MISSFoundation
A COMMUNITY OF COMPASSION AND HOPE FOR GRIEVING FAMILIES

FMLA

By Karla Helbert

"It's not already covered under FMLA?!"

I have yet to talk to a person about my upcoming trip to D.C. who has not responded in a similar way. Expressions of surprise, disbelief, and confusion have been the norm. These reactions are part of my motivation for travelling to our nation's capital this February 2013 with MISS CEO, Barry Kluger and Kelly Farley. These two bereaved fathers are the originators of the Farley-Kluger Initiative to amend the current Family Medical Leave Act (widely known as FMLA) to include the death of a child as a covered condition for taking the unpaid leave guaranteed by the Act. The current FMLA allows workers to take up to 12 weeks of unpaid leave (or to substitute accrued paid leave) with the security of knowing their jobs are protected when they return. The Act, created in 1993 as a major part of President Bill Clinton's first term agenda, allows leave to be taken in the event of the birth of a child, adoption, becoming a foster parent, to care for a spouse, son, daughter or a parent with a serious health condition, if the employee him or herself has a serious health condition, and in the event that the need arises due to a spouse's, son's or daughter's active military duty. As is, there is currently no ability to utilize this federally mandated job protection leave for a parent whose child has died (This is where most people say, "What?! That's not covered!? I can't believe that!").

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MISSing them...

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Submission Guidelines

Want to contribute an article, poetry, news, artwork, or other content for the new MISSing Them newsletter?

Send your submissions to info@missfoundation.org for consideration. Thank you.

News

Moderators Needed

The MISS Foundation is in need of volunteer Moderators for our Online Support Groups. If you are a bereaved parent and it has been more than one year since your beloved child's death and you are not currently volunteering in another grief organization, please contact info@missfoundation.org if you are able to volunteer to help another bereaved parent through their darkest days. This is an online volunteer position. You can live anywhere, as long as you have internet access.

HOPE Mentors Needed

The MISS Foundation is in need of volunteer HOPE Mentors. If you are a bereaved parent and it has been more than one year since your beloved child's death and you are not currently volunteering in another grief organization, please contact info@missfoundation.org if you are able to volunteer to help another bereaved parent through their darkest days.

San Antonio Kindness Walk 2013

Save the Date!

2013 MISS Foundation Kindness Walk for the San Antonio Chapter is set for Saturday, March 2, 2013.

If you have questions or would like to be on the planning committee, please contact Jennifer.

Last year, more than 100 people attended the MISS Foundation's Kindness Walk in San Antonio. Attendees donated 40 pairs of shoes to the San Antonio Children's Shelter as part of the MISS chapter's Kindness Project. The director of the shelter was present to receive the shoes and was very moved by the gesture. The group participated in a memorial walk around Woodlawn Lake in honor of those they miss. The group raffled off a 42" flatscreen TV, among other things. Two local TV channels came and covered the event.

MISS Foundation in the News

MISS Founder Dr. Joanne Cacciatore was featured on NPR's feature "After Tragedy, Nonbelievers Find Other Ways To Cope" by Barbara Bradley Hagerty on Wednesday, January 16, 2013.

Click here to see the full feature.

The MISS Foundation was featured in a Yahoo News article, "Analysis: When families of murder victims speak out" on Tuesday, January 15, 2013.

Click here for full feature.

Fighting The Good Fight Against the DSM V

We are saddened and disappointed by the recent announcement that the DSM-5 task force has finalized the decision to eliminate the bereavement exclusion from the Major Depressive Disorder diagnosis in the upcoming edition of the manual. In the effort to keep our voices being heard, we've got many resource articles online:

Bereaved parents and mental illness: The MISS Foundation mourns the loss of grief…click here to read full feature.

The Death of Grief, the Birth of Mental Illness…click here to read the full feature.

Last Plea to DSM 5: Save Grief From the Drug Companies…click here for link to full feature.

If you have questions, contact info@missfoundation.org.

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As a bereaved mother, I want to say that I also have a difficult time believing that the death of a child is not included in the current FMLA. But, also, as a bereaved mother, I can sadly say that I am really not surprised. We live in an incredibly death denying society. Our society does not like to talk or think about death. This is particularly true regarding the deaths of children. Child death is not pretty, or sexy, or happy. Generally speaking, talk

and thoughts of death make our society very uncomfortable. So, therefore, unless death is thrust into our view and we are made to look at it, we try very hard not to do so. And even when we are made to do so, we (generally) try very hard to look the other way. As soon as possible.

The death of one's child is often labeled a tragedy that is "unimaginable." That actually isn't true. It isn't easy or pleasant to imagine, but it is, in fact, imaginable. That said, if an event is thought to be "unimaginable," how can anyone other than a person who has actually experienced said event really be expected to be thinking of it on a regular basis? I'm pretty sure (and I did do some research, and can't find anything to the contrary, though I could still be wrong) that the crafters and supporters of the original FMLA did not have dead children. After nearly seven years of living my life without my son, I have come to realize that the great majority of people in my life are not thinking of him daily. They are also not thinking of what it's like to live my life as it stretches out before me, without him in it day after day, year upon year. They cannot help it. Feel free to extrapolate this basically to mean that the people who are not thinking of the inalterable fact of child death, because they have not experienced it, cannot help it. This is simply because it hasn't happened to them. They are generally unable and unwilling to allow themselves to imagine what such a reality is like. That's no excuse, it's just reality, I think. They usually can't help it.

What's more tragic than their seeming inability to imagine such a tragedy day in and day out, is the sad and true fact of the lives of those who are no longer required to imagine such a terrible thing. It is our actual reality. We live it daily. I could go on with this, but will spare you. Either you already know what it's like, or you don't want to have to tolerate it being repeated in various ways ad infinitum, and I don't really want you to stop reading.

So, because of the general lacking in the non-bereaved person's capability to imagine the plight of a bereaved parent, it's clear that it would take a bereaved parent to point out the conspicuousness of the fact that the death of a child must, surely must, be included in an act passed by the Federal Government of the United States of America meant to provide job protection for its citizens during life's most crucial transitions. Death of a child is currently not included because unless and until it happens to you, it just isn't something that is on your mind. It's the absolute furthest thing from your mind. Inconceivable, unthinkable, absolutely unimaginable. Until it is. And that's exactly why it should be included in the FMLA. That is my take as a bereaved mother.

As a clinician and therapist working very often and very closely with those who are grieving the deaths of their children, I cannot express my professional support of this initiative enough. Because there does not exist the possibility for individuals to utilize FMLA due to the death of a child, a bereaved parent must figure out another way to make it work so they can take time off (beyond the generally allowed, even more unbelievable, 3-day bereavement leave) without losing their jobs. In order to take the much needed time to… [insert here whatever words make sense to you in regards to a bereaved parent being able to find space and ability to "function"]. Here are some suggestions: to regain some sense of stability, to feel you might be able to go about as a "normal" person in the world again, to come to a place where maybe you don't feel that you must hide your grief or stuff your tears, to come to a place where you consider yourself to be almost like a "real person" again, to feel that you can get out of bed without throwing up, to find the motivation to take a shower today, to feel hopeful that you can go to the grocery store and not fall apart in the aisles, to think that you are not a complete liar when you say, "I'm okay," when asked the socially prescribed, "how are you," to feel able to look other people in the eye again, etc. In order to have the space and time to do those things and more under the currently allowed FMLA, a bereaved parent must have a professional (doctor, therapist, psychologist, etc.) assert that he or she has a "serious health condition."

Generally, that most often means a clinician will provide the necessary documentation that a bereaved parent cannot return to work, not because he or she is grieving the death of a child, but because he or she is displaying symptoms of clinical depression (the symptoms of which, by the way, are nearly identical to those of grief but the two are not the same thing). The professional can then sign off, if he or she chooses, on a Major Depressive Disorder for use of leave provided under the current FMLA. Or if perhaps this parent exhibits near crippling anxiety, a Panic Disorder could suffice, or maybe when she goes out, she has shortness of breath and extreme nervousness, then perhaps a Social Phobia, or possibly the ever-popular Generalized Anxiety Disorder. Perhaps none of these quite fit, but since the death of his child, he has reported feeling extremely sad, and sometimes very angry or highly energetic and can't stop working or engaging in other tasks, and maybe can't sleep. Hmmm, maybe we'll give an unspecified affective problem such as Mood Disorder-Not Otherwise Specified. If the grieving mother or father is having "intrusive thoughts" (meaning unpleasant, upsetting thoughts that are difficult to manage and which create problems with every day functioning), nightmares, and feeling especially tense and "on-edge," maybe a diagnosis of Post-Traumatic Stress Disorder (PTSD) would do it. If the bereaved mother is hearing the cries of a baby who is not in her arms or in his bassinet (as he should be), or the bereaved father sees his daughter (just for a heartbreakingly fleeting moment, out of the corner of his eye) sitting in the bright shaft of sunlight streaming over the breakfast table, or if, for just a millisecond, the grieving mother

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Kindness Project & Walks

In 2012, we had wonderful responses and participation for both our Kindness Project Day and the various Kindness Walks that happened around the world. We'd like to thank everyone who was part of the 2012 events as well as thank all of you who are carrying your Kindnesses into 2013. Happy New Year!

Click image below to get your free Kindness eBook.

You can also get free Kindness Cards for free all year long now. Click the card below to get your free templates.

MISS Foundation's Bereaved Parents Day takes place May 19th to remember and honor our children. Phoenix will hold its third annual Kindness Walk. Other MISS chapters, volunteers and families will participate nationwide. If you'd like to hold an event in your area, please let us know. And click here to get our guidebook on organizing a MISS event.

Today We Walk For You

We come together to remember,
To celebrate and honor too;
Things should have been so different,
Today, we walk for you.

We take the steps you never will,
It causes aching our hearts;
You were loved from the beginning,
Right from the very start.

We'll create a legacy just for you,
By doing a good deed;
Your memories will be passed on,
By helping those in need.

You are surely missed by many,
You're thought about every day;
We'll always have our memories,
And treasure them in every way.

Our lives are forever changed,
You're with us in all we do;
You'll always have a place in our hearts,
And, we'll always walk for you.

Sari Edber, in memory of Jacob

Birthdays & Death Days

January and February Birthdays and Death Days are now online on the MISS website.

Click here to see the Birthdays.

Click here to see Death Days.

Our Donors

We'd like to thank all of you who gave so much to support the MISS Foundation during our end of year campaign. All donor and memorial messages are on the MISS website now.

Click here to see the Donors list.

Research

We now have a full list of articles and journal publications available on the MISS website for any members who are interested in the topic of "The Medicalization of Grief." Click here to get access to all the materials.

The NEED for Increased Grief Sensitivity Awareness and Education

Written by, Sari Edber

In an episode this past week, The Ricki Lake Show featured a newly bereaved couple, just 5 months after the death of their newborn son, Jonathan. Because the subject of infant and child death is so rarely discussed in the media, one would assume that this would be a huge stride towards increased public awareness about the unique grief of bereaved parents. Unfortunately, both Ricki Lake and her TV personality therapist, Dr. Mike Dow (co-host of Logo's That Sex Show, VH1's Couples Therapy, TLC's Freaky Eaters, TLC's My 600-lb Life Special, & author of Diet Rehab), offered advice that many consider to have been both offensive and harmful.

I, along with many other bereaved parents across the country, were triggered with an emotional reaction regarding the ways in which the couple on the show was treated, the insensitive advice that was given, and the ways in which the healing process was both generalized and minimized. Within the four-minute segment of this episode, the show provided it's viewers with information that is completely counter-productive to all of the sensitivity education that we are trying to bring to the often taboo topic of child death.

After our son, Jacob, was stillborn 6 ½ years ago, we were met with similar sentiments from some of our family and friends. My husband and I often felt vulnerable, isolated, and judged when our grief was made to seem trivial, when we were pushed to "move on" in our lives, and when we were told that we were "wrong", "unhealthy", and "crazy" for some of the things that we found comfort in. These hurtful words have stayed with us all of these years, even amidst the immense love, support, and positive healing sources that we've come to find. Truthfully, most of those people just didn't know how to be there for us in the ways in which we needed. And, once we explained, defended, and opened our hearts about the realities of our grief and healing, the majority of them (though, not all), realized that they were not helping us through this painful journey; and in fact, they were making it that much more difficult.

As bereaved parents, we often need to educate, even those who should unconditionally understand and love us, on what WE need most along this path: compassion, patience, validation, and an emotionally safe space to grieve our much loved children. There is a need for increased public awareness when it comes to understanding how one can support and comfort bereaved parents in a way that will be both HELPFUL and SENSITIVE to us.

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I reached out to The Ricki Lake show, as both a bereaved mother and as a representative of the MISS Foundation; and, after emailing with their website executive editor, I was asked to write a blog post with advice for family and friends about grief. Below is a slightly expanded version of what was published. I hope that bereaved parents will feel comfortable to share these guidelines with their own well-meaning family and friends, so that they can become better educated and more sensitive about how to provide comfort and support to their grieving loved ones.

10 Ways Family and Friends Can Support Bereaved Parents

1. Acknowledge that there is no "right" or "wrong" when it comes to someone's grief. Each person's healing process is completely individualized. There isn't just one way to feel or act, and every bereaved parent has to make choices that are right for them in the moment.

2. Recognize that grief is a life-long journey. Grief changes and evolves over time as it becomes more integrated into the lives of bereaved parents. Understand that the emotions do become less raw and intense, but, they are always there. Forever.

3. DO NOT put a time line on the grief of bereaved parents or decide when you think they should be "better". It is incredibly difficult for bereaved parents to face the real world again after the death of a child; and it's that much more challenging if there is pressure from family and friends to "get back to normal." ** Understand that bereaved parents will never completely be back to their "old selves."

4. Grief is not linear, logical, or predictable. Contrary to popular belief, the "stages" of grief are often cyclical in nature. Most individuals talk about their emotions in comparison to a roller coaster – just because they might have had an okay day, it does not mean that they are getting "better" or that the worst is behind them.

5. Be extra sensitive towards the bereaved parents if you are currently pregnant or have living children. Seeing children, hearing stories about their milestones, or being around other expectant mothers can often be a harsh reminder of what they have lost. Along the same lines, DO NOT complain to newly bereaved parents about any parenting or pregnancy issues that you might have (discipline, sleep training, breastfeeding, weight gain, etc.). These parents would trade places with you in a second.

6. DO talk about their child. Do not avoid this topic for fear of upsetting the griever. Not mentioning their child who died is likely to make them feel even more alone in their grief. If the baby was given a name, use it when referring to their child.

7. DO mark your calendars for birth/death dates, milestones, holidays, Mother's/Father's Days, etc. These milestones are often some of the most emotional and difficult. The act of remembering their child and showing compassion to the parents on these dates will mean more to them than you could possibly imagine.

- The week(s) leading up to these milestones can be filled with both sadness and anticipation. Call beforehand to check in and see how they are doing.

- Try saying: "I am thinking about you and remembering your baby today. I hope that you have a gentle day honoring his/her memory. Please know that I am here for you. I love and miss your child always."

8. Be understanding of the complex emotions of a subsequent pregnancy or raising a subsequent child after a loss. Just because you are thrilled that the bereaved parents are either pregnant again or have thankfully welcomed a healthy child into their lives, do not assume that they have "moved on".

* There are many juxtapositions that can accompany a subsequent pregnancy and/or child:
-Joy AND sadness.
-Excitement AND worry.
-Gratitude AND anger/grief.
-Being thankful for this new baby AND still wanting their missing child.
-Being appreciative for being pregnant again AND thinking about how this new baby and the timing of the subsequent pregnancy "should have never been" if the previous child had been okay.
-Trying to be hopeful that everything will be okay AND being filled with anxiety and fear at every moment that something could go wrong.
** And, even once a healthy child has been fortunately brought into this world, there are usually bittersweet emotions that are tied to missing their child that died. In fact, some bereaved parents note that their grief takes on an entirely new meaning once they see and hold their healthy baby: it makes what they lost all the more tangible.

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9. WHAT NOT TO SAY: In one way or another, all of these comments CAN trivialize the child who died, the depth of the loss, and/or the difficult process of healing.

DON'T use any of the following clichés regarding the loss of their child:

-"It's for the best."
-"Be brave, don't cry."
-"Time heals all wounds."
-"At least it happened early on before you got more attached."
- "You're young, you can always have more."
-"It just wasn't meant to be."
-"There was probably something wrong with the baby, and it's better this way."
-"It's time to move on."
-"Be thankful for what you do have and don't focus so much on this."
-"It's just a bump in the road – you'll get over it."
- "Your baby wouldn't want you to be upset."
-"You're doing so much better." OR "It's so good to see you smiling again."

10. DO be sensitive to the fact that everyone has different beliefs about death. Just because you find comfort in one idea/value/view point, not everyone will find it helpful. For this reason, also avoid religious statements like:

- "It's all a part of God's plan."
- "God needed another angel."
- "Your baby is safe and happy with God now."

Some parents might find comfort in some of the above statements but, let them verbalize these ideals to you. Do not put your beliefs onto them.

** Excerpts used from*
"The Do's and Don'ts of Grief Support"
found on the MISSFoundation.org website.
To see the original article,
click here.

Poetry

On Loss

Realization comes slowly

How can this be?

I close my mouth and taste...

Ashes.

By R. Sullivan

Remembering

In loving memory of Jacob Rafael
by Sari Edber, forever your mommy

"We will always be connected,
In our hearts, you're always near;
Because part of our souls went with you,
And part of yours stayed with us here."

Poetry

How? When? What?

How
How am I to find
to find the strength
to hold on
to hold on to my
raison d'être
to live
to live in this world without you?
Always
you have been
you are
you will be
the light of my life.

When
When will there be
be at time
When I'm not
not gasping for air?
A time when my cough
has coughed up all
all the debris, the pain
the pain and grief stuck
stuck in my throat
so I can give voice
give voice to the buried
the buried screams.

The flame inside me
inside me the flame flickers
but does not go out
It does not die
What
What keeps it
from drawing
its last
its very last breath
as you have done?

A poem by Merina Yemaya
in loving memory of
her precious daughter, Kathy Moore,
11/12/1966 to 9/4/2009
Always loved, always MISSed

Home

Another day has passed,
my body still learning to breathe and live without you.
A day of work is done.
I'm on my way home.

My dreams of you are short but sweet
allowing me to kiss your cheek,
and see you smile.
You're always happy.
I'm on my way home.

Missing your perfect face
the gentle hold of your hand,
and your most beautiful sparkling eyes.
You are in my heart, soul, and mind forever.
I'm on my way home.

My songs carry over the wind to a different time and place
as I continue to travel a road with you always with me.
You are mine and I am yours.
I'm on my way home.

I wake up and feel your arms around my neck.
You are smiling and all the tears and pain have been wiped away.
I've missed you so, my Sweetheart. I have so much to tell you.
"I know Mommy" you'll say. For you were with me there all along…
And I am HOME.

For Our Little Baby Jamie Bug
in memory of James Robert Metcalfe
by his mother Gina.

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smells the dearly remembered perfume of her daughter as she stands in the empty bedroom (which she has no plans to change, even an iota), or if this bereaved dad hears the laughter of his teenage son, or that grieving mother sometimes thinks she hears the call of "Mom, I'm home!," while she's loading the washer or drying her hair (but, then of course, he's never there when she runs to the door), well, then they can surely qualify for a Psychotic Disorder (with or without Hallucinations, or Delusions, but probably just the garden-variety Unspecified type will suffice).

How many grieving parents have experienced any of these phenomena and more? I know I can check off several on the list. I am fervently opposed to the pathologizing of grief. Grief is not a mental illness or disorder. To paraphrase Dr. Joanne Cacciatore, if grief is a mental illness, so then is love. We grieve in the same measure with which we love. However deep our love, so the depths, breadths and lengths of our grief. For parents whose children have died, that measure is indeed beyond imagining. As so many others who have not lived it (thankfully) cannot imagine what it must be like for your beloved child to die, we who have experienced it cannot imagine the day when our love is not reflected somehow in the immensity and protractedness of our grief. This is not illness. This is normal. This is hard and it is sad, but it is normal.

What we really need is a society that supports us in living with the aftermath. The Farley-Kluger Initiative to add the death of a child to the list of reasons for eligible leave under FMLA is a huge step in recognizing that grief following the death of a child is a significant event in the life of a family. Because of this, I am honored, pleased, and proud to travel to our nation's capitol with Barry and Kelly the first week of February 2013 to meet with nearly 30 members of Congress to discuss the initiative. I will do whatever I can, as my son's mother, as a clinician and grief professional, as a member of the MISS Foundation, to support this effort begun by these two dedicated and committed fathers.

Please join me in helping the Farley-Kluger Initiative to amend the current FMLA become a reality. Sign the petition. Help us reach 50,000 signatures and beyond. Forward it to your friends and family. Share the petition on Facebook and Twitter, write your congressional representatives and your senators. In the midst of the worst grief imaginable, no parent should have to fear for job security. Let it be known that we believe parents grieving the deaths of their children deserve to be able to take time and space to grieve and to mourn, without the fear of losing their jobs. Let it be known that we believe bereaved parents should not have to accept the label of a mental illness in order to have time and space to grieve the deaths of their children, also without fear of losing their jobs. Let it be known that we do not believe they should have to return to their workplaces with the stigma of mental illness in addition to the isolating effects of bereavement. This grief is already hard enough. For all these reasons, and for reasons of your own, stand with us. Send the message that we believe all bereaved parents, now and in the future, deserve this recognition of our grief.

It shouldn't take an Act of Congress to send such a message, but if you and I have anything to do with it, it can, and it will.

http://www.farley-kluger.com

Credits

Newsletter is co-edited by Amy Paul in memory of her son, Jacob; Kelli Montgomery in memory of her daughter, Madeleine; and creative design by Kara Jones in memory of her two sons, Kota and Zuzu.

GRIEF • COMPASSION • COMMUNITY • HOPE

MISS FOUNDATION

Thank you for your continued donations and support of our work!

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