

UNITE Notes

Winter/Spring 2020 Vol. 39, no. 1

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Untitled

I never knew I could feel this much I never knew I could hurt this much This much pain This much sorrow This much longing For what might have been. I never knew I could love this much My heart bursts And aches And cries out For my baby. To hold him in my arms To look into his eyes To make him feel my love Remembering the pregnancy test Remembering the ultrasounds Remembering the scans and images and tests No matter what My darling, my love No matter what My sweet baby boy I will honor you I will cherish you

Maggie Rousis

I will remember you.

If you or your organization would like to sponsor an edition of *UNITE Notes*, please contact us at 484-758-0002 or via email at administrator@unitegriefsupport.org.

Thank you for your support.

Professionally Speaking... by Denise M. Paul MA, CT, CPLC

PTSD Following Miscarriage and Stillbirth

Post-Traumatic Stress Disorder (PTSD) is caused by the involvement in or exposure to a traumatic event. This disorder is often spoken about in reference to veterans who return from war with memories of horrific scenes of suffering and death. When a traumatic event occurs, the brain usually switches from survival mode to a state of restoration, but with PTSD the brain is unable to restore itself, leaving the survivor in a constant state of emergency.

Studies are recently emerging that show that mothers who experience miscarriage or stillbirth often suffer from PTSD. The diagnosis is made by meeting certain criteria that are outlined in the DSM-5, the Diagnostic and Statistical Manual of Mental Disorders.

The Criteria are as follows:

<u>Criteria 1:</u> The person was exposed to a traumatic event, such as death, threatened death, or a threatening serious injury.

The mother and father are confronted with a pregnancy that ended abruptly. Moreover, the death occurred inside the mother's body. The mother carried her baby until she experienced the pain and trauma of labor. The mother experienced the physical and emotional trauma of delivering her dead baby, and the father intensely participated in the birth of their baby, which resulted in the demise of their hopes and dreams. CRITERIA MET.

<u>Criteria 2</u>: The traumatic event is persistently re-experienced in one or more of the following ways: Unwanted upsetting memories, nightmares, flashbacks, emotional and physical distress.

Mothers often have recurrent distressing flashbacks of the moment they heard the words, "no heartbeat" and "I'm sorry that your baby is dead" from the doctor or nurse. Nightmares of the birth, or dreams about other family members or future babies dying are common. Mothers often experience intense psychological and physiological distress from triggers that remind her that her baby is dead. These triggers include: hospitals, babies, pregnant women, the empty nursery, the baby section of a supermarket, etc. CRITERIA MET.

Criteria 3: Persistent avoidance of the stimuli associated with the trauma.

Mothers put great effort into avoiding activities, places, or people that arouse recollections of the trauma of losing their babies. These places include: baby showers, Christenings, doctor's offices, friend's newborn babies, and just about anywhere where they might encounter a pregnant woman or a baby. Mothers have told me that they actually survey the scene of every place that they go for possible triggers. CRITERIA MET.

Criteria 4: Negative thoughts or feelings.

Mothers always report an assortment of the following things: overly negative thoughts about themselves, lack of interest in activities, feeling isolated, exaggerated blame of self or others for causing the trauma, irritability, difficulty focusing on anything but the grief, a negative affect, and difficulty sleeping. CRITERIA MET.

<u>Criteria 5</u>: Symptoms create significant distress or impairment of everyday functioning.

A bereaved parent's life is never the same. Family, friends, and co-workers don't understand. The trauma that you have experienced is the only thing on your mind, but the rest of the world is oblivious to your pain. Friendships are sometimes destroyed because the grieving parents are not supported in their grief. Insensitive co-workers or family members think

that you should "get over it", leaving you to grieve alone. A simple trip to Target can be difficult because you cry every time you walk by the baby section. The grief of losing your baby overtakes your mind, making it difficult to concentrate on work and everyday activities. Parents often prefer to stay in the security of their own home while avoiding social activities. CRITERIA MET.

<u>Criteria 6:</u> Persistent symptoms of increased arousal.

Mothers often have difficulty falling or staying asleep. They can be irritable or even aggressive in behavior. They have difficulty concentrating and a heightened startle reaction. They are hypervigilant, fearing that some other trauma will hurt them. CRITERIA MET.

Criteria 7: Duration of the experience is more than one month.

I have people in my support group who have been coming for 2, 5, and even 12 years following the loss of their baby. The initial trauma isn't always felt instantly. Parents are often in shock during the first month, protecting themselves for the deep trauma that may be felt in the weeks and months to come. CRITERIA MET.

I have a feeling that many of you have experienced most of the criteria needed to confirm a PTSD diagnosis. As distressful as these preoccupations and flashbacks are, they also serve as a survival mechanism. You are reliving the experience in order, unconsciously, to gain a sense of mastery and control over an overwhelming event. Grief affects you physically, cognitively, socially, spiritually, and emotionally. Very often parents feel that they are going crazy as they feel the impact of the tremendous weight of profound grief following the death of their baby. By giving what you are experiencing a name, such as Post-Traumatic Stress Syndrome, it acknowledges that the impact of your loss is as difficult, if not more difficult, as what our veterans feel after returning from war. It is not meant to label you with a psychological disorder, it is meant to confirm that you need to be treated kindly. Hopefully, your mind and your heart will find a way to integrate your baby's loss into your lives in a meaningful way, and the trauma will eventually soften to a pain that you can live with and honor, as you keep your baby's memory alive in your heart.



Take Care of Your Heart

I know your heart feels ripped apart. When you buried your child, you buried your heart. It feels like God doesn't give a damn, And you'd give your soul for His helping hand.

Trust me, I know what I'm talking about, When I talk about having your guts turned inside out.

Some days you'll feel you can't go on like this, The pain is too much and your child amiss.

Believe it or not, your heart is still in its place. Although it's in many pieces and feels like an empty space,

It needs much repair and a whole lot of healing. But for the rest of your life, this pain you'll be feeling.

Be good to your heart, be kind and be gentle. Let the tears flow and be extremely sentimental. Only you can give your heart tender loving care. And I know it sounds impossible, don't let anger fester there.

Take care of your heart, get out what's inside. If you keep it all in, even worse pain will abide. I know you'll want to give up, but please try hard to care.

After all, your precious child is now residing there.

Peggy Phelan

In loving memory of Henry Michael Phelan III



Death and Humanity

You will always be your child's mother/father. Death cannot take that from you. It is your title for all eternity. Though it was short, your baby had a life. Your child now exists in the realm of creation, was formed from nothing into a state of being, and became human. Like a star that may be snuffed out after a few million years, it is no less a star than another that will be snuffed out after a hundred billion.

Your feelings, those things that can't be touched or seen by others, are real and in any given moment define who you are at the core of your own creation. That's why we use sentences like:

I am sad. I am devastated. I am broken.

Respect these feelings even if your spouse, parent, or best friend can't. Respecting who you are moment to moment is the beautiful reality of self-acceptance. Being able to accept where you are right now has the underlying assumption that you will feel differently in ten minutes, two hours, tomorrow, next week, next month, or next year. Then you will be able to use sentences like:

I am calm. I am recovering. I am content.

It's best not to run away from what you feel but to respect that very intricate part of your own humanity.

Death doesn't change the essence of life. Death does not make your child less than human. And by heightening your own feelings, whether we want it to or not, Death shows us what it means to be fully human.

Geraldine Donaher



Grief Relief-Seven Ways to Reduce Stress

(By Victor Parachin, The following article was lovingly lifted from Bereavement Magazine March/April 1989, Bereavement Publishing, Inc. 4765 North Carefree Circle Colorado Springs, CO 80917-2118 (888) 60-4HOPE (4673))

The medical reality is that grief is very stressful. Every loss has a tremendous psychological and physical impact. While stress is always a by-product of loss, one should not feel totally helpless when dealing with grief. It is possible to reduce tension and help fight off the effects of stress. Here are seven suggestions for breaking the cycle of stress:

IMAGE POSITIVELY

Imaging is a term which has recently come into vogue. It involves forming a mental picture or visualizing an ideal situation one would like to experience. The theory behind imaging is that what you see is what will be.

BALANCE YOUR TIME

Balance your time with work and play, leisure and labor, activity and rest. Everyone needs space, variety and a change of pace. If a situation is wearing you down, seek ways to equalize and lighten your life.

EXERCISE REGULARLY

A variety of studies provide ample evidence that physically fit individuals have the edge over others in dealing with stressful life events. A study that tracked the health habits of seventeen thousand Harvard graduates for twelve to sixteen years, found that individuals who exercised habitually, suffered fewer heart attacks and significantly increased their overall health and longevity.

The exercise does not need to be rigorous, just regular. It is not necessary to become a long-distance jogger or marathon swimmer. Daily walking at a comfortable pace delivers great benefits in stress reduction.

WRITE OUT THOUGHTS AND FEELINGS

Anything that objectifies experiences is generally healthy. During stressful times, many people begin to write in a journal. It can be a therapeutic way to get in touch with deep feelings and emotions. Keeping a daily record allows you to spot the main stresses in your life. That knowledge, in turn, can help you respond better.

SHARE YOUR WORRIES AND CONCERNS

Seek out someone who can listen and is non-judgmental.

Good friends whom you have come to love, trust and respect can be very helpful when stress is tearing you up. Don't hesitate to tell them that you need to talk. They may not automatically realize that.

Support groups can be valuable as well. Sharing of sadness always serves as a catalyst for healing and growth.

ACCEPT YOUR FEELINGS

After a loss of any kind, we do not choose our emotions, they choose us. It's important to let the feelings flow naturally. Robert, who lost both his wife and oldest daughter in an automobile accident, writes: "I've had my share of tears and sadness over my tragedy. And I've had my share of a whole flood of other feelings too: anger, helplessness, hopelessness, fear, guilt, loneliness. I've learned that it does no good to fight such feelings. Pushing them down only seems to make them come back with even greater fury. But when I have embraced them as part of me, and normal, then I've been able to ride the crest of that wave of emotion to a new place in my recovery process."

MAINTAIN ADEQUATE NUTRITIONAL RALANCE

Following a loss of any kind, people often suffer from eating disorders, the majority of them finding mealtimes unpleasant and even impossible. However, grievers need to be extra careful about providing themselves with important nutrients. As much as possible, every attempt should be made to eat daily portions from the four basic food groups: meat, fruit and vegetables, grains, dairy products.

It is also important to maintain an adequate fluid intake because it is easy for the griever to override a sense of thirst. Additional fluid intake should be encouraged while avoiding caffeine and alcohol.

Stress resulting from loss cannot be avoided, but it can be managed and minimized. By applying these techniques, you will be rewarded with better health and more enjoyment of life.

Thank You!

UNITE, Inc. would like to extend our heartfelt thanks to all of UNITE's volunteers but especially to Danielle Kennedy who volunteered as the UNITE President and Stephanie DeAngelis who volunteered as the UNITE Treasurer. Danielle and Stephanie recently stepped down from their positions after being a part of the UNITE family for several years. All of the UNITE volunteers give their time to help UNITE continue the mission to be there for grieving families today and in the future. We are forever grateful to them all.

Thank you from the UNITE Board and Facilitators



"Sometimes the smallest things

take up the most room in your heart"

A.A Milne



Healing Power of the Pen

by Alice J. Wisler

The first year after the death of a child is like having the worst noise possible running through your head each day and night. There is no way to turn the horrendous sounds off because there is no off button.

I wrote through that noise. I wrote from the heavy bag of emotions bereaved parents must carry—anger, guilt, sorrow and confusion, all the "what ifs" and "how comes" and "whys."

I wrote of longing for a blond-haired boy with blue eyes whose laughter brightened hospital rooms. A quiet spot under weeping willows at a local park is where I carried my pen, journal and pain. As I wrote over the course of many months, I was, although I didn't realize it at the time, providing therapy for myself.

Some days when the weather did not permit a trip to the park and my body and mind harbored excruciating pain, I shut myself in a room, away from my other children and husband. I'd grab my journal and let the experiences of the day and my feelings freely emerge onto each white page. Grammar didn't matter; penmanship went out the window. These aren't a concern when you are writing to survive.

Writing the heartache, complete and honest, is a way of healing. Our cry is, "Help me with this pain!" We find ourselves lamenting as King David did in Psalm 13:2, "How long must I wrestle with my thoughts and every day have sorrow in my heart?" David wrote many of his psalms starting with anger and agony and gradually, ending with hope.

Writing can do that for us. We enter into our devastation, get a good grip on what our struggles are and something about seeing them on paper causes us to realize the pain is not only within us anymore. It is shared, even if only on a sheet of notebook paper. It is documented and the more we write, the better we are able to understand and deal with our intense sorrow.

Some people think only the creative types write, when in reality, writing through the pain is available to anyone who has suffered the loss of a child. "I don't have time," many say. "What will I write?" others wonder. The blank page scares some because they think they have to fill it with something profound.

But just writing a memory of your child or a few lines about how you felt after he died is a notable start. If we think of writing as a private endeavor and an effective tool, not a paper to be graded by a high school English teacher, we will conquer many of the doubts about our ability. In time, we will see that writing helps us become better in tune with our feelings and thoughts. It clarifies our lives and gives us understanding.

Other reasons to take the time to write are:

To experience personal growth.

To leave a legacy or a keepsake so that there will be recordings of what and who our child was.

To demonstrate a way of cherishing our child. To feel a connection to our child as we remember the things we shared here on earth.

We also are honoring our grief, our pain and what has happened to us. We are validating its existence. As studies have shown, writing is healthy for our minds and bodies.

Professor James Pennebaker claims that writing actually helps the physical body when the writer is able to open up, by sharing deep feelings on paper over a period of time. In his study, half a group of students at Southern Methodist University in Dallas, Texas, wrote their heartfelt thoughts and feelings about a stressful event from their lives; the other half wrote about superficial topics. Each group wrote for twenty minutes a day, for four consecutive days.

Before writing and immediately after writing, blood pressure and heart rates were tested and a galvanic skin response was done. Six weeks later, the students had their blood tested again.

The group that had written about trivial topics showed no sign of changes. But the group that had poured their pain onto paper, claimed writing had actually calmed them. Their skin was drier after writing and both heart rate and blood pressure had decreased. Their blood work even showed an increase in lymphocytes, the white blood cells that work to keep the immune system healthy.

Writing through the heartache of losing a child is some of the best therapy I have found on this journey. I didn't know how helpful it was, I just knew I needed to organize my thoughts and get them out on paper. Now, four years since my four-year-old son Daniel's death, I see that when all the evidence is presented, there is no reason not to

write. It causes dim skies to light up when not only the pain, but also the love and cherished memories, are recorded.

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http://www.geocities.com/griefhope.index.html

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"You can only go halfway into the darkest forest; then you are coming out the other side"

Chinese Proverb



Winter/Spring 2020 Donations

We Are So Grateful for Donations Given Throughout the Year

Donations

Paris Margaritis
Stephane Boyer & Amanda Nivault
Kendra Wood
Barbara Fynes
Adam and Beth Borrelli
James and Denise Paul

Linda Nuccitelli Stephane Boyer

Cindy Hunn - "In memory of Ethan and Samantha", Thinking and loving you both always and forever. I draw so much strength from you everyday. My angels, Ethan and Samantha. XOXO, Mommy

Mary Clavin

Andrea Devenney – Giving Tuesday

Dennis Boyle – In memory of Anthony Manus Devenney **Stacy Dougherty** – In loving memory of Anthony Devenney.

Love the Dougherty's

Andrea Devenney – In memory of Anthony Devenney for his 2^{nd} birthday.

Christina Quinci

Walk to Remember donations 2019

Sally Chiarlone

Walk to Remember Donations 2020

Linda Nuccitelli – Ridley Creek State Park – Walk to Remember 2020

Walk to Remember 2020 - Luminaria's

Elaine Porter – In memory of Shalom Armstrong Elaine Porter – In memory of Shalom Armstrong Elaine Porter – In memory of Shalom and Sherri Elaine Porter – In memory of Sherri Maria Porter Elaine Porter – In memory of Sherri Maria Porter

Butterfly Memorial Wall

Barbara Fynes Cindy Hunn

Haley Joyce Powers – 10th Anniversary 4/12/2010 – given by

Lynn Healy

In Honor of Danielle Kennedy

In Honor of Stephanie DeAngelis

In Honor of Cathy Plaisted

In Memory of Judith Douglass

Grants

St. James Church of Christ – Kevin Brightbill **The Superhero Project, Inc**. - In Honor of Denise Paul and all the amazing work you do to help! **Merck**

Johnson & Johnson





New Mailing Address and Phone Number

Please note our new mailing address: P.O. Box 298, Oxford, PA 19363

New Phone Number

Please note our new phone number: 484-758-0002

Walk to Remember – Save the Date

The 2020 10th Annual Walk to Remember will be held at Ridley Creek State Park on Saturday, October 10th. The Invitation and Sponsorship form can be found at the end of this newsletter.

Safe Arrivals

We would love to hear about your safe arrival so we all can celebrate in your joy. So we can put it in the newsletter, please send information on your new bundle of joy to administrator@unitegriefsupport.org

Home Page Info

www.unitegriefsupport.org

Virtual Butterflies: The donation cost for placing one of these virtual items on the page is \$25 and will be in memory of your baby. You may donate through PayPal by clicking on the Buy Now icon. Note: On the PayPal page, where it states, "Instructions to the Merchant," type in your baby's name, etc.

Newsletter Submissions

Please send your original poetry, short stories, articles, and letters to *UNITE Notes*. The beautiful writings that we receive from UNITE's bereaved parents are what make our newsletter so special. If you have written poems, articles, etc. that you would

like to share with other parents, please send them soon. Note that the newsletter is now being uploaded to the UNITE website which allows all who are searching for comfort and support due to the loss of their child(ren) to see your written story.

Acknowledgments

If anyone has not received an acknowledgment for their donation, please contact the administrator@unitegriefsupport.org, or call the UNITE line at 484-758-0002. Please leave your name, phone number, and the best time to return your call.

AmazonSmile Foundation

The Foundation runs a program in which Amazon donates 0.5% of the purchase price of eligible products to charitable organizations. To shop go to smile.amazon.com from your web browser on your computer or mobile device and choose UNITE, Inc. Products will be marked "Eligible for AmazonSmile donation" on their product detail pages. You may also go to our web page: www.unitegriefsupport.org and click on the icon/banner, which will bring you to smile.amazon.com. You should bookmark this page so that you go directly to your Amazon Account and start shopping. Purchase of digital content, such as Kindle e-books or MP3's, is not included.

Fundraisers Wanted

We are looking for some fresh ideas in fund raising! Do you have an idea to share? We'd love to hear about it. Please contact UNITE at administrator@unitegriefsupport.org.

Support Groups

For information about the group nearest you, please contact UNITE, Inc. at 484-758-0002 (leave a message on the tape), write to UNITE Inc. at P.O. Box 298, Oxford, PA 19363, or email administrator@unitegriefsupport.org. New members <u>must</u> contact the group coordinator before attending their first meeting. UNITE, Inc. does not discriminate on the basis of gender, age, marital status, religious belief, race, sexual orientation or economic status.

Pennsylvania

UNITE, Delaware County Memorial Hospital (Drexel Hill)

Meets 2nd Wednesday, 7:00pm-8:30pm

Facilitators:

Kathy Macagnone kmac356@comcast.net

610-212-5849

Debbie Rafferty broomallraffs@aol.com

610-246-9179

Michelle DePrince michelle.deprince@comcast.net

484-432-6439

UNITE, Holy Redeemer Hospital (Huntingdon Valley)

Meets 3rd Thursday, 7:00pm-9:00pm

Facilitators:

Denise Paul denisepaul22@comcast.net

215-260-0389

Liz Steward mommyofangels3@msn.com

215-368-4038

UNITE, Jennersville Regional Hospital (Chester County)

Meets 1st Tuesday, 7:30pm-9:00pm

Facilitator:

Karen Powers <u>fundraising@unitegriefsupport.org</u>

484-620-9267

UNITE, Lankenau Hospital (Wynnewood)

Meets 3rd Tuesday, 7:30pm-9:00pm

Facilitator:

Paris Margaritis pmargari@yahoo.com

484-680-6531

UNITE, Riddle Memorial Hospital (Media, Delaware County)

Meets 1st Thursday, 7:00pm-8:30pm

Facilitator:

Carol Kealey carolkealey@hotmail.com

610-220-9551

Regina Fazio regwalker@gmail.com

UNITE's services include:

- Support Group meetings in Pennsylvania and New Jersey.
- Hospital In-service Programs and community education.
- Conferences for bereaved parents, professionals and the community.
- Literature and newsletter.
- UNITE group development assistance and training programs for group facilitators and support counselors.

Referral assistance

Sheila McCabe <u>mccabes_02@mlhs.org</u> 610-742-3650

UNITE, Pennsylvania Hospital

Meets 1st Tuesday, 6:30pm-8:00pm

Facilitators:

Michelle Ferrant ans Kelly Colby <u>pahosp@unite.org</u>

215-829-5040

UNITE, University of Pennsylvania Medical Center

Meets 3rd Tuesday, 7:00pm-8:30pm

Facilitators:

Kelly Zapata kelly.zapata@uphs.upenn.edu

215-300-7151

Vicki Kroesche <u>vkroesche@yahoo.com</u>

UNITE, Paoli

(Paoli Pointe Medical Center, next to hospital)

Meets 2nd Monday, 7:00pm-8:30pm

Facilitators:

Sue McAndrew Mcandrews@MLHS.org

484-883-2198

Gerri Donaher geraldinedonaher@yahoo.com

410-490-5893

New Jersey

UNITE, Penn Medicine Princeton Medical Center

Meets 1st Monday, 7:00pm-9:00pm

Facilitators:

Bernadette Flynn-Kelton

bernadette.flynn-kelton@pennmedicine.upenn.edu

908-229-5815

UNITE, Virtua at Voorhees

Meets 1st and 3rd Mondays, 7:00pm-9:00pm

Facilitator:

Ann Coyle tacoyle91@aol.com

609-502-7552

UNITE Notes staff

Editors: Theresa Fisher and Kathy Macagnone

Administrator: Barbara Bond-Moury

Submissions: We welcome your original poetry and articles. Your contributions are important to UNITE's work of reaching out to bereaved parents. We reserve the right to edit and select from submissions. Please send all submissions to:

UNITE Inc.
P.O. Box 298
Oxford, PA 19363
484-758-0002
or email administrator@unitegriefsupport.org

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You are invited to UNITE's 10th Annual Walk to Remember

When: Saturday, October 10, 2020 12:00 PM to 3:00 PM (Rain or Shine)

Where: Ridley Creek State Park, Picnic Site #17

http://www.dcnr.state.pa.us/stateparks/findapark/ridleycreek/index.htm

What:

The "Walk to Remember" is an opportunity for the UNITE community to join together to remember our children and raise funds for UNITE. Please bring your own picnic lunch. Drinks and soft pretzels will be provided. Lunch will begin at 12:00 PM and the walk will begin promptly at 1:30 PM. The walk will be no farther than 1 mile (you can turn around at any time) or you are welcome to remain at the pavilion during the walk.

Fundraising:

There is no registration fee for this walk and fundraising is not required. However, if you would like, you can ask your friends and family to sponsor you (or even sponsor yourself!). Your fundraising efforts will allow UNITE to continue supporting bereaved parents in our community. A sponsor form is available from your group facilitator or by contacting fundraising@unitegriefsupport.org. Additional sponsor forms will be available the day of the event.

Please RSVP:

RSVP to 1-484-758-0002 or <u>fundraising@unitegriefsupport.org</u> by October 1, 2019. Family and friends are welcome to attend! For more information, please call or email.

Directions:

The main entrance to Ridley Creek State Park is Sandy Flash Drive South at Gradyville Road. From main entrance, pass by the Park Office and follow directional signs to picnic area #17.

For GPS, use the following address:

351 Gradyville Road

Newtown Square, PA 19073.

Or find detailed directions at:

http://www.friendsofrcsp.org/Directions2Ridley.pdf



Support me as I participate in the 2020 UNITE, Inc. 10th Annual Walk to Remember



	Participant's Name:
	Yes! I will make a contribution to help UNITE, Inc.
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or Deliver the form to the person you are sponsoring with your check.