearly five years ago, shortly after the death of our daughter, Katie. Katie was 12 years old when she died from cancer and had been sick for 10 months, during which time she endured every procedure and treatment (including five rounds of chemotherapy and an 18-hour surgery) with courage, humor, and strength. She faced her own death with dignity and grace beyond her years, even making a Will and leaving half of her money to charity.

After Katie's passing, I found it very hard to know what to do with myself. Caring for Katie had been a full-time job. And when she died, I had my husband and son to look after, but very little joy in my heart, and a lot of time on my hands. I spent a lot of time in reflection, reading, talking to God, and listening. I was trying to figure out what my relationship with Him could be—and my life's purpose—after such a loss.

I took daily walks, spoke to a spiritual director, and had massage therapy. I read about life after death, about grief, and I read spiritual books. During this period, I learned that when I was most depressed—when life seemed the darkest—doing something for others was the only thing that helped me get out of the “pit.” From that awareness came an idea, which has blessed me and hundreds of others.

When Katie was in the hospital, she clung to her favorite quilt—one that I had made for

her. I am not a great seamstress, but the fact that it was made by my hands, in fabrics that were soft and visually appealing to her, brought great comfort to Katie. She used it in myriad ways: its busy pattern was a distraction when she wanted to look away during a blood draw, and, when she needed, it became a lap robe, odor shield, bathrobe, screen, and a special hiding place. I realized that other children could benefit from a quilt or blanket just as Katie had, so I founded Katie's Comforters Guild to provide handmade blankets and quilts for children who are patients at Seattle Children's Hospital.

Last year, Katie's Comforters and Quilts donated 603 quilts and blankets to the hospital. It is very encouraging to receive letters from patients and parents, telling us how much their blanket comforts them. It's especially important when a child is not expecting to go to the hospital (or not expecting to stay there) and has no time to pack comfort items from home.

Before Katie was diagnosed with cancer, I was a full-time homemaker and community volunteer. Having a degree in Fine Arts, I was always seeking to create beauty and express myself creatively. About a month after Katie's passing, I started a blog

([www.karengberger.blogspot.com](http://www.karengberger.blogspot.com)) where I wrestled with the day-to-day issues of life after the death of a child—spiritual, emotional, and physical. Writing was revealed to be the form of expression I had been seeking; it helped me process my feelings, and I met some wonderful people online who encouraged and enlightened me.

I had opportunities to speak and raise funds and/or awareness for such groups as Camp Goodtimes West, the Moyer Foundation, and the Warren Moon/Steve Pool Guild at Seattle Children's Hospital, the Hope and Empowerment Event in Indianapolis, Indiana, and the Annual Memorial Service at Seattle Children's Hospital. These activities



brought me into community and made me realize that though I was deeply bereaved, I could still contribute in meaningful ways. Life was worth living, though it was not easy.

My husband and I shared Katie's story in the Ben Towne Foundation's feature video last September. That foundation is spearheading t-cell research at the new Ben Towne Center for Childhood Cancer Research at Seattle Children's Hospital. This is a positive way to fight back against cancer: work to eradicate it! I wanted Katie's legacy to be one of light and blessing, not one of darkness and depression. I felt that I owed it to her to be grateful for what I had left, and to share that gratitude and love with others.

To that end (and with Katie's input before she passed away), our family founded the Katie Gerstenberger Endowment for Solid Tumor Research at Seattle Children's Hospital, which has raised over \$167,000 in principal to generate income to support research into cures for cancer. Great progress is being made right now in the Jensen Lab at the Ben Towne Center for Childhood Cancer Research, supported by our endowment. Getting to know people like Carin and Jeff Towne—who created a foundation in their son's memory—has been a pleasure and has given me hope. To see people whose hearts are broken working to prevent the same heartbreak from happening to others is very inspiring indeed.

Because of what I've learned from Katie's experiences, I made a video (funded by Seattle



Karen and Katie

Children's Hospital) intended to train residents and other medical staff about family-centered care—about the specific needs and feelings of patients and their families. I want to teach this paradigm of care to new staff and other institutions. Working on the video inspired my book, which is called “Because of Katie.”

These days, I'm promoting the book and video, hoping that they will transform medical care around the country. I mention these activities not because they are proof of anything special about me, or solutions in and of themselves, but because they illustrate part of the process of integrating Katie's 12 ½ years of life on this earth with us, into our life without her physical presence now that she is gone from this earth. They are the best ways I know of living with her memory, when I would prefer to live with her presence.

One of the most challenging aspects of this path is parenting a grieving sibling. David, our son, and Katie were best friends; separated by less than 2 ½ years in age, they spent most of their free time together and were absolutely devoted to each other.

We had to move from our home in the country to live in the Ronald McDonald House in the city in order to support Katie in her cancer journey. That meant four of us living in one room, sharing a bathroom, under difficult conditions. We grew even closer as a family during this time. David withdrew from his school and enrolled in the Hutch School, a small, intimate and wonderful school for children whose family members are in treatment at the Seattle Cancer Care Alliance. David spent as much time as possible with Katie every day, even when she was

unconscious after her surgery.

Her passing has been horrific for him, just as it has been for us. The issues that came with ministering to his needs while being deeply bereaved ourselves have been real and daunting. We have done our best to keep communication open, and have offered assistance when indicated. By grace, David made the transition back into his old high school, participated in many enriching activities, enrolled in a university, which is a wonderful fit for him, and is now thriving. I pray that he will continue to do so.

*I* learned that when I was most depressed...doing something for others was the only thing that helped me to get out of the 'pit.' ”



Ellie Boren (Katie's grandmother), Julie Greves (Hematology-Oncology Child Life worker) and Karen

Another huge issue is the difference between the way men and women grieve, and the way different cultures deal with their emotions. I am from an open, emotionally expressive family; Gregg is from a quiet, emotionally controlled family. Our ways of dealing with our feelings have been different, to the point of incompatibility, at times. For example, on Katie's birthday or the anniversary of her death, I want to talk about her, look at photos and share memories—exactly the opposite of what Gregg wants to do on such days. David is somewhere in-between Gregg and me on this issue, so this creates difficulties for all of us. Another example of this is my inclination to go back to the hospital where Katie was treated and to be involved with their mission in some way. For me, working to support research into a cure for cancer is a positive way to strike back at the disease that took my daughter's life. Gregg is willing to support such work, but from the sidelines. He wants to think about other things, and tries to put the world of cancer behind him. Both of these are legitimate points of view, but to integrate our ways of living them is an ongoing challenge.

There are many ways to go on after the death of a child. We have the privilege of choosing how we will live, and the freedom to learn from the example of others who are farther along on this path than we are. GriefHaven's video, “Portraits of Hope,” the forum boards, and Susan's messages all gave me hope that my path would become lighter—that I would survive this heartbreaking loss and be able to function usefully and joyfully again. Though I will never stop missing Katie, though I struggle mightily through some days, I can honestly say that my life is a gift—one for which I am thankful. To fellow travelers on this path of grief over the death of a child: I pray that you will be blessed with comfort and peace, and that the pain in your heart will be gradually transformed into love and joy.



Gregg, David, Karen and Katie