
Winter

(Editor's Note: As we have made it through the winter months and are heading into the spring season, I would like to share this beautiful message that was written in 1999 by our Executive Director, Janis Keyser. Janis lost her courageous battle with cancer in spring of 2004, but we will never forget all that she taught us.)

This time of year holds intrigue for me. It's not that I particularly like winter – actually, I've learned to appreciate it as a concept, but not as a reality! But it is the winter solstice, the day of longest darkness that draws my attention. The idea of coming to the darkest point-- the time of greatest despair that the light will be wiped out forever, that all hope will be lost-- and finding instead that the light has begun to seep back in through the cracks, ever so slightly, but with great promise, gives me strength. Joseph Campbell, with his wisdom about mythology and life, wrote, "One thing that comes out in myths is that at the bottom of the abyss comes the voice of salvation. The black moment is the moment when the real message of transformation is going to come. At the darkest moment comes the light." It is our story, too, in rising from the ashes of our grief.

UNITE's wish to you is consistent with our mission all year through-- for patience and strength through all the unknowns of our grief, for companionship through the pain, for love and acknowledgment of our children's lives, for healing that comes from facing the darkness as we hold onto hope for the light.

Peace.

Janis Keyser
UNITE Notes, winter 1999



Note From the Editor

I first joined UNITE in 1998 after my twin boys, Eric and Joshua, died at just three weeks old. The UNITE newsletter was a continuous source of comfort over the years, arriving quarterly in my mailbox. I love the newsletter because it gives us the chance to share our children with each other in writing. It has been an honor to share my sons with all of you...and a privilege to have known your children, as well.

After being a member of UNITE for eight years, at the bequest of Linda Nuccitelli, the then newsletter editor, I stepped up in 2006 to assist her as co-editor of *UNITE Notes*. I was a bit hesitant to commit since I had two young daughters at home and didn't know if I would have the time to give it my all. So, I committed to just "helping" Linda out. And, 20 years later, I am still here. After Linda retired in 2014, I moved to editor and Kathy Macagnone volunteered to be my co-editor. Kathy retired in 2020, and I have been the sole editor since that time. I must admit, something that I was so hesitant to commit to, turned out to be the most rewarding experience of my grief journey.

Unfortunately, after almost 20 years of working on the newsletter, I have decided to step down as editor. While I really enjoy being a part of the newsletter, I believe it's time to move on and bring in younger, fresher eyes with newer ideas to improve the newsletter. My last edition will be the spring edition. Hopefully, we'll have a new editor by then so I can guide him/her through the process. It would be sad to have no one step into the position because that would mean the newsletter will be paused until a new editor comes along.

Ideally, it would be great to have an Editor and Co-Editor who will work together. It's always good to have a second set of eyes reviewing the articles. Laurie Holper was a God send when she stepped up two years ago to help proof-read and write articles. I really needed her help and we worked well together. But, over the years, while I was the only editor, I missed some editions or combined two editions into one due to various things going on in my life. During that time, if I had someone else to work with, editions would not have been missed.

If anyone is interested in taking over the newsletter, please reach out to me at newsletter@unitegriefsupport.org and let me know. It doesn't take much time. I would say approximately 10 to 15 hours, give or take, to get an edition out. There are four editions a year, one for each quarter. Of course, whoever takes over can put out more than four a year and make any changes deemed necessary, for improvement. Just because I am stepping down as the editor does not mean I will walk away. I will gladly be around to guide the new editor(s) with the transition and assist in any capacity until he/she is comfortable moving forward without me.

Being the editor of *UNITE Notes* has been a major part of my grief journey. While it has been very rewarding to comfort those in need, it is the best job I wish I never had. It would be wonderful if there were no need for newsletters like ours. Thank you for allowing me to be a part of your grief journey and thank you for helping me through mine.



Theresa Fisher

*Mommy to My Two Angel
Babies
Eric Joseph and Joshua Ian
7/12/98 to 8/4/98
And
My Two Rainbow Babies
Jessica Erin and Abigail Rose*



Professionally Speaking.....

By Denise M. Paul MA, CT, CPLC

Grief is a Handicap

Nora McInerny writes in her book, *No Happy Endings*, that there can be new beginnings following a devastating loss. The author suffered a miscarriage, followed by the loss of her young husband to brain cancer. As a grief therapist, I was particularly struck by the chapter that she called “Armless.”

After the death of her husband, Nora dreamed that she was walking through the world completely armless. She noted that the people in her dream life fell into two camps: those who pretended not to notice her armlessness, and those who were irritated by what they felt was her obsession with it. This may have been her dream, but it was also her reality. I suspect that many grieving people can relate to this.

I bookmarked this page because I knew that this metaphor symbolized how many parents feel after losing a baby. Imagine going about your day with no arms! You’d feel broken and helpless, and unable to perform the tasks that you would otherwise be able to accomplish. Grief can be immobilizing, causing you to feel armless.

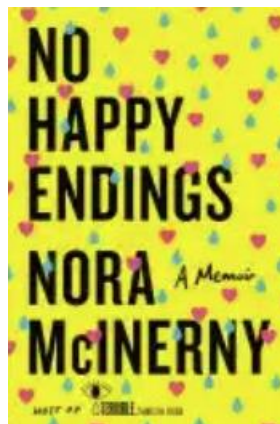
Losing a baby affects you physically and mentally, often leaving you to feel disabled. You often have no desire to even leave your house! Attending parties or events with family and friends is the last thing that you want to do mainly because you’ll be faced with triggers in the form of pregnant people, babies, or well-meaning people who say the wrong things. You will encounter people who either don’t know that you’ve lost a baby, or people who do know, but are too uncomfortable to acknowledge your loss. You are hurt by the people who do not notice or recognize your armlessness. You identify as a handicapped person, and while you’d like to be treated like a normal person, there is a part of you that certainly wants to be recognized as someone who is grieving, and in need of special care. Your grief, and everything that goes with it, is your handicap. Family and friends want you to be back to normal very quickly, while you are secretly identifying as a handicapped person. And that’s ok. You are grieving.

The other group of people are the ones who are irritated by what they believe is life and want you to “get over” the loss, so that it makes everyone else feel better. Family and friends give people a few months, or as little as a few weeks to grieve, then expect you to be back to normal. Employers may give mothers only a few days to grieve. People have a very difficult time acknowledging miscarriage and stillbirth. It’s much easier to offer condolences to someone that has lost an elderly grandparent than a precious baby. You hold onto your grief because you want people to know how much this loss has hurt you. In a subconscious way, you believe that if you stop feeling the pain of your loss, then you are forgetting about your baby. If you continue to talk about your baby and replay the story of your loss, people sometimes think that you are obsessed with your grief, and they don’t know how to respectfully honor your feelings.

Getting back to Nora McNerny's dream ~ she recalls one of the people in her dream shouting at her at the dinner table when she cried that she couldn't eat the soup because she had no arms. They said, "Use your FEET!" She spent a year drinking soup with her feet. Not literally, but she was trying to unpack the psychological obviousness of this dream and draw some parallels. The message here is to do the best that you can. You will feel handicapped for perhaps a long time. You will learn to "fake it till you make it" on many occasions. You will learn to accommodate and improvise when situations feel challenging. Only you know that you have no arms.

You may also feel like you have no eyes or ears. Grief may make you blind to the beauty of your world, and the people in it. Grief may prevent you from hearing the loving and supportive things that people are saying to you. It's normal to feel handicapped. Take the time that you need to submerge yourself in the pain of your baby's death and honor your baby in any way that you can. However, I encourage you to realize that you are not actually without arms ~ so hold those people whom you love. You are not without eyes ~ so behold the beauty of this world in which you live. You are not without ears ~ so hear the kind words of love and support from the people who care about you.

Look forward to the new beginnings following your loss.



Coping with Miscarriage and Infant Death in the Long-Term

Laurie Holper



It is always assumed that the period of time immediately following a miscarriage or infant death, will be a difficult one, filled with grief and sadness. But what about the months, or even years, after this tragedy? It may be thought by others, and even by the parents, that as time passes, they will no longer think much about this loss.

Surely, as time goes by, the parents will no longer dwell on this loss as they initially did. However, painful reminders will appear, thus resulting in difficult memories. Friends and relatives may have newborns, making it problematic to spend time with them, especially if the parents have not had another baby since their loss.

Certain dates, occasions, and holidays may conjure up the grief again. For instance, the Thanksgiving holiday may result in thinking that the baby would have been part of this celebration, and how thankful the parents would have been for this new family member. At first, every month, then, eventually, every year, on the anniversary of the baby's birth and/or death, the parents may think of how old the child would have been. Would he or she be having a birthday party with friends sharing in the special day?

Eventually, many years later, the parents may realize that their child would have graduated from high school or college or reached another special milestone at this point in time.

Parents may also need to deal with questions from well-meaning others. For example, they may be asked how many children they have. Do they include the deceased child in their answer?

I will never forget an incident when, at the time, I had two daughters, one born before my infant son died, and the other, after. A photographer, taking their pictures, asked, "So, will you try for a boy?" I immediately responded, "We had a boy who died two hours after birth." The photographer was shocked and apologetic. I hadn't said this to make him feel badly, but, rather, to make him realize that he may not want to ask such questions in the future.

If there are other children in the family, parents may become overprotective of them. They may be overly concerned if the children get sick or hurt. During a subsequent pregnancy, they may deal with anxiety and fear that this baby will die, too. Parents may even feel that conceiving another child will betray the baby who died.

So, what would be helpful to parents dealing with all these emotions? Getting individual or couples counseling, and/or being part of a support group with others experiencing the same things, are helpful ways to cope with all these feelings and occurrences. Of course, supportive family and friends can always be a wonderful source of comfort.

Although these reminders or instances that occur throughout life may bring sadness to the parents, some positive feelings may also arise. Reminders may bring happiness when thinking about their baby. This enables the parents to memorialize their child, keeping him or her alive in their thoughts. There have also been cases where parents have created non-profit charitable organizations in the name of their baby. Thus, the baby became the reason for helping others. THANK YOU, BABIES!

Living My Life in DJ's Honor

Amy Kate Lobel
DJ's Mom

On August 19, 2022, we lost our firstborn son, DJ, after spontaneous premature labor led me to deliver him at 22 weeks, and his little body did not survive the birthing journey. He was perfect and healthy, and yet my body had failed him. My heart has ached every minute since then for my sweet baby boy. Many days during the last few years, I have had to put on a brave face when I did not want to do so. I wonder what life would have been like with him here. I wonder what it would feel like without this grief always hanging nearby. It's the smallest things that remind me of the gravity of it all, how almost no one can understand what we've been through. And yet, we move forward, in his honor.

The next summer, my husband and I recorded a few podcast episodes with 'Still A Part Of Us', a podcast run by Winter and Lee who lost their son, Brannan. It's a legacy they've built for their son to offer other parents a place to share their stories, and I listened to it fervently in the weeks after our loss, feeling less alone. To go on their show was such a gift, and on the week of DJ's 1st anniversary, they published the episodes.



On that 1st anniversary, we held a memorial gathering for DJ. It was something my husband really wanted to do, and as scary/strange/uncomfortable it felt, I knew I needed to do it, for him and for my son. We

held it at a park nearby where he was born, which had special meaning to us. We had a big cookout by the beach, bonfires galore, and shared tears and hugs and laughter. We made tiny preemie hats like the one he wore, to donate to CHOP. We had a plaque installed on a bench on the bike trail we like to ride on.



Remembering him and honoring our community was one of the most beautiful days I could have ever imagined. I am so glad I pushed outside of my comfort zone and let people in to care for us. Our village is strong, and I can't even begin to share my gratitude to those that leaned into this journey with us. But first, we had to let them in.

DJ taught us love and hope and joy and sorrow and endless awe. It was the privilege of my life to carry him, safe in his little home where he only knew love. I hope to continue to live my life in his honor.



The Pit of Grief

The day my child died, I fell into the pit of grief.
My friends watched me struggle through daily life,
Waiting for the person I once was to arise from the pit,
Not realizing that “she” is gone forever.

The pit is full of darkness, heartache, and despair.
It paralyzes your thoughts, movements, and ability to
ration.
The pit leaves you forever changed,
Unable to surface the person you once were.

Some of my pre-grief friends gather around the top of
the pit,
Waiting for the old me to appear before their eyes,
Not understanding what’s taking me so long to emerge.
After all... in their eyes, I’ve been in the pit for quite
sometime.
Yet, in my eyes, it seems as if I fell in only yesterday.

Not all my pre-grief friends are gathered at the top of
the pit.
Some of them are helping me with the climb out of the
darkness.
They climb side-by-side with me from time to time,
But mostly they climb ahead of me, waiting at each
plateau.
Even with these friends, I sometimes wonder if they
are also waiting for the pre-grief me to magically
appear before their eyes.

Then, there are the casual acquaintances.
You know the ones who say, “Hi, how are you?”
When they really don’t care or really don’t want to
know.
These people are the people, who sigh in relief,
that it was my child who died and not theirs.
You know...the “better them, than me” attitude.
(Not that I blame them for that sigh or attitude,
I too wish it happened to someone other than myself.)

My post-grief friends are the ones who climb with me,
Side-by-side, inch-by-inch, out-of-the-pit-of-grief.
They have no way of comparing the pit climber to the
pre-grief person I once was.
You see, they started at the bottom of the pit with me.
They are able to reassure me when I need reassurance,
Rest when I need resting,
And encourage me to move forward when I don’t have
the strength.

They have no expectations, no memories, and no
recollection of how I “should be.”
They want me to get better, to smile more often, and
find joy in life,
But they’ve also accepted the person I’ve become.
The “person” who is emerging from the pit.

Cindy Early, November 1999

Lovingly Lifted from The M.I.S.S. Website
<http://www.missfoundation.org/>



I Missed You Quietly

Becky Hemsley Poetry 2024

I missed you quietly today. So quietly that no one noticed.

I missed you as I climbed out of bed, as I brushed my teeth; when I waited at the lights on the drive into work, and as I heard the rain outside my window.

I missed you as I ordered lunch and as I kicked off my shoes when I got home; as I switched off the lights and climbed into bed for the night.

I missed you without tears or noise or fanfare.
But oh how I felt it.

I felt it in the morning, at lunchtime, in the evening and at night. I felt it as I woke, as I waited, as I worked. I felt it at home, on the road, in the light, in the dark, in the rain.

I felt it in every one of those moments, each one sitting heavier and heavier as the weight of me missing you kept growing and growing.

Yes, I missed you so quietly today.

But I felt it so loudly.



Love In Every Tear

Author Unknown

O precious, tiny, sweet little one
You will always be to me.
So perfect, pure, and innocent
Just as you were meant to be.

We dreamed of you and of your life
And all that it would be.
We waited and longed for you to come.
And join our family.

We never had the chance to play,
To laugh, to rock, to wiggle.
We long to hold you, touch you now
And listen to you giggle.

I'll always be your mother,
He'll always be your dad.
You will always be our child,
The child that we had.

But now you're gone...but yet you're here
We'll sense you everywhere.
You are our sorrow and our joy,
There's love in every tear.

Just know our love goes deep and strong
We'll forget you never
The child we had, but never had
And yet will have forever!

Winter 2025 Donations

We Are So Grateful for Donations Given Throughout the Year

Susan Henderlite

Linda Nuccitelli

Haylee Bernstein

Robin Wright

Maureen Marcolina

Eric Woolfe

Kristen Gallagher

Donna Kupniewski

Janet Filer

Nancy Sklar

Environmental Women's Charity

GRANTS

Jewish Federation Grant – Linda and David Groverman
Johnson and Johnson

UNITE offers a number of services to grieving parents and their caregivers including the following:

Peer to Peer Grief Support Groups

- * Literature
- * Educational Programs
- * Training Workshops
- * Group Development Assistance

Without Your Most Generous Donations, UNITE Would Not Be Able To Continue These Services



News

Mailing Address and Phone Number

Please note our new mailing address:

P.O. Box 21715, Philadelphia, PA 19346

Phone Number

Please note our new phone number:

484-758-0002

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 newsletter@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* at newsletter@unitegriefsupport.org. 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 boardchair@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.

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 boardchair@unitegriefsupport.org.

Support Groups

For information about the group nearest you, please contact UNITE, Inc. at 484-758-0002 (leave a message), write to UNITE Inc. at P.O. Box 21715, Philadelphia, PA 19346, or email boardchair@unitegriefsupport.org. New members must contact the group coordinator before attending their first meeting. **All UNITE Meetings, except for Riddle Memorial Hospital, are virtual and are by invitation only. Please call 484-758-0002 if you would like to attend a UNITE Support Group.** UNITE, Inc. does not discriminate on the basis of gender, age, marital status, religious belief, race, sexual orientation or economic status.

Pennsylvania

UNITE Redeemer Health (Formerly Holy Redeemer Hospital)

Huntingdon Valley, PA

Meets 3rd Thursday, 7:00 PM – 8:30 PM

Facilitators:

Denise Paul

UNITE, Lankenau Hospital

Wynnewood, PA

Meets 3rd Tuesday, 8:00 PM - 9:30 PM

Facilitators:

Paris Margaritis

Michele Rafferty

UNITE, Riddle Memorial Hospital - IN PERSON

Media, PA

Meets 2nd Thursday, 7:00 PM – 8:30 PM

Facilitators:

Regina Fazio

Sheila McCabe

UNITE, Paoli

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

Facilitators:

Sue McAndrew

Lisa Natalizio

UNITE, Pennsylvania Hospital

Philadelphia, PA

Meets 1st Tuesday, 7:00 PM - 8:00 PM

Facilitators:

Karen Donnelly

Kelly Colby

UNITE, Chester County Hospital

West Chester, PA

Meets 2nd Monday, 7:00 PM – 8:30 PM

Facilitator:

Ryan Olivere

New Jersey

UNITE, Penn Medicine Princeton Health

Meets 1st Wednesday, 7:00 PM - 8:00 PM

Facilitator:

Bernadette Flynn-Kelton BSN, RN

UNITE, Virtua at Voorhees

Barry D. Brown Health Education Center

Meets 1st & 3rd Monday 8:30 PM -10:00 PM

Facilitator:

Ann Coyle, RN

Specialty Groups

Subsequent Pregnancy Group

Meets 1st Monday 7:00 PM – 8:00 PM

Facilitators:

Denise Paul

Sandy Smith

Father's Group, Dads Only

Meets 2nd Tuesday, 7:00 PM – 8:30 PM

Facilitators:

Matthew Sklar

Simon Hindle

Grieving Grandparents Group

Meets 2nd Tuesday of Each Month, 7:00 PM – 8:00 PM

Facilitators:

Nancy and Steven Sklar

UNITE Parenting After Loss Group

Meets 2nd Wednesday, 7:30 PM – 9:00 PM

Facilitators:

Cathy Plaisted

Hali Sklar

UNITE, Loving Choices (Termination for Medical Reasons)

Meets 4th Monday, 8:00 PM – 9:30 PM

Facilitator:

Ann Coyle

UNITE Notes Staff

Editor: Theresa Fisher
Co-Editor: Laurie Holper

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 21715

Philadelphia, PA 19346

484-758-0002

or email boardchair@unitegriefsupport.org

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