



# The Q.U.I.L.T. Quietly United In Loss Together Block

July 2013

Volume 1, Issue 1

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## A Story From Our Founder Nneka Hall

On August 26, 2010 I went in to my OBGYN's office for a routine 39 week checkup. I was expecting to hear my daughter's heartbeat and that I could deliver at any time. I even took my children, then ages 5 and 10, with me so they could hear their little sister's heartbeat. The nurse took them out of the room for my OB to examine me. After the examination she took out the Doppler and placed it on my stomach to hear my daughter's heartbeat. Only mine could be heard. We walked what seemed like an eternity down the hallway to a room for me to have an ultrasound. My OB and a second OB was present at the time of the scan. My OB looked at me as we all looked at the motionless screen and said, "I'm sorry, there's no heartbeat." The other doctor said as an aside "It's very recent." He said some other things but I was not in any condition to hear him. We walked the equally long trail back to my OB's office where she gave me my options and concluded with "These things happen".

It's been nearly three years since I've said hello and goodbye to my daughter, Annaya Marie Edwards, who entered this world to the tears of strangers who assisted in her delivery that early morning of August 27, 2010. She was 6lbs 12 ounces, 18 ½ inches long with a head of beautiful straight black hair. She had 10 little fingers and 10 little kissable toes. She was perfect in every way but one, she had died the day before her birth in my womb while I waited to see my OB. The ache has dulled with time but not a day passes that I do not look at her siblings and wonder what she would be like as a 2 year old.

Quietly United In Loss Together (Q.U.I.L.T.) is a Pregnancy and Infant Loss Awareness Campaign. Our goal is to raise awareness about losses that occur from conception through the first 24 months of life. We do not discriminate as Pregnancy and Infant Loss Awareness Day was meant to honor every type of loss. Q.U.I.L.T.'s planning committee is made up of PAILA organizations, groups, businesses, grieving parents, grandparents, aunts, uncles, siblings, friends and birth

workers.

I came up with the idea while sitting around one day. I began to think about the AIDS memorial quilt event that took place in 1987. I then asked myself, what if we (members of the PAIL community) did something similar? If I remembered an event that happened some 26 years ago, perhaps a similar event would be remembered down the line.

On October 15, 2014 (International Pregnancy and Infant Loss Awareness Day) we will march as a united body to remember children who would otherwise be forgotten. We will march to raise awareness about the many causes of pregnancy and infant loss. We will take this time to grieve openly without judgment. We will march to a memorial quilt that will honor the many lives lost in this epidemic. Q.U.I.L.T. is one event that is happening in five locations, the US, the UK, Canada, Australia and New Zealand (in order of signing on). The US march will take place in Washington DC, the others are to be determined.

### PAIL Terms

- \* P.A.I.L.: Pregnancy and Infant Loss
- \* RAINBOW BABY: Baby born after the loss of another baby
- \* Sunshine Baby: Baby born before the loss of another baby
- \* B.L.M.: Baby Loss Mama
- \* T.T.C: Trying to Conceive
- \* Angelversary: The anniversary of the death of an infant/stillbirth/pregnancy loss
- \* SIDS/SUIDS: Sudden (Unexplained) Infant Death Syndrome
- \* Stillbirth: Loss of pregnancy after 20 (US) 24 (UK) weeks resulting in a sleeping birth
- \* Miscarriage: The spontaneous loss of pregnancy before 20 weeks gestation



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## Remembering Our Angels

Angel: Jordan Myers  
Date: July 20, 2011  
8 weeks  
Parent: Lynette Myers

Angel: William Gaines Lowe  
Date: July 27, 2010  
41 weeks  
Parent: Liz Lowe

Angel: Gabriella Lynn  
Bernstein  
Date: July 14, 2010  
28 weeks 4 days  
Parent: Linda Bernstein

Angel: Jocelyn Rose Lahr  
Date: July 29, 2011  
18 weeks 5 days  
Parent: Lisa Bartsch Lahr

Angel: Y'hoshua Samuel  
Curtiss  
Date: July 25, 2011  
31 weeks 4 days  
Parent: Billie Curtiss

Angel: Kaidyn Ellyse  
Date: July 2, 2012  
35 weeks  
Parent: Michelle Donahue  
Murphy







Angel : Henry Phillip  
Date : July 5, 2006  
Parents : Sara and Richard  
Samul

Angel : Munchkin  
Date : July 8, 2009  
Parent : Kathy Winnie

Angel : Jamie Lynn Mezera  
Date : July 25, 1992  
Parent : Janet Renee  
Mezera

Angel:Charlie Shelby Zook  
Date: July 2, 2008  
41 weeks  
Parent:Shelby Lee Zook

## Quilt's Goals

-  Lift the stigma associated with pregnancy and infant loss by introducing society to our angels.
-  Educate people about the various causes of pregnancy loss and infant death.
-  Encourage expectant mothers to be more proactive in their prenatal care.
-  Convince some doctors, midwives and doulas to incorporate a kick counting component to all prenatal care.
-  Show Grieving families where and how to tap into the supports available to them.
-  Raise awareness by marching to a location where a memorial quilt, comprised of lost pregnancies and infants who have died, will be on display.

## Book of The Month

### *Grief and Grieving*

A book to help you find happiness, joy, relief from grief, peace of mind, and contentment, in your life once again. This book is designed to give you a general understanding of what grief is and how the grieving process works in easy-to-understand layperson terms. Daniel Wheeler, author, life coach, and motivational speaker explores many types of loss, from the loss of a loved one, to the loss of a job or home, loss from a divorce or separation, loss in status or lifestyle, and loss of our freedom or health. In his book, Daniel also shares proven coping techniques to help you find joy, happiness, success, and contentment.

Daniel's Book is available at most major on-line book sellers, and also on his website: [www.horizpro.com/Publications.html](http://www.horizpro.com/Publications.html)

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*Daniel Wheeler*

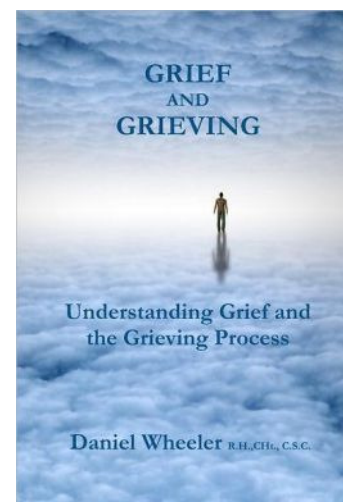
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*"In every song we sing, our spirit soars higher."*

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# The Q.U.B.B.T. Quietly United In Loss Together Block



## Things Left Unsaid: Letters to Our Angels

Arranged by: Deborah Hassan



**From: Jamie Hartel To: Rhyleigh Kaye**

Hey Bubbles-

I hope you're having fun up there, it's been a hard three years without you but I'm coping. It's hard to watch your siblings grow up without you. It's amazing how fast time does go by. Sometimes you being gone don't seem real. Some days I wonder who you would be today. Would you get along with your siblings? Know how to ride a bike? Could you read yourself a story or count to ten? Could you say I love you mom or read me a story? Would you have been a Mama's girl or a Daddy's girl? These are questions that can no longer be my reality because your reality slowly faded to a memory. We are all doing well here, apart from missing you every day. I have taught your brother so much about you; he can even say 'Sister Rhyleigh' and give your pictures loads of kisses. Your older brother prays for you every night and enjoys telling me his memories of you. He is getting so big. We plan on telling your new baby sister all about you too when she gets to be a little older. There isn't a day that goes by me and your Daddy don't look at each other and say 'Rhyleigh used to do that too' when talking about your siblings. Your father and I have as many great memories. Like how you would crawl over or roll over with your favorite book just so mommy could read you stories and how bath time was Daddy time and nobody else's time. You would scream for your Daddy just to have those memories with him. You loved to blow bubbles and that's how you got your nick name, and Dora was your best friend on TV. The expressions you made when you would scrunch up your nose and head bang to Daddy's rock music were priceless. I can't help but listen to that music and as we call it 'do the Rhyleigh'. Your older brother remembers reading you stories and going to parks with you. We all miss you baby girl but we all have such wonderful memories we are so very

thankful for. We would give up almost anything to have you back with us, but reality won't let us so all we have left is memories that you have left us with. Some days are harder than others as you can see. Crying those special tears just longing to hold you and get my special hugs and kisses. You always brought a smile to my face no matter how hard life was so just ignore the tears baby girl Mamas doing just fine down here. Please keep watch over us as we continue this journey without you. One day I will see you again, wrap you in a hug give you lots of kisses, but until then I'm going to cherish every memory because that's all we have left. Love you baby girl & I miss you like CRAZY!!

Mom

**From: Hazel Flint To: Mattie**

Dear Matthew,

Words cannot express how proud I am to be your mummy. The day I gave birth to you and had to say goodbye was the hardest day of my life, but I also know that I was blessed for being able to say I am your mummy. Daddy and Robert miss you so much too, you always will be a part of our lives and a part of our dreams. So much I have started in your name to help others and I hope that you are proud. I see you in so many things I do. We see the signs you send like letting your brothers music start up my turtles all moved to face the same way and butterflies every day since you have been gone. I know you are with Aunty Kala and I am sure having loads of fun with her, and I know she will be giving you all the hugs & love, that I wanted to if you were here with us. Please give her a huge hug from me and tell her I love & miss her too. Always come and visit us sweet baby boy, and if you see me cry just know it is because I love you so much. You are always in my heart now and forever, until we meet again in heaven.

Loads of Love,

Mummy

## Love of a Sibling

Infant loss affects us all and that is why there is a special section in the letters for a sibling to reflect, whether they were born before or after the loss, they can share their thoughts of missing that sibling [here](#).

**From: Safiyo To: Zahraa & Bilal**

Dear Bilal and Zahraa, I love you both so much! I wish that I could have had the chance to see you but Allah needed you more. You are having the best time ever in Heaven. Please watch over us and protect us from danger. I think about you every day and wish you would both come and visit me in a dream! Love from,  
Safiyo (big sister)

**From: Taybor To: Rhyleigh**

Dear Rhyleigh,

I miss you Rhyleigh. I Can't wait to see you again my Beautiful Princess. You made me giggle all the time. I was so happy when you were born. You sat so good when I read your favorite book. I can't wait to see you again.

Love Your Big Brother,

Taybor



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## Penned With Love For Our Angels Above

Poems Written To and For Our Angels  
Arranged by: Deborah Hassan



### Sands of Time

By: Dawn Molisky ©  
August 1, 2006



Come and gone, a year has past.  
Like sifted sand, in the hourglass.  
Each grain of sand slips through times  
portal,  
Reminding me we are all mortal.

Reflection leads to fantasies;  
Of stealing grains for you and me.  
To reunite for one more touch ...  
One look, one smell, it hurts so much.

The world's around me moving on;  
While I try to just hang on.  
Though I know I don't obsess,  
I feel as though I must confess.  
I still drift back to that room,  
When it was just me and you.  
Wondering is what I do;  
Did I somehow do wrong by you?

A happy face my mask reflects,  
To ease the world of my sadness.  
Alone in the dark; sometimes behind  
closed eyelids,  
I weep from the part of my Heart and  
Soul,  
That stays with you wherever you go.

One day I'll be stronger, this I know.  
Just please be gentle and let me go.  
For this Life lesson has no script.  
I must walk alone and finish this trip.  
Judge me not if I shed a tear;  
Just listen and be here throughout the  
year.

As a final plea through my weepy eyes,  
I beg of you to recognize ...  
That I am not a proud Mom of 3,  
But rather of 4 beautiful babies.  
It just so happened that one of my ba-  
bies,  
Was called home to knock upon  
Heaven's Door.

### Thoughts

By: Deborah Hassan ©



I have so many feelings and thoughts  
about you  
I am happy that your sister is there with  
you too  
And although I never met you and saw  
your face  
Here in my heart for you there is a place  
Family is not measured in breaths that  
you take  
Nor is it measured in the plans that you  
make  
And even though you are far from this  
Earthy home  
Far from my thoughts you could never  
roam  
I love you and your sister so very much  
indeed  
And I am happy that your little souls  
were freed  
Though I would have loved for you both  
to stay  
That was not up to me, I think of you  
everyday  
To have the memory of you in my mind,  
in my womb  
Sad that you never could blossom or  
bloom  
Flowers in the garden remind me of you  
both a lot  
Happy with the few memories that I have  
got  
So please always remember that I think  
of you each day  
Words from my heart is all I ever get to  
say  
Heaven gained 2 Angels, I gained a loving  
guard  
Saying goodbye to you and Zahraa was  
very hard  
Take care of each other until we meet  
again, dear  
Stay with us always, please always be  
near  
I have thoughts, they are of you two  
Remember that I will always love you

### Gone Too Soon

By: Deborah Hassan ©  
November 21, 2000



You could have lived and had a life it wasn't meant  
to be  
And it makes me sad to think your face I'll never  
see  
I'll never have a chance to say all I wanted to  
But I had a chance to know that inside of me you  
grew

It wasn't long, but it was time a time we shared  
Always know that I have always cared  
Even now that you're gone I'll always love you  
And I hope that somehow you love me too

But I'll remember the images I saw once or twice  
And I'll remember that having you was nice  
Though you are no longer here with me  
You'll always be here as a part of me

I guess sometimes you just don't know what's next  
No one ever really knows what's written in our text  
You'll always be a part of me and be within my  
heart  
Even though together we never had a start

A plan of life together with your sister and me  
But something happened that we just didn't see  
It wasn't meant for you to live inside this world  
But you'll always be my special boy or girl

Don't you ever think that I didn't care  
Because with you a life I wanted to share  
But I guess that you'll never be in my life  
But it's okay you're within another life

You're up in Heaven with Great Uncle and Great  
Grandma  
Other family like your Great-Great Grandma and  
Grandpa  
They'll take good care of you I know they will  
Even though now that your little heart is still

Though you'll never breathe a breath of air  
That don't change the fact of how much I care  
I won't forget you or let your memory fade  
But I surely wish that you could have stayed



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## Rainbow Pasta Salad

1 package tricolor or regular spiral pasta  
1 cup broccoli florets  
1 cup cauliflower florets  
1 cup shredded carrots  
2 cups cherry tomatoes, halved  
1 or 2 small cans of black olives, if desired  
1 chopped red pepper  
1 chopped green pepper  
1 chopped yellow/orange pepper  
Salad dressing

### Directions:

Cook pasta according to package, drain and rinse in cold water. Place in large bowl and mix in vegetables and dressing. Optional; sprinkle cheese on top and/or when plating lay a bed of baby spinach down first and then put pasta on top. Cover and refrigerate until ready to eat.



## Oreo Pudding

1 bag of Oreos crushed  
8oz cream cheese, softened  
¼ cup butter softened  
1 cup powdered sugar  
3 cups milk  
2 small boxes of instant vanilla pudding  
½ tsp vanilla  
12 oz cool whip

### Directions:

Mix together cream cheese, butter, powdered sugar, and vanilla. In separate bowl mix milk and pudding chill until set. Fold in cool whip after pudding has set. Add in cream cheese mixture. Layer so it is Oreos, pudding mixture, Oreos, pudding mixture and so on. Chill until ready to serve.



## Kisha's Food Pantry

Cooking for Large Groups

By: Nikisha Perry



I am a mother to three, a son named Raekwon who was born still and two daughters who are 4 and 1. I am also a foodie. I love to eat, cook, and serve people. If you come to my house I would like to know in advance so I can make sure to have some type of dish prepared. I am the type of cook that prefers not to cook food that will feed a group smaller than six.

Over the years I have accumulated recipes that are great for large gatherings. When planning food for large crowds you want to make sure that it reheats well, it is not time consuming, and inexpensive to make. I say inexpensive and not time consuming because people tend to be creatures of habit and may be afraid to try something new. I made a healthy dish once and took it to a gathering and it was hardly touched. The ones that enjoyed it took plenty of leftovers home.

So what types of recipes are good to make for gatherings like a memorial, anniversary, or get together? I personally like to stick to casseroles or one pot meals. These recipes will also be good to take to a family who has just lost their baby or loved one as well as families who have just had a baby. Let's start with Rainbow Pasta Salad. There are many ways to make this salad. I think it is a very simple recipe especially if you think of it as a salad. All you really need to do is get all the fresh vegetables you love to eat and cut them up and put them in a bowl and then mix in your cooked pasta. I am a cheese lover so I add shredded cheddar. I also adjust my dressing to the wetness I like. A lot of times when I Google the amount of dressing it does not seem to be enough and since we are in an age of healthiness than adjust to your liking. You cannot mess up this salad. Now for the actual recipe, remember adjust the vegetables and dressing to your liking. I always use ranch for the dressing but you can choose your favorite. **Now for the main dish Shepherd's Pie. After I had my daughter some friends brought over meals every other day and the Shepherd's Pie was awesome. It was so simple and so good. All it is, seasoned ground meat, fresh or frozen vegetables, and mashed potatoes. Now for the seasoned meat I just add my favorite seasonings and Worcestershire sauce. Again, I do not measure my ingredients so I season to taste. I usually use garlic, salt, pepper, and the Worcestershire sauce. When cooking for others I try not to season heavily or too light. When it comes to vegetables I do not prefer peas and carrots but a lot of people use the mixed vegetables with corn, peas, and carrots. I use either just frozen spinach and broccoli or the oriental mixed vegetables. The potatoes you can either do instant potatoes or make them fresh. Fresh always taste better.**

**For the dessert, Oreo Pudding, not sure what the real name of the dessert is but you will have no leftovers. One thing to remember when cooking for others is to take your time and cook like you are cooking for yourself. When you need to double a recipe and you are not used to cooking large quantities then just follow the recipe for or each container you want to fill instead of trying to double the recipe for one big dish. Another piece of advice is if you have not cooked a recipe before do a trial run so you know what you need to adjust when making it for others.**

## Shepherd's Pie

1 ½ lbs ground beef  
1 onion chopped  
1-2 cups vegetables chopped  
carrots, corn peas  
1 ½ - 2 lbs potatoes (3 big ones)  
1 stick of butter  
½ cup beef broth  
1 teaspoon Worcestershire sauce

Salt, pepper, other desired seasonings

### Directions:

Peel and quarter potatoes, boil in salted water until tender (about 20 minutes).

While potatoes are cooking, melt 4 tablespoons of butter in large frying pan.

Sauté onions in butter until tender over medium heat. If adding vegetables, add them according to cooking time. Put any carrots in with the onions. Add corn or peas either at the end of the cooking of the onions, or after the meat has initially cooked. Add ground beef and sauté until no longer pink. Add salt and pepper. Add Worcestershire sauce.

Add half a cup of beef broth and cook, uncovered, over low heat for 10 minutes, adding more beef broth as necessary to keep moist. Mash potatoes in bowl with remainder butter, season to taste. Place beef and onions in baking dish. Distribute mashed potatoes on top.

Rough up with fork so there are peaks that brown nicely. You can also use fork to make designs in the potatoes as well. Cook in 400 degree oven until bubbling and brown (about 30 minutes).



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# The Q.U.I.L.T. Quietly United In Loss Together Block



## A Shared Grief

By: Sherri McKibbin



It was a beautiful August morning. The sun was shining and it was as if the world knew something special was happening. Our family was welcoming my third granddaughter, Aniyah Hope. She was breath taking a head full of dark hair and startling blue eyes. I held her in my arms but little did I know I was holding an angel. My daughter and her girls were living with us. Her other little girls were 3 and 2 at the time. On the morning of September 12, 2010, grandparents day our lives were changed forever. We happily played on our bed with our older grandchildren waiting for Aniyah and my daughter to wake up. We had plans to take the girls out for breakfast, even though Aniyah was only five weeks old and could not eat food, we wanted to bring her with us. At 9:30 am we heard Aniyah cry. Our daughter changed and fed her, I looked into her room and she was being burped. My daughter put her back down because Aniyah had fallen back to sleep. She came into our room. She was there less than five minutes when she heard a strange noise come from Aniyah. The next thing I heard was my daughter's screams, No, No Aniyah! Breathe baby!! I called 911 and handed the phone to my daughter. I put the baby on the floor and started CPR. I never got a heartbeat again. Aniyah Hope was gone. My life and the lives of every member of my family were forever changed. What many do not understand is that my heart broke that day along with my daughters. I have to grieve twice. I grieve for Aniyah, my legacy. The relationship I would have had with her. I also grieve for my daughter. She is not the same young woman I raised, she is changed. I have to watch her go through the pain of the loss of her baby. I spent my life kissing skinned knees with magic mommy kisses. Fixing broken hearts from some boy who left her reeling. Fighting battles for her when others treated her unjustly. This is something I will never be able to fix. There are no magic kisses and no fixing this broken heart. How do I go through life knowing that my daughter has become someone I hardly know anymore? I guess the same can be said about me. I was a force to be reckoned with,

strong and out spoken. Today I have only remnants of myself. Now instead of fighting a battle with a strong conviction, I cry. I watch as my husband, the great protector of our family is now afraid for our living grandchildren. He wants to protect their every move. Somewhere in this place of grief we have learned to hold on tighter to each other and our family. We value every second we have with our grandchildren. Today we still miss her, I am sure we always will miss her. Today we view life as a precious gift and our granddaughters are the prizes we have for living right. Our daughter has much healing to do still but we are sure she will one day get to a place where her grief journey leads her to a place of peace.



Instead of Aniyah being my legacy, I have started hers. I now run A memory bag program in her memory along with my involvement with QUILT.

She WILL be remembered.

Aniyah Hope



## Grieving Out Loud

By: Delynn Burrell



## United We Stand

**United:** a verb  
**meaning:** to join, combine, or incorporate so as to form a single whole or unit.

I've heard it said, that united a group of people can move mountains, divided they fall. I've been within the Baby Loss Community for many years, 18 to be exact. I've seen the good, the bad and the ugly. I've seen groups formed, groups torn apart from within due to fighting. I've also seen the good; groups coming together with people from all walks of life who have been placed on this journey to love and support each other while helping to heal broken hearts. The purpose of these groups is to help promote and bring more awareness to Pregnancy and Infant Loss. To be the voices of our children, whose voices will never be heard.

Society has long swept the issue of Pregnancy and Infant Loss under the rug, to pretend it doesn't exist or that if it does it just doesn't happen to people they know. However, as we all know, the statistics of Infant loss are staggering. 1 in 4 will experience a miscarriage within the first 3 months. Many more will be stillborn each year just in the US alone. The statistics for outside the US are just as astonishing. However, it's always been society's stand to not speak of it. Uniting we can change that; we can be the voice of the voiceless. We are the ones who can make that change happen. Many great things have been occurring within the Baby Loss Community with the speaking out by Hollywood's elite such as Hugh Jackman, Gwyneth Paltrow, and Beyonce who have all publicly spoken about their losses in recent months. States are changing how they handle Stillbirth by the issuing of Certificate of Stillbirth, not all states currently do this, but many do you just have to know to ask for it. It's not automatically issued like a Birth Certificate. Groups are being formed every day to provide Memory Boxes and Bags so that families leaving the hospital do not have to go home with empty arms or the funeral home as some provide them directly to them. Groups are forming that are providing online support, love, encouragement to the broken hearted.

While great, many of these groups feel the need to compete with each other, to say we have the bigger group, so we're better than the smaller one that while may not have the same numbers has the same heart and desire to help those families. It's become a "game" of whose group or program is better than the next. We need to put an end to fighting that occurs within this community to join together for the common goal that we as grieving parent's share, that is one of healing, love, support, and encouragement and to bring awareness. We are stronger when we are united than we are when we are divided. A

common single voice can bring more attention to a cause that needs to continue to grow in support and research than many single voices that are clashing with each other. United we can Stand tall, united we can bring about more change, support from outside the community, and more attention to the need for more research into the causes of many of the issues surrounding Pregnancy and Infant Loss.

If we continue to stand divided then what good are we doing? How are we helping to bring more attention and awareness to a cause that is so dear to all our hearts because we are the heart of this cause? This is a call to unite, a call to come together as one, to be that group that moves mountains instead of falling to the ground. A call to Honor the lives of our children by being One Voice.





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# The Q.U.I.B.T. Quietly United In Loss Together Block

## Heartfelt Connections

Anonymous

Arranged By:



### What are some ways to remember a loss?

#### Some ways to remember a loss

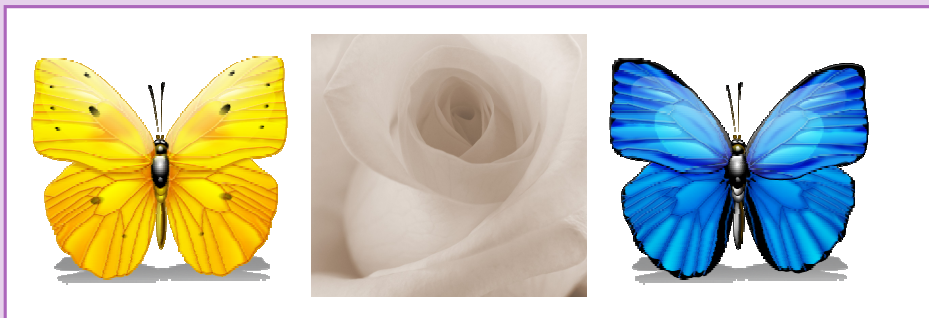
Well there are a few ways that really come to mind. One way is to have a memory or trinket box. Make a little card about the day you found out you were pregnant, on this card put how you told daddy, family, & friends.

Another good thing to put in the box is the first sonogram pictures, if there are any. If you lost your angel after birth or during delivery, you can put your angel's birth hat, first pair of shoes, and even the bracelet that you and daddy get.

Do something special on the day you lost your angel. Have a tradition that you do every year to acknowledge that this little one won't be forgotten.

Another good thing to do is keep a journal, it's meant only for thoughts and feelings about your angel. This is a great way to express openly how you're feeling about your loss.

Hoping that your question was answered, Angel families remember them and know that they are always with you.







# The Q.U.I.B.T. Quietly United In Loss Together Block



## One Step Forward– A Step by Step Guide to Healing

By: Samantha Allington



### Relaxation Guide

Try to find time for 'me' - this time is vitally important for each of us, but particularly when times are hectic, chaotic or stressful. Stress can have such a harmful effect on the mind, body and soul and continue to have repercussions on our external lives and those around us which then extenuates the internal stress and anxiety we may feel creating a vicious cycle of stress, guilt, more stress, more guilt and so on. No matter how busy our lives we can always set aside at least 15 minutes a day for 'me time'

Suggestions on how to utilise 'me time':

- ⇒ Create a peaceful 'space' for your 'me time'
- ⇒ Ensure your 'space' is free from clutter - you don't need a massive tidy up just clear an area free from stressors and distractions.
- ⇒ Set the scene with for example candles, soft or atmospheric lighting, soft music
- ⇒ Your space could be in your bedroom, spare room or bath (just a few examples)
- ⇒ During this time any family members or housemates should know you are not to be disturbed, pre warn them in advance and set some boundaries that they will abide by. Perhaps create a do not disturb door sign to let them know this is now your time for you. (make it clear what you consider as urgent or emergency so they understand what the exception to the rule is)
- ⇒ Unplug your phone or turn it to silent so as not to be disturbed
- ⇒ Try to ensure you are comfortable, perhaps surround yourself with sensory items that help you such as things soft to touch or silky, anything you enjoy the texture of, cushions, blankets etc..
- ⇒ Decide whether you prefer to let your mind wander on its own ensuring that you keep your mind trained on positive thoughts or affirmations or just pondering on things that don't cause you any stress, or visualisation (we'll go in to this deeper later with some further suggestions) or if you are able and enjoy the experience of a 'blank canvas in your mind' Do not put pressure on yourself to have a completely blank mind as this just causes further stress, if your mind automatically starts to wander that is fine as long as its focussing on non stressors.
- ⇒ Some people may find during these exercises they fall asleep so may like to set an alarm if needed, do not worry about falling asleep as long as it's a time that's okay to do so, and as long as you are in a safe place to do so (not the bath)
- ⇒ Set a timer or alarm for your 15 minutes or 30 minutes or however long you have managed to set aside. Ensure you utilise the full amount of time available to you and don't shorten it without necessity. Don't clock check! (hence reason for alarm) as this puts stress and pressure on you.

The next topic will cover visualisation techniques.

Further topics will focus on grounding skills, stress management, sensory items, aromatherapy, crystal therapy, treating yourself gently, positive thinking/affirmations, assertiveness skills, self-healing and meditation.





## Necrotizing Enterocolitis (NEC)

Arranged By: Grace Phillips



Necrotizing Enterocolitis (NEC) occurs when the intestines die, most often affecting sick or premature babies. While the cause of the disorder is unknown, it has been said that decrease in blood flow may affect the amount of mucus being produced in the bowels, which leaves the lining unprotected. Another cause may be from an over abundance of bacteria being present in the intestines (A.D.A.M Medical Encyclopedia, 2011).

Symptoms of NEC often resemble other digestive conditions and vary from infant to infant. Those symptoms can include one or several of the following:

- ⇒ Poor tolerance to feedings
- ⇒ Feedings stay in the stomach longer than expected
- ⇒ Decrease in bowel sounds
- ⇒ Abdominal distention (bloating) and tenderness
- ⇒ Greenish (bile-colored) vomit
- ⇒ Increase in bowel movements, or lack of stools
- ⇒ Blood in the stool

There are less obvious signs of NEC which can include—apnea, bradycardia (slowed heart rate), diarrhea, lethargy and fluctuating body temperature. The more advanced cases will also show signs of fluid buildup in the abdominal cavity, infection of the membrane lining of the abdomen (peritonitis) or even shock (KidsHealth.com. Reviewed by J. Fernando del Rosario, MD, 2011). Treatments of NEC fluctuate depending on the severity of the case and most cases are treated before surgery is needed. Medical treatment can consist of; stopping all feedings and using intravenous (IV) catheter to give nutrients to the baby, placing a nasogastric tube extending from the baby's nose to the stomach in order to suction out air and fluids from the stomach and intestines, antibiotics to treat any infections, checking for blood in the stools, giving blood tests often to check for infection or imbalances in the baby's chemistry, giving oxygen or mechanically assisted breathing if swelling in the abdomen affects the baby's breathing, in extreme cases platelet and red blood cell transfusions.

If medical treatments do not reverse the presence or damage of NEC, or a hole in the intestines is discovered through x-ray surgical treatment will be needed; which is done by an abdominal laparotomy, a procedure that opens the abdominal wall to examine the bowel. If the damage is severe enough the bowel that has no chance of recovery will be removed to prevent further damage. In some cases a rubber tube may be placed to assist in draining the infected fluid. With the most severe cases a temporary ostomy, an opening in the wall of the abdomen, is needed to allow the bowel to recover and heal. With a ostomy a stoma is placed to allow stools to pass from the bowel. Usually a second surgery is performed 24 to 48 hours later to evaluate and determine if NEC is progressing (UCSFchildrenshospital.org; Reviewed by health care specialists at UCSF Benioff Children's Hospital).

Necrotizing Enterocolitis affects approximately 25,000 babies per year. For babies weighing less than three pounds the chances of developing NEC escalate to approximately 1 in 18 babies and accounts for 1/7th of deaths occurring after one week of life. The largest cause of death is overwhelming infection of the body and sepsis (The American Pediatric Surgical Association). NEC is a serious and dangerous disease with a death rate approaching 25%, though early detection and aggressive treatment greatly improve the outcome (U.S. National Library of Medicine).





# The Q.U.I.L.T. Quietly United In Loss Together Block

## The Baby Loss Community – the Good, the Bad and the Beautiful By: Charlotte Stanley (Guest Writer for QUILT's Newsletter)



I sadly became a member of the baby loss family in 2009 when my first pregnancy ended in a missed miscarriage. I was devastated and felt so very alone. At the time I had no idea this loss family existed. It seemed that people I had known all my life were members without me ever having a clue. They suffered in silence. But after news of my loss came out, they started approaching me. In my small circle of people there were at least 10 people who had experienced a pregnancy loss. I soon came to realize just how common miscarriage and infant loss are. At the time, I did not understand why everyone kept so quiet about their experiences. Maybe if they hadn't, I wouldn't have been so blindsided by the experience. But then again, at that point I had not experienced the looks of reprimand for not being "over it yet", the whispers because of all the random tears, the awkwardness whenever certain subjects came up and the thoughtless comments. It didn't take long for me to experience my fair share of this and come to understand why other angel moms kept quiet when out in the "normal" world. It is just easier.

### The GOOD:

While my loss was new and the heartbreak was fresh, I sought out support groups. And to my surprise in my large city, there was nothing. So I turned to online support. Thank goodness I found a couple of groups that were awesome. And then later on I found Facebook and UTPAIL. A whole new wellspring of support existed. It was so very healing. I made some wonderful friends, who are not just Facebook friends but true friends.

This is an amazing community full of very wonderful, kind hearted people. I have seen angel moms band together to raise money to help newly bereaved families bury their children. I have seen angel moms turn their heartache into legacies to honor their precious babies by giving back to the loss community. I have seen people come together to pray and remember all the babies lost too soon.

The increased popularity in social media has allowed this once quietly mourning community of isolated individuals and small groups to explode in size and voice. And these moms are doing amazing things. They are networking to combine talents in order to create and donate memory boxes. They are generous in giving of memorial items to honor other angels. They are supportive. They create, they auction, and they give. These loss moms provide a shoulder to cry on and a virtual hug when one is having a bad day. They do balloon releases, make wishing jars, and write names in the sand, all in order to freely honor the angels of people they have only met online. These moms are promoting a movie to bring the reality of stillbirth public. They are uniting under the banner of QUILT to make the world aware of how common and devastating pregnancy and infant loss truly is. These moms forming this community bound by loss are an amazing group of women. And most days I am so very proud of what this community has accomplished.

### The BAD:

But some days I am astonished with how some of these loss moms treat each other. It seems the darkness that taints the outside world taints our community too. It is too bad that the bright light represented by all our angels isn't strong enough to chase away the shadows. Now I know each member of this group is grieving and will have bad days where lashing out at the world is the only viable option. That is not what I am talking about. I am talking about cruelty, bullying, and just plain rudeness. In just the past few months I have seen angel mothers hurt each other in totally uncalled for ways.

For example I watched daily as a fellow angel mommy battled with the doubts that her preemie twins were in fact real. This angel mom was only seeking prayer support for her children who were in critical condition, yet daily she was harassed by other angel moms who for some reason didn't trust that her story was true. And then when one of the precious babies passed away to join a sibling in heaven, the cruel statements that were posted on her page about the situation were totally uncalled for. If a loss mom doesn't believe another's story for some reason, then she should simply quit following the page. If the mom is running a scam, believe me she will get what is coming to her one day without anyone having to sacrifice her own integrity to challenge the story. If someone doesn't believe that particular mom, then that someone shouldn't send money, shouldn't say prayers, but also shouldn't be negative. Because the simple fact is the questioning mom probably does not know for sure, she just suspects. And on the chance that she might be wrong, does she really want to be responsible for depriving a child struggling for life much needed prayers?

I have seen angel mothers go beyond simply disagreeing to stooping to name calling and heaping hatred just because of a misunderstanding. Many of these people are not of high school age so really have no legitimate excuse to act as teenagers. If an angel mom has a misunderstanding with a person, she should go to that person and talk it out. If the issue can't be resolved, then part ways, move on, unlike her Facebook page. If that person is cheating loss mothers, it will come out without name calling. And she will get what is coming to her without the need for belittling her. When people resort to name calling, it actually says more about the person calling names than it does about the person being attacked. It makes the name caller look bad.

I have watched loss moms, who set up pages to help others in the community as a way to honor their angels, have to choose between living under such animosity and running from the community that was supposed to be their family. Bullying another angel's legacy really is stooping low. There is no good reason for it. Jealousy over her success, feeling like she stole your idea, desire to have something she has, not receiving a thank you from her, etc. are not reasonable excuses to push someone out of the community. There are enough grieving, hurting hearts out there for everyone to help. There is no need to fight like this is a popularity contest. And if the page reaches even one hurting heart, then it justifies keeping that page going.



# The Q.U.I.B.T. Quietly United In Loss Together Block



## The Baby Loss Community – the Good, the Bad and the Beautiful (Cont.)

By: Charlotte Stanley (Guest Writer for QUILT's Newsletter)



I have seen angel moms complain about an item that they won in a free giveaway in order to get the creator to change it to suit her wishes. Really, another mother has taken her time to create something she feels is beautiful and she is offering it for FREE to help another hurting mom and the winner has the nerve to complain about how it looks. Because it doesn't suit her, she wants it remade. How about if a mom doesn't like how something looks, then she shouldn't enter the giveaway because she is taking a chance away from someone who really will love it for the piece that it is. Or if she wins something she doesn't like, she should pass the good fortune along and gift or donate it. And when someone wins an item that has already been created, it shouldn't take three months to send it to the winner.

I have seen angel moms expect to get their stuff made and shipped at the drop of a hat, just because they are a fan of the page. Some people do not once consider that most of these vendors create these angel works in their spare time. They have jobs and families as well. All the "vendor" angel moms that I associate with really appreciate every single fan. But they do not always have the time to cater to every single fan. They would love nothing more than to spend every spare moment creating things to aid others in the healing process in order to preserve their angel's legacy. These angel businesses are not trying to make a profit. They are trying to honor their child's memory by doing something for free or inexpensively so that other angel moms can have items in honor of their own children. So loss moms, be patient with them if it takes them a while to create the items. Be understanding when they simply can not make what is asked for. And realize that they do not control the postal system. Likewise vendors, page administrators, and auction organizers need to be as professional as possible and not have lengthy delays in getting people items that they have paid for or won. Communication is key. Vendors and customers need to be in touch and explain why payment has not been made or why an item hasn't shipped two months after the sale. Talking with each other will go a long way to keeping everything cordial with transactions among loss moms.

I have also seen angel moms attempting to minimize other moms' losses. This is probably the thing I am witnessing that is the most distressing. I realize that each type of loss is not the same. A miscarriage isn't the same as a stillbirth which isn't the same as an infant death. And I am not an expert on each type of loss or what it feels like. But each of these losses shares the common threads of grief, heartbreak and a life that ended much too soon. The differences are really just formalities. A broken heart is still broken whether it is broken into five pieces, fifty pieces or five hundred pieces. A piece of each mother's heart is gone no matter what took her baby away. I am not trying to equate my grief with anyone else's. I am just saying that telling me that I only had a miscarriage is pretty cruel. It still hurts. Each loss type has its own set of cons and absolutely no pros to go with it. No one knows the entire circumstances around another's situation. Nothing good is accomplished by ranking grief. It is not a contest. Every loss mom is sad. The members of this community need to support each other. I read an article on this recently and one of the comments was the perfect analogy. This mom said that it is like being hit by a truck going 45 mph or getting hit by a truck going 60 mph. Does it really matter which truck ran you over? Both impacts are different, but the resulting pain is still devastating and you probably won't walk away unscathed.

### **The BEAUTIFUL:**

I personally am not on the end of any of the negatives that I described other than having my loss minimized. So don't think I am writing this to personally punish anyone. I am simply drawing attention to what I have observed that really adds a negative element to this community. I know each person in this community is in a different place on this grief journey. The path is a long winding road, with ups, downs, twists, turns and endless circles. It is a path each mom was put on against her wishes. And being on it causes sadness and anger. But daily carrying grief does not have to lead to bitterness. And feeling anger does not have to lead to hatred. It is OK to be mad and angry and sad. But the target of those emotions shouldn't be another mom walking the same path that wasn't her choice either. Losing a child and feeling grief is not a choice but meanness is.

For the most part this community is made up of grown women, women who should not need policing, women who are capable of making informed decisions for themselves and women who have the ability to control what comes out of their mouths. They do not need "parental figures" to slap them on the wrists and scold them for bad behavior. Each loss mom needs to take responsibility for her own actions. The leaders of this community should not have to be concerned with refereeing squabbles among members. The leaders of this community have one main purpose – to serve as a mouthpiece for the cause that unites this community. They should not have to tell other adults how to behave.

The real world is hard enough on angel moms. The community needs each member, so try to build other loss moms up rather than tearing them down. And if an angel mom simply can't bring herself to support or build up a particular program or person, at the very least she should do no harm to them. She should walk away, not say anything and just move on. The community needs to live according to some basic lessons taught to children: "If you don't have something nice to say, then don't say anything at all" and "Do unto others as you would have them do unto you" not as you have been done unto.

The programs, acts of kindness and general behavior of angel moms are legacies to their children. Each loss mom should do her best to conduct herself in a manner that makes her angel proud. There are countless angels represented in this community. They are remembered and loved and missed everyday. Their mothers are strong, and beautiful and hurting. Each of the mothers has the potential to be kind and supportive and good. If each one tries to help all she can and make an effort to police her actions in an attempt not to hurt anyone then this community could accomplish even more than it already has. It would be unstoppable and the rest of the normal world would have to take notice. They would see this community is broken but not damaged, grieving but not bitter and worthy of sympathy not pity.



# The Q.U.I.B.T. Quietly United In Loss Together Block

## Blurbs

### Dangers of Listeria

**We have always heard about eating lunch meat during pregnancy.**

Is there a good reason behind it or is it just a myth?

I have to confess when I was pregnant with my first daughter I craved Subway sandwiches and I did eat them. The reason we are not supposed to eat lunch meat during pregnancy is because of Listeria. Listeria is a type of bacteria that is found in water and soil. It has also been found in uncooked meats, uncooked vegetables, unpasteurized milk, and processed foods. You can kill Listeria by pasteurization and cooking. The reason we hear do not eat lunch meat or hot dogs is because they can become contaminated after cooking and before the meat is packaged. If you want to eat lunch meat or a hotdog during pregnancy then make sure you reheat the meat to at least 160 degrees F.

Society says they want you to move through this grief thing and hurry. They want to see a smile on your face because it is not acceptable to be in this place. I've cried a million tears trying to figure out how to make it through days months and even years... What is this "new normal" they talk about... It is like I'm stuck in time can't go back, but having a hard time moving forward. It feels like I'm living someone else's life. I move into denial for protection because this can't be my life... My heart is broken. Sometimes it is hard to put into words. And so a lot goes unspoken. But it's expressed with my tears. I try not to focus on the times that lead up to that dreadful day, instead I focus on your life and how you gave me joy each and every day. Then to think you are actually gone. There are days I don't want to go on. As time passes, we learn to play roles that at least are "normal" again. The truth is I will never be the person I was before, because a piece of me went with you forever to be. Trying to live my life without you is the hardest task I've been asked to do. Right now I can't see how it is possible. That could/should be "normal", because every day I miss you.

BY : Rhonda Peacock