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“We’ve All Got Buttons: Now What Can We Do About Them?”

— by Susan Whitmore, Erika’s Mom

When I do speaking engagements, I often give the following task to portray how difficult it is for anyone to understand what we who have lost a child are going through. Task: *Mothers, here is your task: Explain to a man exactly what it’s like to give birth, including adequately describing the pain and giving a realistic, detailed picture of what you experienced inside and what you needed from those around you during the various hours of birthing. Your goal is to make sure men fully understand the birth and the pain so they ‘get it.’* I would bet my lottery winnings (okay, I don’t have any, but if I did . . .) that no mother anywhere can do justice in describing the true pain and the birth process. That’s because adequate words can’t be strung together for any man to fully understand what it is that a woman is going through with the pain of birthing. He can “see” that what you have gone through is extremely intense and painful, and I am sure he is also thinking, “Man, I’m glad that I’m not ever going through that!” And so it is with anyone trying to understand the pain of grieving the death of a child.

Words. I’ve written about this very subject many times, spoken about it regularly, and shared various perspectives with you in newsletters, but this time we need to approach the subject from a different perspective. Words and phrases such as “closure,” “getting over it,” “moving on,” “acceptance,” “healing,” “How are you?” and “moving through it” are just a few of the hundreds of words and phrases that can evoke intense reactions in grieving parents. I’ve heard of parents walking away with a heavy heart, telling people off, bursting into tears, feeling angry, standing there speechless with a pit in their stomach, avoiding someone, and even yelling at the one who dared say certain words or phrases that pushed them over the edge after their child died.

In the beginning, even I—even though I am mildly tempered—have had my share of getting really upset at certain words or phrases. A wonderful man, as he lovingly hugged me and patted my back as I sobbed on his shoulder, softly said, “I know, I know.” I

reacted, “YOU DON’T KNOW! YOU WILL GO HOME TONIGHT TO YOUR BEAUTIFUL CHILDREN! DON’T SAY YOU KNOW WHEN YOU DON’T.” Yikes! I could see that shocked look in his eyes, as if he were saying, “Geez, Susan. I didn’t mean to upset you.” Oh, and then there was the reaction to my friend over the phone who dared ask near the second anniversary of Erika’s death, “So what do you think triggered your grief this time?” I responded, “I KNOW EXACTLY WHAT TRIGGERED IT! ERIKA DIED!” In my mind I thought, “What a stupid question. Isn’t it obvious? Does there have to be some specific trigger? Isn’t it enough that Erika died? People! They are so clueless—they have no understanding.” Today I think back and say, “Yow! Those poor people.” I’m grateful they are still my friends.



Please do keep in mind that I now share this perspective with you six years later, and, as they say, hindsight is definitely 20-20 vision. And I now know that I was at least right on one count—they are clueless; they have no understanding. How can they? They can’t. And do we really want them to fully understand this pain anyway? Of course we don’t. I mean these people were at least *there* for me, trying to do or say something. The worst thing anyone can ever say is nothing. And who can say the exact right words to each of us anyway, since what pushes my buttons might not push yours?

For example, I had one parent tell me he can’t stand the word “acceptance,” yet that word for me says much about this journey. It is, in fact, my very acceptance that I am here, that Erika is not, that she’s not coming back, and that I am the sole creator of my new life without her that is the very thing that propels me forward—the very thing that helps me rebuild my life to include new meaning, joy, love, and happiness. To me, acceptance does not mean that it is okay with me that Erika died. It’s not okay. It sucks! But in order to go forward, I

have to accept all that has happened and make a new and good life for myself. I believe without acceptance I would not be able to create a good life again, and I deserve to have a good life. So I love the word “acceptance.” But say it to me, not him. Another father once told me that the phrase “lose a child” just drove him up the wall. He said, “I didn’t lose my son. I know exactly where he is.” But then there are thousands of parents who prefer the word “lose” because they can’t bear to say or hear the word “died.”

So what are we to do with all of this? You can already see the challenge before our friends and family. What can they say or do that is okay with us? And whose responsibility is it to let them know? And what happens if we turn the tables? Imagine that it is not your child who died, but rather your friend’s, and you have to console him or her. Would you have done any better?

In a recent article entitled “Empathy and Brain Pain Relief,” Bob Baugher writes this about people trying to console grieving parents: “Many people react almost instinctively to reduce their own pain caused by the empathy they feel as they listen to the story of the tragic death of a child . . .” And therein lies the connection we par-



ents make when something is said that hurts or angers us—we believe others are trying, on some level, to comfort themselves, not us. But can we truly blame others for not getting it right? Most of the time, no. Some of the time, yes. Some people are just plain self-centered and insensitive, but that is really not the norm. Most people are compassionate and caring.

And should the onus of getting it right be solely on them? After all, there are only a few phrases that are truly universal enough to ensure no one will be offended, such as, “I am so sorry.” Then, the death of a child is everyone’s worst fear, and they are now witnessing it firsthand as they watch you in so much pain—pain they can’t begin to understand and you can’t begin to explain. And not even we knew before our children died what was okay to say, so how can they? Also, many of us live in the United States where not only is the death of a child an unspoken issue, but death itself is rarely ever discussed, even though it’s the one thing we are all guaranteed to experience one day. Last, an initial reaction to a child dying is to find some justification why it happened to “your” child and can’t possibly happen to “my” child. Baugher, who has worked with hundreds of bereaved parents for over 20 years—the very person who “should” know better—realized his own culpability in this area. Baugher cites a meeting where a father was sharing about his son’s car accident and said, “. . . and he had alcohol problems.” Baugher found his thoughts shifting from the upsetting idea that “Oh, a car accident could happen to my children” to “I see. He had alcohol problems—that’s it. That explains how this senseless tragedy could have taken place.” He states, “For a moment the senseless seemed to make at least some sense.” He was shocked at his internal reaction and then found himself thinking, “I see? What am I doing? This father is describing the death of his son and I’m feeling somewhat relieved? It was as if a part of my brain was trying to ease my pain by saying his alcohol problem

made it happen, [so it won’t happen to my children because they don’t have alcohol problems].”

As I face the sixth year since Erika’s death, I find myself thinking differently about so many things, and one of them is the difficult job others who love and care about us have. They must be willing to sit with us while we are in that unspeakably painful place and show their compassion and love. Not everyone has the stomach for that. Looking back now, I see that they can’t possibly know what we are going through any more than a man can know the pain of childbirth.

So whose responsibility is it? Both ours AND theirs. That is what life and love is all about. Both of us need to help the other. We need to let others know, as lovingly and calmly as possible, what does and does not work for us. If there are certain words or phrases or actions that don’t work for you, let others know and explain why. If someone says, “How are you?” and that question drives you crazy because you think, “How am I? How do you think I am, you idiot?” Instead you might say, “That’s such a general question. But I can always tell you how I am right now.” If someone is trying to comfort you and says, “I know, I know,” instead of doing what I did, you could say, “I know you mean to comfort me when you say that, but the truth is that you really don’t know, and I never want you to know.” Unite together as a team to be able to help each other. Even if you are very uncomfortable asking for what you want, do it for you and for your loved ones. If you get caught off guard, tell the person later what you would prefer and prepare yourself ahead of time so you aren’t caught off guard again. AND forward this email to others and ask them to read it.

To friends and family, we encourage you to figure out what your grieving friend needs by asking them. And don’t be surprised if they simply don’t know. In that case, take control and do what you believe to be the most loving thing you can do. Encourage and make it safe for them to tell you what does and doesn’t work. Added to that, we encourage you to educate yourselves so you will know what you can say or do to be supportive. Read books, go to griefHaven.org where you will find a plethora of information you need, search the internet, and generally learn what will and won’t work.

To mothers, fathers, and siblings who are doing the best you can with what you know at this difficult time in your grieving process, we suggest that you prepare yourselves ahead of time with what you will say when those words or phrases are spoken that you find troubling. Don’t be caught off guard. It’s better to say something than to walk away wounded or angry. If you work as a team with others, the end result will be that your friends will be more comfortable because they know what to do and say and you will get what you need. Although it might seem unfair that, in the midst of our grief journey we have to help others help us, it is one of the only ways to guarantee your needs will be met. And that is something you deserve.



**We are dedicated to you
and your journey . . .** *Susan*

A GRIEF JOURNAL FOR TEENS

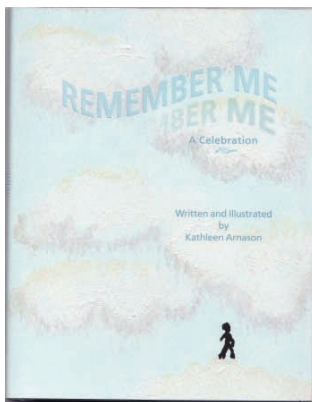
As you know, griefHaven is proud to support other organizations and the amazing work they do. The organization "Our House" in Los Angeles is one of those with whom we have partnered over the years, and we are happy to let you know about Our House's newest and very-much-needed new book.



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DEAR MR. HALLMARK

—Author Unknown

*I am writing to you from heaven,
And though it must appear
A rather strange idea,
I see everything from here.*

*I just popped in to visit
Your stores to find a card--
A card of love for my mother,
As this day for her is hard.*

*There must be some mistake, I thought,
Every card you could imagine,
Except I could not find a card
From a child who lives in heaven.*

*She is still a mother too,
No matter where I do reside.
I had to leave, she understands,
But, oh, the tears she's cried.*

*I thought that as I wrote you,
You would come to know
That though I live in heaven now,
I still love my mother so.*

*She talks with me, and dreams with me,
We still share our laughter, too.
Memories are our way of speaking now--
Would you see what you could do?*

*My mother carries me in her heart,
Her tears they cloud her sight.
She writes poems to honor me,
Sometimes far into the night.*

*She plants flowers in my garden,
There my living memory dwells.
She writes to other grieving parents,
Trying to ease their pain as well.*

*So you see Mr. Hallmark,
Though I no longer live on earth,
I must find a way to remind her
Of her loving, wondrous worth.*

*She needs to be honored
And lovingly remembered too,
Just as all the mothers' children
Still living on earth will do.*

*Thank you, Mr. Hallmark,
I know you'll do your best.
I have done all I can do now,
So to you I'll leave the rest.*

*Please find a way to tell her
How much she means to me,
Until I can do it for myself
When she joins me in eternity.*

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On
Mother's Day**