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Each time a new family contacts MEND or comes to one of our support groups, I am deeply saddened to hear their story. However, my heart breaks in a unique way every time parents share their experience of losing one or more of their babies who were part of a multiple pregnancy. It does not matter if the baby(ies) passed away shortly after conception or several days or weeks following delivery; the set is still broken and will never be whole again.

As a twin myself I cannot imagine my life without my sister Rachael. We have remained very close and in fact have lived next door to each other for the past 7 1/2 years. Our entire lives we have been asked, "What's it like to be a twin?" and our answer is always, "What's it like to be a single? We don't know any differently." But what about people who lost one or more of their counterparts? How do they answer such questions? I have to believe they will always feel a part of them is missing and incomplete.

Every milestone and discovery the surviving child(ren) achieves such as waving, clapping, sitting up, crawling, walking and talking is always somewhat thwarted by the parents wondering if the demised sibling(s) would have accomplished the feat at the same pace, before, or a little later. The birthday of the multiples can be extremely hard since that the family's emotions are torn between celebrating the living child(ren) yet grieving the one(s) who passed away. Holidays are equally as difficult as moms and dads will never experience the joy of purchasing special occasion outfits and gifts for all their babies, and they will always know that Santa Clause and the Easter Bunny should have more on their knee for the picture taken at the mall

Parents who have experienced such a loss suffer hearing well-meaning, yet very hurtful comments such as, "At least you got to take *one* home" or "At least you will only have to chase after *two* instead of *three*" or "At least you won't have to buy so many clothes now." Hearing these "at least" remarks only makes the parents feel the person saying them is suggesting they should be grateful for their loss instead of mourning the death.

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Some parents are even encouraged to move on and solely focus on the remaining child(ren) and should simply be grateful for the child(ren) who lived. But I feel parents should never apologize for grieving their loss nor should feel guilty if they have difficulty giving 100% of themselves to their living child(ren) while enduring the grieving process. Just because the parents were able to take one or more newborns home never means the one(s) who passed away should be forgotten and ignored as if they never existed.

Another issue with which parents face is whether or not to tell the living child(ren) he/she was part of a multiple. I have read and heard psychologists give conflicting advice regarding this, but as a twin I strongly recommend that the child(ren) be told the truth. I read an account on the Internet a few years ago where a regretful mom poured her heart out to those of us on the listserv explaining that she had recently told her teenage daughter that she was born a twin, but her sister had died shortly before birth. The teen became violently angry with her mother explaining that since a small child she had been confused as to why she sensed a part of her was missing and felt these emotions could have been avoided if her parents had been honest with her from the beginning.

Every year at our Christmas Candlelight ceremony, we provide the families with white tapers and give them the opportunity to come forward to acknowledge their baby(ies) who died as they light their candle. Two years ago Scott and Jo Ellen Slough came forward with several family members as Jo Ellen had 10 month old Hunter on her hip. Hunter's identical twin Jared passed away 5 weeks after birth due to a heart defect. I was overwhelmed with emotion when I noticed that as Jo Ellen held the lit candle in memory of Jared, little Hunter could not keep his eyes off the flame and stared at it with deep intensity. Although I'm sure in reality it was the bright glow that caught his attention, I couldn't help but wonder if somehow he knew who that bright light represented.

Whether you lost one of your twins, one or two of your triplets, one or some of your quads, etc., I express my deep condolences to you. I fully understand that despite the fact that your arms are not completely empty, you have a void in your heart that will never entirely be filled. I hope we at MEND can offer you the love and hope you may need for several years as your surviving child(ren) will always serve as a constant reminder of the great loss you have suffered.

Rebekah Mitchell



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Suggestions for wording birth announcements after a loss

These samples can be used for both a subsequent birth after a loss and the birth of a living twin when one is lost. In these examples, Matthew is a baby in heaven, Mary is an older living sibling, and Michael is a living child born after Matthew's stillbirth.

Ways to include all children in body of announcement:

- * "Much loved baby sister of Mary and Matthew"
- * "We celebrate the safe arrival of Michael, (insert birth statistics here) and the memory of our child lost, Matthew, January 19, 1998"
- * "Matthew joins us in welcoming Michael into our family"
- * "Michael, little brother to Mary and Matthew, was born January 19, 1998, (insert birth statistics)"
- * "We celebrate the safe arrival of Michael (insert birth statistics here) and remember the life of our son Matthew, January 19, 1998"
- * "In Remembrance of our dear son Matthew"
- * "Remembering always with love Matthew"
- * "One to hold in our arms
 One to hold in our hearts
 Matthew, January 19, 1998"
- * "Michael, watched over lovingly from beaven above by our angel Matthew, January 19, 1998"

These suggestions were submitted by Angela Priesman in loving memory of Isabella Jewel (Bella) Priesman, "Precious Gem Given to God", born still on June 16, 1999, at 37 weeks after a flawless pregnancy, cause unknown.

Parents: Angela and David Priesman Big sister: Victoria Morgan (Toria) Little sister: Juliana Carleigh (Jules) Ways to list all children's names at end of announcement:

- * "Remembering Matthew, forever in our hearts."
- * "Proud big sister Mary Remembering Matthew"
- * "Proud biz sister Mary In Memory of Matthew"
- * "Proud brother watching from beaven: Matthew"
- * "Ançel baby Matthew"
- * "A moment in our lives, a lifetime in our bearts Matthew James"
- * "Heavenly brother Matthew"
- * "Matthew, forever in our hearts"

Other ideas:

- * Use a song lyric.
- * Use a Bible verse of your choice.
- * Any special thing you call your baby in heaven (for Angela it was Precious Gem Given to God, since that is what her daughter's name meant).
- * Use any theme you think is appropriate or reminds you of your baby in heaven. Some suggestions are stars, rainbows, angels, baby animals, burnies, etc.

~~ Mommy misses you Bella~~

Things You Should Never Say to a Parent Who Has Lost a Twin

"At least you have the other twin"

No-one replaces anyone, not even a genetically identical person born at exactly the same time. (WiSSPERS 1994) While the bereaved parent is usually grateful for the surviving twin, nothing can take away the pain of losing a baby. The baby who died was not an "extra" or a "spare" baby, the baby lived (if only in utero) and breathed (if born alive.) When someone loses a parent, no one would dare say to them, "Well, at least you still have your other parent". Just like parents, babies are not interchangeable!

"You can always have another baby"

This cannot be assumed. If the parents have undergone fertility treatment, pregnancy may not ever happen again. Even if it did the chances of having twins again are very remote. Parents whose twin dies lose not only the baby but the special twinship that exists between twins. The surviving child may grow up as an only child and this may be especially painful when the parents know their child did not start out life alone, that they should have a twin as they grow up.

"It was God's will"

God does not purposely take babies away from their families, nor is this a punishment for something the bereaved parents did. What could they do that was so bad that God would punish them by taking the life of their child? Nothing! God doesn't work that way! This falls into the category of "stuff happens".

"If you had to lose him, at least it happened now instead of after you had really gotten attached to him"

Parents, particularly mothers, become attached to their babies very early in pregnancy. I have heard Dr. B. Raphael say, "The younger the child the worse the grief." This is because you don't often get the opportunity to make many memories; people don't often say to you "remember when your baby/child did this." Memories and reminiscing help in the grieving process. If memories are few, then the grief is more painful, not less. One mother said:

We had 24 short days with Zachary. I would have treasured even one more hour with him.

"The one you have keeps you up all night and demands all of your attention, how would you have managed having two?"

People who say this fail to understand just how difficult it is to look after one baby while you are grieving for the other. Most bereaved parents of twins probably feel that they would have managed better with a few extra sleepless nights and frazzled days than the constant grief and painful reminders. Moreover, as the years go by anniversaries hurt and remind. The first smile, crawling, walking, riding a bike, first day at school all happen to the surviving twin and as each milestone passes the bereaved parents wonder what it would have been like with two.

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Imagine the joy of discovering you are pregnant! Then imagine the joy of finding that instead of one baby, you are having two! It is unbelievable how people around me fussed, told me how clever I was, and also constantly reminded me of the heavy workload that would lay ahead when my two youngsters were born.

Now imagine the pain when you are told by medical staff that one child has died. Think of the agony of having to perhaps carry a dead child for an unknown number of weeks, in order to give the surviving baby a simple chance of life.

In March 1990 I gave birth to twins: a beautiful healthy son named Rhys Antony, and a precious stillborn daughter named Megan Louise. I spent seven weeks in a women's maternity hospital in Adelaide alone and afar from home.

It almost broke my heart when a few days later I had to fill in details for Rhys' birth certificate, for I had given birth to two children, and to write information for just one of them seemed quite unnatural. The only people who wanted to talk about Megan mainly came from the funeral parlour! The young nurse on duty could not understand why I wanted to cry each time I tried in vain to feed my young child. Something did not seem right - but I could not explain it to anyone.

As each birthday passes, my husband and I try to think of positive ways to show our love for Megan. My husband, our sons and myself all visit Megan's grave. We take a bunch very special flowers and sometimes a card. We all sit and try to answer the questions about a "big" sister as best as we can. There is so much guilt because I feel sad about Megan, yet I don't want to spoil the day for Rhys. All our three boys have grown up, knowing about their special big sister, and they quite openly show their love and affection for her. We have no other girls, and that makes it all the more painful, at times.

By Lynne Schulz, excerpt from her home page, http://www.geocities.com/Heartland/Cottage/7991/index.html

Kroger Shoppers Can Now Help $M.\square. N.\square$.

Those of you who shop at **Kroger** can help M.E.N.D. Kroger will donate a percentage of all purchases of those shoppers who have and use a Kroger Share Card. To obtain your Kroger Share Card, Please call or e-mail Rebekah via one of the ways listed on page 12 of this newsletter. Be sure to let us know how many you would like.

Do You Shop at Tom Thumb?

Anyone who is a Tomb Thumb shopper can help M.E.N.D. with their purchases. If you have a

Tom Thumb Reward Card, please ask the cashier to link your card with

M.E.N.D. *Our number is 6265*. If you are already linked to another organization, they will split your purchases between the organizations. Tom Thumb will donate 1% of all sales back to M.E.N.D. If you don't have a Reward Card, it only takes about five minutes to get one.

The Reward Cards can also be used at Randalls and Simon David stores.

March/April Topic

Living with a Loss After Five Years or More

Deadline - January 31, 2001

May/June Topic

Mother's Day and Father's Day Deadline – March 31, 2001

Stories, poems, thoughts, and/or feelings regarding these topics are welcomed. Submissions must be received by the deadline to be considered for publication in the newsletter. Unfortunately, there is not enough room to include all submissions. Choices will be left to the discretion of the editors. Please see the back page of the newsletter for the appropriate address to send your submissions. Any submission printed in our newsletter will also be posted to our website indefinitely unless we receive notice in writing that you are only granting permission for your submission to appear in the printed version of the newsletter.

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M.E.N.D. Support Group Meetings

Join us in a time of sharing experiences.

Regular M.E.N.D. meetings

are held the 2^{nd} Thursday of every month from 7:30 - 9:30 p.m.

Mommies AND Daddies are both welcome at all of our meetings.

Threads of Hope, Pieces of Joy Bible Study

Please contact Jana Spigener at (817) 468-9963 or gaspigener@aol.com if interested.

Playgroup

For families with children born prior to or subsequent to a loss Contact Pam Morren At (972) 335-8202 ashtonsmom98@hotmail.com

Our Daddies Group

meets the 2nd Thursday of March, June, September, and December From 7:30 – 9:00 p.m.

This is a special time for Daddies to get together and discuss concerns unique to them as fathers. Our moms and dads meet together for introductions before dividing into two groups for discussion

For more information or directions, Call (972) 459-2396.

Subsequent Pregnancy Group meets the 4th Tuesday

meets the 4th Tuesday of each month from 7:30 - 9:00 p.m.

For families who are considering becoming pregnant or are currently pregnant after a loss

All support group meetings are held at:

1159 Cottonwood Lane, Suite 150 Irving, Texas (Las Colinas) 75038

(This is on the west side of MacArthur Boulevard, across the street from the Four Seasons Resort. There is a Holiday Inn Express at the entrance of Cottonwood Lane.) $A = A \setminus A =$

Birthday Tributes to Our Special Babies

Happy First Birthday to our precious little angel girl,
Kennedy Ryen Johnson,
January 16, 2000.
We'll always love you!
Love,
Mommy and Daddy

Dear Lord,

Please give us our baby back. Only you have the power to do it, But if our request is impossible, Lord.

Please grant us the power to get through it.

We felt so blessed when we first heard the news.

A baby for us -- all our own? We know that she was a gift straight from you.

How tragic it is that she's gone! We hurried and scurried to make her a place.

(We just couldn't wait to see her.) At night, we dreamed of her sweet angel face

And counted down the days 'till we'd meet her.

It was so hard not to blame you at first.

(Even I know the unborn can't sin.) We thought our lives were at their worst;

I wouldn't ever get pregnant again! Now I know that the fault isn't yours (And neither, of course, is it mine). Please keep her safe behind Heaven's

'Till we get there, please keep her from cryin'.

We thank you Lord, for keeping her with you.

Tell her Mommy and Daddy will soon be there too.

And your blessing is what we will try hard to earn

For this special favor that we can never return.

Love,

Her Mother and Father

P.S. Tell our special angel we love her.

In loving memory of Kennedy Ryen Johnson, born and died 1/16/2000 due to premature labor caused by early loss of a fraternal twin. Parents: Brian and Stacy Johnson

Written in memory of Kennedy by Crystal Blackwell, 1/17/2000



In loving memory of Dana Angelyn Erickson Stillborn December 9, 1999 Cause: unbalanced chromosone translocation

Happy 1st Birthday in Heaven baby Dana!!

We miss you so and our hearts are filled with sorrow and joy as we think of you. We know your celebration there is the best ever and we look forward to being greeted by you one day!

Your big brother, Kelby, doesn't quite understand, and isn't sure he wants to go there; he'd rather you come to us. But when we talk of the possibility of a big band in heaven, he responds with enthusiasm: "baby Dana will play the cymbals; I have my drum sticks, and Jesus... (pause) will play the saxophone!!" That'll be just grand!

Thank you, Heavenly Father and precious Dana, our glory baby, for giving us a vivid glimpse of Heaven and reminding us of what truly matters, for eternity.

With love,

Steve & Anna Erickson, and big brother, Kelby Daniel

"O come, Thou Dayspring, come and cheer our spirits by Thine advent here; disperse the gloomy clouds of night, and death's dark shadows put to flight. Rejoice! Rejoice! Immanuel shall come!"



Happy 3rd Birthday Maya. We Love You!

Mommy, Daddy and Erin

In loving memory of Maya Denise Ates, stillborn January 6, 1998, due to a clot in the umbilical cord

Parents: Tammie & Horace Ates

Little Sister: Erin Ates



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Happy 1st Birthday, "Little Eric" We Love you so much Love, Mommy, Daddy, and Kenley

"Our Little Angel"

Our little angel so sweet and true The Lord made a halo just for you.

Even though we may never watch your little hands grow In our hearts our little angel is in Heaven we know.

Even though we will never hear you speak a word, In our hearts our little angel will always be heard.

Even though we will never see you walk around, In our hearts our little angel will always be found.

Even though we may always wonder why? In our hearts we know, Our little angel had to fly.

In Loving Memory of Eric Blaine Poindexter January 14, 2000 (3 hours old) died due to trisomy 13 Parents: Eric and Tangi Poindexter Happy 4th birthday Amanda. We miss you and love you.

Mommy, Daddy, Sydney and Jack.

In memory of Amanda Morgan Galleger, stillborn January 7, 1997, due to Trisomy 18 Parents: Diane and Steve Galleger

Lauren, Happy 1st Birthday on February 13 in Heaven! May you have the best Birthday party with Jesus. We love you!

Mommy, Daddy, & twin brother Zachary, and in loving memory of Blake Leland

In loving remembrance of Lauren Grace Allen, stillborn February 13, 2000, due to unknown cause. Parents: Jan and Sean Allen Twin brother: Zachary Brother in heaven: Blake Leland, April 21, 1999, due to preterm labor/incompetent cervix

"There is not one minute, one hour, or one day
That you are not thought of."

With beart felt remembrances of Bradley Taylor Houston, December 7, 1996 - December 17, 1996, A boy whose beart touched so many others.

> We love you and we miss you! Meemaw Flo and Aunt Sherry

Parents: Kerry & Steve Houston Little brothers: Ryan & Korey Houston



M.F.N.D

Music Resources

The following music has been helpful to others during their time of grief.

Angel Unaware
Words and music by
Shari Buie and Tamara Miller
HeartSong 96
P.O. Box 450204
Garland, TX 75045-0204



Home Free

Words and music by Wayne Watson Watson's *Home Free* CD can be found at most Christian bookstores.

Together We Can Heal
A beautiful collection of music for bereaved families. Call or write:
Source Music
P.O. Box 1543
Colorado Springs, CO 80901
719-442-0152/ 800-338-4312 (orders)
http://www.sourcemusic.com/heal
(This URL takes you directly to the recording.)

Thought You'd Be Here
Words and music by Wes King
From his CD A Room Full of Stories,
available for purchase at most Christian
bookstores.

I'll Meet You in the Morning
By Karen Ritchey
http://www.members.cnx.net/kritchey/
e-mail: kritchey@cnx.net

With Hope

By Steven Curtis Chapman From his CD *Diving In*, available for purchase at most Christian bookstores.

Goodbye for Now
Words by Kathy Troccoli, music by Scott
Brasher and Kathy Troccoli
From Troccoli's CD Corner of Eden,
available for purchase at most Christian
bookstores.

Glory Baby

Written by Nathan and Christy Nockels Found on Watermark's *All Things New* CD, can be purchased at Christian bookstores



Strictly speaking, we don't become angels in afterlife

Billy Graham

Question: Our precious little baby died several months ago, and I can't tell you how hard it's been.

Is she an angel now?

I find comfort in thinking so, because I know angels are supposed to surround us and maybe she is with us still, even if we can't see her.

Answer: Although I know its popular to think of loved ones becoming angels when they pass away, the Bible actually teaches that angels are a special class of spiritual beings whom God created before the beginning of the world. Strictly speaking, therefore, we don't become angels when we go to heaven.

However, take comfort that your baby is now safely in God's loving care, and nothing can ever change that.

She is now in a place where death and pain will never touch her, for in Heaven "There will be no more death or mourning or crying or pain, for the old order of things has passed away" (Revelation 21:4).

I often think of Jesus' words when I hear of a child's death: "Let the little children come to me, and do not hinder them, for the kingdom of God belongs to such as these" (Mark 10:14).

Take comfort also in the knowledge that God loves you, and he wants to bring peace and comfort to your hearts.

No, I can't explain why God allows tragedy to touch our lives, and there can be no greater heartache than the loss of a child. But I do know this: God knows what it is to lose a son, for Jesus Christ died on the cross for our sins.

If you have never done so, turn to him and invite him into your lives, and then rejoice that some day you will be with your child, and with Christ, forever.

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In Memory of Bryan

Bittersweet the grieving joy, The death and birth of our twin boys. One this world will never know, One alone will live and grow. Conceived and carried as a pair, In birth alone one breathed the air. His Cry assured us he'd be fine: His brother silent came behind. Bryan now in heaven will dwell. Jared will play and laugh and yell As all strong boys are wont to do. He'll learn in time he's one of two And wonder at what might have been, What life would be like with his twin. The sharpest sting of grief will pass And Jared will grow up too fast As happens with most every child. I know at times we'll see him smile And recall our other son Who was so like this living one. So pain won't end, can't go away, But joy grows stronger every day As we experience life anew, Seeing the world as children do.

To see our new son sing and dance.
To help him learn, to watch him grow,
These all are pleasures we will know.
Yet through the joy and love and care
We'll remember Bryan is not there.

We're grateful that we'll have a chance

Elizabeth A. Pector, M.D. in memory of Bryan Samuel Pector, stillborn from a cord accident at 33 weeks, delivered a minute after Many thanks to the following sponsors who supported our Christmas Candlelight Ceremony:

Byron L. Mitchell, D.D.S. Starbucks Coffee

Thanks also to the following committee members:

Rebekah Mitchell
Amy Allred
Aimee Shaw
Denise Gradel
Paula Miltenberger
Jan Allen
Samantha Iliff
Lori King
Anita Martinez
Pam Morren
DaLana Barsanti

Subsequent Births

Rae, Bill, and Chanie Scrivner

of Flower Mound, Texas, are proud to announce the birth of Casidy Rae "Cassie",
December 1, 2000,
at 1:12 p.m.
8lb., 5oz.,
20 inches.
The Scrivner's lovingly remember
Rianne Ellisa
March 4 - March 7, 1997,
Severe Hydrocephaly.

Jan and John Heffley, along with their children Jonathan and Jasmine,

of Denton, Texas,
joyfully announce the arrival of
Jillian Ashley,
born November 29, 2000, at 5:20 p.m.
She weighed 8 lb., 9 oz.,
and was 20 inches long.
The Heffleys lovingly remember
Jordan Ashley,
who was born and died
July 5, 1999 (lived for 9 hours),
from Trisomy 13.

Andy and Misty Potter

of Huntington, Utah,
proudly announce the birth of
Abigail Misti.
She was born September 11, 2000,
weighing 7 lb., 9 oz.,
and measuring 21 inches long.
The Potter's lovingly remember their angel,
Kyla Jane,
stillborn September 3, 2000,
due to a cord accident.

Jeannie and Steve Snyder

of Inwood, West Virginia
welcome their beautiful son,
Sean Patrick,
born December 3, 1999, at 7:55 a.m.
He weighed 9 lb., 1 1/2 oz.,
And was 20 inches long.
The Snyders lovingly remember
Randi Mae,
stillborn October 1, 1992,
due to obstetrical negligence.

Corbin and Luppaine Washington

of Centreville, Virginia,
announce the birth of their son
Pierce Gabriel,
March 27, 1999.
He weighed 7 lb., 6 oz.,
and was 21 inches long.
The Washingtons remember with love
Luppaine Bryce,
stillborn April 7, 1998,
due to umbilical cord entanglement.

Sherri and Todd Huff

of Dallas, Texas,
announce the birth of
Berklee Renae,
born December 4, 2000, at 2:29,
weighing 7 lbs., 5 oz.,
19 1/2 inches long.
The Huffs lovingly remember
Jackson Levi,
stillborn July 19, 1999,
due to a cord accident,
and
Baby Huff,
miscarried January 2000.

Stephanie and David Schneider

of Jarrettsville, Maryland, joyfully announce the birth of Emily Hope, born October 4, 2000, 6 lbs., 4 oz., and 19 1/2 inches long. The Schneider's lovingly remember Joshua David, stillborn September 11, 1999, due to a cord accident.

Tricia and John Oliver

of Opelike, Alabama,
joyfully announce the birth of
Ashleigh Elizabeth.
She was born on September 3, 2000,
weighing 6lbs., 4 oz.
and measuring 20 inches.
They lovingly remember
Madison Taylor,
who died in utero in June 1998,
and Jonah Michael,
born and died November 26, 1998,
due to incompetent cervix.

A DIFFERENT CHILD

A different child, People notice there's a special glow around you. You grow surrounded by love. Never doubting you are wanted; Only look at the pride and joy In your mother and father's eyes. And if sometimes between the smiles There's a trace of tears, One day you'll understand. You'll understand There was once another child. A different child Who was in their hopes and dreams. That child will never outgrow the baby clothes. That child will never keep them up at night. In fact, that child will never be any trouble at all. Except sometimes, in a silent moment, When mother and father miss so much That different child! May hope and love wrap you warmly And may you learn the lesson forever How infinitely fragile is this life on earth. One day, as a young man or woman You see another mother's tears Another father's silent grief Then you, and you alone will understand And offer the greatest comfort. When all hope seems lost, You will tell them with great compassion, "I know how you feel, I'm only here because my parents tried again."

By Pandora Diane Waldron

Submitted by Jan Heffley on the birth of her daughter, Jillian, in memory of Jillian's little sister Jordan, born and died 7/5/99, due to Trisomy 13.



Organizations and Internet Support

Pregnancy Loss & Grief Support

Angel Babies – Forever Loved

http://www.welcome.to/Angels4ever.com

Antiphosphlipid Syndrome

http://hometown.aol.com/AmAmail/Anti.html

Bereaved Families of Ontario

http://www.inforamp.net/~bfo/

CHERUBS-The Association of Congenital Diaphragmatic Hernia

Research, Advocacy, and Support e-mail: cherubs@gloryroad.net

www.cherubs-cdh.org

P.O. Box 1150

Creedmoor, NC 27522

919-693-8158

Children and Grief

http://www.bcm.tmc.edu/civitas/

Footprints Ministry

13611 Merton Woods Ln., Charlotte, NC 28273-9008

GriefNet

http://rivendell.org/index.html

H.A.N.D.

(Houston's Aid in Neonatal Death)

http://www.hern.org/~hand/

H.A.N.D. (Helping After Neonatal Death) of Santa Clara County

P.O. Box 341, Los Gatos, CA 95031-0341

408-732-3228

http://www.h-a-n-d.org e-mail: info@h-a--n-d.org

Hygeia

http://www.hygeia.org

Infanlos

e-mail: majordomo@taex001.tamu.edu

Type "Subscribe Infanlos"

Visit the Infanlos Family Website and

http://www.amets.net/infanlos

M.E.N.D.

(Mommies Enduring Neonatal Death)

P.O. Box 1007

Coppell, TX 75019

972-459-2396/ 1-888-M.E.N.D.

http://www.mend.org

Mending Broken Hearts

http://camalott.com/~libbys/mbh/mbh.htm

MIDS

Miscarriage, Infant Death & Stillbirth

16 Crescent Dr.

Parsippany, NJ 07054 e-mail: MIDS@nac.net

M.I.S.S.

Mothers in Sympathy and Support

Joanne Cacciatore (voice) 602-979-1000

(fax) 602-979-1001

Julie White (voice) 602-584-0805

http://www.misschildren.org

Morning Light Ministries

c/o St. Mary Star of the Sea Church

11 Peter Street South

Mississauga, Ont. L5H 2G1

905-278-2058

For bereaved Catholic parents who have experienced the death of their baby through ectopic pregnancy, miscarriage, stillbirth or early infant death, including up to one year old.

Nathaniel's Friends

P.O. Box 2372

Frazier Park, CA 93225

http://NathanielsFriends.com

bayonne@bigvalley.net

Precious Children Remembered

P.O.Box 534

Huron, OH 44839

http://www.accnorwalk.com/~mom2nich/

PCR - Chat Room

Monday 10 p.m. Eastern

Contact Shanna at Ladyinno@aol.com or

HostAHTHShanna@aol.com for info. Pregnancy/Infant Loss Center

1415 East Wayzata Blvd. #30 Wayzata, MN 55391

612-472-9372

Pregnancy Loss Newsgroup

http://web.co.nz/~katef/sspl/

Resolve Though Sharing

LaCrosse-Lutheran Hospital

1910 South Avenue

LaCrosse, WI 54601

608-785-0530

S.A.N.D.S.

http://www.sandswa.org.au

http://www.sandsvic.org/au/

St. Joseph Health Center

300 First Capitol Dr.

St. Charles, MO 63301-2893

314-947-6164

S.O.F.T. (Support Organization for Trisomy 18, 13 & Related Disorders)

c/o Barb Van Herreweghe

2982 S. Union St.

Rochester, NY 14624

716-594-4621

800-716-SOFT (7638)

e-mail: barbsoft@aol.com

http://www.trisomy.org/

SPALS (Subsequent Pregnancy Afer Loss)

http://www.inforamp.net/bfo/spals/

Tom Golden's Crisis, Grief & Healing

http://www.webhealing.com/

UNITE, Inc. (Perinatal grief support)

7600 Central Avenue

Philadelphia, PA 19111-2499

215-728-3777

Zoom

http://www.premier.net/~zoom/

Continuing a Pregnancy After Adverse

Prenatal Diagnosis **Abiding Hearts**

P.O. Box 5245

Bozeman, MT 59717

e-mail: hearts@imt.net

Anecephaly Support Foundation

http://www.asfhelp.com/

Abundance of the Heart

C/o Mark & Tonya Bayonne

P.O. Box 2372

Frazier Park, CA 93225

http://www.abundanceoftheheart.org/

Infertility

Hannah's Prayer

Providing Christian Support for Fertility Challenges. Online newsletter available. P.O. Box 5016, Auburn, CA 95604-5016 775-852-9202, http://www.hannah.org/

INCIID

http://www.inciid.org/

Infertility

http://www.fertilethoughts.net

Journey to Jordan

A ministry for families dealing with infertility and adoption. Publishes a newsletter for a small fee.

4511 E. Gatewood Rd.

Phoenix, AZ 85024-6938

Reproductive Medicine Program http://repro-med.net

Resolve

http://www.resolve.org/

Stepping Stones

Offers Christian hope, encouragement, and support to infertile couples. Publishes a

bi-monthly newsletter.

c/o Bethany Christian Services

901 Eastern Avenue NE

P.O. Box 294

Grand Rapids, MI 49501-0294 http://www.bethany.org/step/

Multiple Loss

CLIMB (Center for Loss in Multiple

e-mail: climb@pobox.alaska.net

www.climb-support.org Limbo-L List,

Loss in Multiple Birth Outreach

For parents who have lost one or more children in a multiple birth situation.

Contact Terry Callaghan at

Terryc45@hotmail.com http://www.geocities.com/Heartland/Lake/5142

The Twin to Twin Transfusion

Syndrome Foundation 411 Longbeach Parkway

Bay Village, OH 44140 440-899-8887

http://www.tttsfoundation.org

Twinless Twins 11220 St. Joe Rd.

Ft. Wayne, IN 46835-9737 219-627-5414

SIDS

SIDS Network P.O. Box 270, Ledyard, CT 06339

800-560-1454

http://sids-network.org

e-mail: sidsnet@sids-network.org

Cot Life Society

http://www.geocities.com/Heartland/Trail/5955

Spanish

Fundacion Esperanza

www.geocities.com/Heartland/Bluffs/7102/ e-mail: carlarh@ivillage.com

Helpful Reading ...

A Deeper Shade of Grace

by Bernadette Keaggy. Sparrow Press, Nashville, TN, 1993.

A Silent Sorrow

by Ingrid Kohn.
Bantam Doubleday Dell Publishing
Group, Inc., 666 Fifth Ave., New York,
NY 10103, 1992

Empty Arms: Emotional Support for Those Who Have Suffered a Miscarriaghge Stillbirth, or Tubal Pregnancy

by Pam Vredevelt. Multnomah Press, Sisters, OR, 1984

Empty Cradle, Broken Heart – Surviving the Death of Your Baby by Deborah L. David, PhD. Fulcrum Publishing, 350 Indiana St., Golden, CO 80401, 1991

Free to Grieve

by Maureen Rank. Bethany House Publishers 6820 Auto Club Rd. Minneapolis, MN 55438

Heaven's Not a Crying Place

by Joey O'Connor.
To order, visit his website at http://www.joeyo.com/
or e-mail joey@joeyo.com/

I'll Hold You in Heaven

by Jack Haford. Regal Books Ventura, CA

Letters to Gabriel

by Karen Garver Santorum, wife of Senator Rick Santorum To order, call 800-935-2222.

Loss and Grief Recovery Help Caring for Children with Disabilities, Chronic or Terminal Illness

by Joyce Ashton with Dennis Ashton. Baywood Publishing

Miscarriage – A Shattered Dream

By Sherokee Ilse and Linda Hammer Burns.

Wintergreen Press, Maple Plain, MN 55359, 1981



Morning Light – Miscarriage, Stillbirth and Early Infant Death from a Catholic Perspective

by Bernadette Zambri. To order, call 905-278-2058 (in Canada).

Pregnancy After a Loss – A Guide to Pregnancy After a Miscarriage, Stillbirth, or Infant Death

by Carol Cirulli Lanham. Berkley Books, a Division of Penguin Putnam, Inc., 375 Hudson St., New York, NY. To order directly, call toll-free 1-877-853-3595.

Silent Grief

by Clara Hinton. Published by New Leaf Press

The Christmas Box and Time Piece

by Richard Paul Evans. Simon and Schuster, Rockefeller Center, 1230 Avenue of the Americas, New York, NY 10020, 1995-1996

The Rocking Horse Is Lonely – and Other Stories of Fathers' Grief

by James D. Nelson, Editor. Pregnancy and Infant Loss Center, 1421 E. Wayzata Blvd., Suite 30, Wayzata, MN 55391, 1994

36 Hours with an Angel

by Lindsay Roberts.
Richard and Lindsay Roberts Ministries,
P.O. Box 2187, Tulsa, OK 74171

When a Baby Dies: A Handbook for Healing and Helping

by Rana Limbo and Sara Wheeler Bereavement Services/RTS, LaCrosse Lutheran Hospital, 1910 South Avenue, LaCrosse, WI 54601, 1985

When God Doesn't Make Sense

by Dr. James Dobson. Published by Tyndale House Publishers, Wheaton, IL, 1993

When Hello Means Goodbye

By Paul Schweibert, M.D., P., and Kirb. Perinatal Loss, 2116 NE 18th Ave., Portland, OR 97212, 1986

When Pregnancy Fails: Families Coping with Miscarriage, Stillbirth and Infant Death

By Susan Borg and Judith Lasker. Bantam Press, 1989

SIDS ...

The SIDS Survival Guide

by Joani Nelson Horchler and Robin Rice Morris. To order, call 301-773-9691.

Subsequent Pregnancy ...

Still to Be Born

by Paul Schweibert, M.D. Perinatal Loss, 2116 NE 18th Ave., Portland, OR 97212, 1986

Another Baby? Maybe ... Thirty Questions on Pregnancy After Loss

by Sherokee Ilse and Maribeth Wildre Doerr.

Contact Centering Corporation www.centering.org 402-553-1200

For Children ...

Let's Talk About Heaven

by Debby Anderson. Chariot Books, David C. Cook Publishing Co., Elgin, II, 1991

Molly's Rosebush

by Janice Cohn, D.S.W. Albert Whitman & Company, Morton Grove, IL 1994

Mommy, Please Don't Cry – Tender Words for Broken Hearts

by Linda DeYmaz. Multnomah Publisher, Bend, OR Contact www.multnomahbooks.com

Someone I Love Died

by Christine Harder Tangvald. Chariot Books, David C. Cook Publishing Co., Elgin, IL, 1988

The Cherry Blossom Tree – A Grandfather Talks About Life & Death by Jan Godfrey.

Augsburg Fortress, 426 S. Fifth St., Box 1209, Minneapolis, MN 55440, 1996

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Living with grief after pregnancy loss: Perspectives of African American women

A report of a study by Paulina Van-Patterson, RN, Ph.D.

During the summer of 1999 I sought African American women who have experienced pregnancy loss for participation in my dissertation research project. Rebekah graciously extended her help in recruiting participants. She posted a recruitment notice in a M.E.N.D. newsletter, and as a result I received quite a response from some of you. It was an honor and a privilege to be the recipient of your most personal stories about your losses. I promised to give feedback about the results of the study. Of course, it took much longer than I had anticipated to analyze and interpret the results. This report represents a small segment of the project. I have chosen to report on some of the strategies the women reported using to manage their personal grief and responses to the loss of their pregnancies or babies. I have provided a foundation by giving a brief summary of what currently exists in the literature about African American women and grief, followed by information on how the data was collected, a profile of the participants, and selected results from the interviews.

Background

What do we know from the current literature about African American women and their pregnancies and grief experiences? *African American Women and their pregnancies*

African American women experience pregnancy losses (miscarriages or tubal pregnancies) and infant losses (birth to less than one year of age) at rates of at least twice those of women from other ethnic/racial backgrounds. Although this disparity exists, African American women are included in a limited number of studies related to losing a fetus or baby. Therefore information available about their experiences is limited. I searched for pregnancy loss articles [in nursing, psychology, medicine, and sociology literature] for the period 1970-2000 and found only three articles that included African American women. The number of women was few and represented women from only the most at-risk (i.e. lowest socioeconomic status and educational levels) of the African American community.

Grief

Grief is a normal response after the loss of a loved one. Grief responses may consume and/or affect every aspect of the individual's life, such as physical, emotional, social, psychological, and spiritual. How one grieves after the loss of a loved one is influenced by cultural values, beliefs, and social and religious and spiritual factors. A social expectation for the "normal" grieving period for someone who has experienced a loss is about one year. At that point it is expected that an individual should be able to resolve the feelings and resume normal daily activities. In reality, one may experience that the accepted time to grieve is much less than a year. After a few weeks or months loved ones and friends may stop speaking about the pregnancy or baby and expect a bereaved mother to "get on with life."

Grief that is intense or lasts a long time (i.e. more than a year) can have negative effects on a woman's emotional, physical, social, and psychological health. The most common adverse condition is depression and its associated conditions (i.e. sleep and appetite disturbances, inability to carry out normal daily activities).

Perinatal grief (related to loss of a pregnancy or baby) has many unique characteristics. The most prominent is the characteristic of being invisible. Grieving after the loss of a pregnancy is often not recognized as normal. This is particularly the case with women who experience miscarriages or early pregnancy losses. The age of the fetus at the time of the loss experience seems to influence the grief experience. The further along one is in the pregnancy at the time of loss, the more intense or longer the grief experience may be.

This was a brief summary of the existing literature. In the next section I will describe how I collected the data.

The Study

Purpose

I examined the African American experience with grief after the loss of a pregnancy and its impact on health. I also examined the strategies that these women used to cope with their grief. The latter is the focus of this report.

I recruited participants for this study using face-to-face approaches at a variety of community sites (i.e. private and public OB-GYN clinics, social service agencies, church services, a health-faire). Family and friends also assisted in the recruitment. Using the M.E.N.D. newsletter as a vehicle to announce the study and request participants was very effective, but this was not the case with other publications. Recruitment ads in newspapers (Northern California) with predominately African American subscribers did not generate a single inquiry for participation.

The Participants

Women were sought for the study who met the following criteria: self-identified as African American, "Black" or of African descent; were at least 18 years of age; communicated in the English language; and who self-reported a history of pregnancy loss within approximately three years prior to recruitment for participation in the study. Over 100 women responded (10 from the MEND organization).

The Study Participants

An exciting finding from this study was that the participants represented a cross-section of African American women. This defied the stereotypical profile for African American women that exists in the current literature. A description of a profile of the typical participant in this study is: 30 years of age, married or living with a partner, employed for a wage, attained advanced training or education in a technical or college setting. One third of the participants reported annual family incomes of less than \$10,000 and another third in excess of \$50,000.

At the time of their participation in the study the average time since their loss experience was about two years, and losses were experienced at about 14 weeks gestation or pregnancy (range of gestation at loss was 4 weeks to full term infant). *Tools used to collect the data*

I had the privilege of interviewing every woman for this study. By far, I spoke to most women face-to-face and about 15 % over the phone. The face-to-face interviews were audio recorded with each woman's permission. For the phone interviews, which mostly represent the M.E.N.D. members, I took detailed notes. The main questions during the interview were: What did the loss of your pregnancy or baby mean to you? What was helpful and not so helpful for you when managing your reactions after the loss? *Analysis*

The audiotapes and detailed notes were transcribed by a professional transcriber for use during the analysis activities. I listened to each of the recorded interviews at least 3 times and read the transcriptions numerous times in order to facilitate my understanding and extract meaning from the personal stories. I sought the assistance of many experts in interpreting the study results. Those consulted included some of my participants; my nursing colleagues in public health, academic, hospital and clinic settings; and African American OB-GYN physicians and nurse practitioners, midwives, and clergy. *The Results*

The participants reported having to cope with several aspects of their lives after experiencing the loss of their pregnancies or babies. In this report I will focus on the four strategies (*I talked, Haven't dealt with it, I prayed, Going inside myself*) used by these women to cope with their personal reactions after their loss experiences. Experts from selected interviews are used to illustrated strategies. The strategies were labeled/named using actual words from participants. "I talked"

The first strategy is "I talked." Most participants identified the need to speak to others about their loss as an important coping strategy. Expressions from a participant who experienced the loss of her baby during her first trimester is typical of some of the comments received:

If I talk to people who have had losses or miscarriages, then it doesn't bother me. I feel like I'm related to someone who's been through the same thing I have... It feels better at the time,...it may not last a long time...

"Haven't dealt with it"

Over half of the participants reported not having dealt with the loss of their babies for some period. Among the many reasons for avoiding thoughts or discussions about the loss were feelings of guilt or responsibility for the loss. A participant who experienced the miscarriage of her first pregnancy illustrates perspectives similar to other participants:

I didn't tell people right away. I isolated myself. I didn't tell my husband until after the D&C - in the evening after I left the hospital and he came home from work. I felt guilty (for losing the baby). I waited a few days to tell my family and a week or so to tell my friends. I didn't speak to anyone. I did cry and was angry."

"I prayed"

About 98% of the participants reported that religion was very important in their lives, and about 94% of the participants reported attending religious services at least once a week. Praying and participating in religious and spiritual activities was another coping strategy frequently reported by participants. The following quote is from a participant who experienced a stillbirth and is representative of religious and spiritual activities in which some participants engaged:

Every month on the anniversary of her birth I would go to my husband's church and light a candle and say a prayer and feel like I was still connected with her that way... That way it felt really good...I would just pray that she was in a better place and that she was happy and that God was doing what I couldn't do which was holding her and to tell her that I loved her and that I missed her and that I can't wait to see her when I get there.

"Going inside myself"

Going inside myself is the fourth strategy most frequently reported by the participants as being helpful with coping after their experience of loss. This strategy represents the use of inner instinctive resources to cope with grief. A participant who experienced the loss of her baby during her second trimester shared her experience with a common theme reported by the other participants:

I guess after about two or three months they (family and friends) would just talk about other stuff. And so I started finding myself getting depressed and decided that I should probably do something about it.... So I started really making a real effort to fight being depressed and to not just get into a spot and stay but to really use all of my...well, everything I knew to do I started doing. ...and just started looking deep into myself to see what could I do to try and get over this.

Summary

This group of women used a variety of strategies to manage their personal responses after experiencing the loss of their babies. Grief experiences are highly individualized, therefore responses will be equally diverse. A common theme was the need and desire to speak with others about the loss of the baby. Speaking to others included praying and the use of quiet time to hear the "inner voice."

If you would like to share your comments with me about these strategies please feel free to contact me at my email address: paulina-2000@home.com,or write to me at P.O. Box 1019, San Leandro, CA. 94577.

My most sincere gratitude and appreciation goes to all the women who contributed their time and personal stories. I am committed to continuing this work and spreading the knowledge gained so that all women who experience this type of loss may be helped and supported.

This project was partially funded by the following: University of California, San Francisco (Alumni Association, Graduate Student Division, President's Office); Sigma Theta Tau Nursing Honor Society; (AWHONN) Johnson & Johnson-Marshall Klaus Award.

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Blake Leland Allen

April 21, 1999 Preterm labor/incompetent cervix

Lauren Grace Allen

Stillborn February 13, 2000 Unknown cause Parents, Jan & Sean Allen Lauren's twin, Zachary Chase Given by grandparents, Leonard and Melba Smith

M.E.N.D.

gratefully acknowledges these gifts of love given in memory of a baby, relative, friend or given by someone just wanting to help. These donations help us to continue $M = N \cap S$ mission by providing this newsletter and other services to bereaved parents free of charge. Please refer to the back page of this newsletter for more information regarding where to send your donations and what information to include. Thank you so much!

Patrick Lanham

Stillborn May 15, 1994 Velamentous insertion of the umbilical cord Given by parents, Sean and Carol Lanham

Jonathan Daniel Mitchell

Stillborn June 24, 1995 Cord accident Parents, Rebekah and Byron Mitchell Given by grandparents, Dennis and Sue Brewer

Jonathan Daniel Mitchell

Stillborn June 24, 1995 Cord accident Given by parents, Byron and Rebekah Mitchell and big brother, Byron, Jr.

Jonathan Daniel Mitchell

Stillborn June 24, 1995 Cord Accident Parents, Byron and Rebekah Mitchell Big brother, Byron, Jr. Given by grandparents, Lyle and Marnie Mitchell

Ross Donoho Kennedy, III

Stillborn October 29, 2000 Cord accident Given by parents, Ross and Nicole Kennedy

Michael Joseph Böer

Stillborn July 17, 1996 Trisomy 18 Given by parents, Lynne and Paul Böer and siblings, Paul, Jr. and Maggie

Lauren Elizabeth Pearson

October 31 - December 8, 1999 Prematurity - TPN - Induced Colistasis Nectritizing Inter Colitis Given by parents, Darrell and Lorraine Pearson

Garrett Mayer

October 12 - December 18, 1999 Heart Problems Parents, April and Tony Mayer Given by Teresa Walker and Jeffrey Brady

Kyle Charles Walton

November 19, 1998 Group B Strep and lack of proper nourishment from placenta Parents, Jason and Kristen Walton Siblings, Jessica and Laura Given by Millie Ruchti

Jacob Dominic Stuckey

Stillborn August 19, 2000 Unknown Cause Parents, Brandon and Michelle Stuckey Given by grandparents, Schuyler and Phyllis Stuckey

Amanda Morgan Galleger

Stillborn January 7, 1997 Trisomy 18 Given by parents, Steve and Diane Galleger and siblings, Sydney and Jack

Joseph Charles Libby

Stillborn May 26, 1999 Cord accident Given by parents, Wim and Sharlene Libby, big brothers Will and John, and little sister Mary Grace

Joshua David Schneider

Stillborn September 11, 1999 Cord accident Given by parents, Stephanie and David Schneider and little sister Emily

For Danni and Kaitlyn

Little toes;
You have walked
Across our souls.
For many long months
You secured your imprint
Inside of us,
Where no one else could see.
Now you've walked
Outside our world
And still no one can see
What we've seen
From the start;
Your tiny wrinkled footprints
Forever upon our hearts.

-Cheryl Mills

From Bereaved Parents Share ... Poems of hope and comfort, page 22



"Hi! My name is Molly Holkesvik, and I am the mother of five, one of whom is now in heaven. Robert Eugene Holkesvik was stillborn on February 10, 1993. I wasn't able to completely deal with the pain of losing him at that time, but I have recently taken it upon myself to start working through the pain by writing my own story. Just getting my thoughts and feelings on paper has opened my eyes a lot!

I also want to help others who are trying to deal with the death of their stillborn children. There are so many feelings of guilt and shame when you know your child died inside of you. Reading other people's stories really helps bring home the fact that these feelings are normal, not wrong, and that they will pass. Things do get better.

I am searching for mothers of stillborn children who would be willing to share their stories with me. I want to compile the stories and find some common themes. My hope is that my findings will someday comfort other parents who are thrust into the situation of dealing with such an immense loss."

If you would be willing to share your story with Molly, you can e-mail her at <u>Holkesvm@silver.nicc.cc.ia.us</u>.

Christen Clower, a graduate student in clinical psychology at the University of North Texas, is conducting a survey of people's reactions to the experience of pregnancy loss. She would like to contact mothers and fathers who have lost children due to ectopic pregnancy, miscarriage, stillbirth, or neonatal death.

If you would be willing to help Ms. Clower with this project, please contact her via correspondence, telephone, or email using the contact information below. She would then mail you a packet of information. This packet will include some materials for you to complete.

Ms. Clower is very excited about this project. She is hoping to gain a better understanding of the experience of pregnancy loss, so that she can share it with the psychological community. A better understanding of pregnancy loss will facilitate an increase in public awareness of pregnancy loss and public education on this topic. Additionally, Miss Clower intends for this project to lead to more appropriate services for families who experience pregnancy loss.

Christen Clower
Department of Psychology
P.O. Box 311280
Denton, Texas 76203
(940)206-5231
ceclower@gte.net

Grief Materials

Birth and Life 141 Commercial St. NE Salem, OR 97301 (503) 371-4445

Centering Corporation PO Box 4600 Omaha, NE 68104 (402) 553-1200

Wintergreen Press 3630 Eileen St. Maple Plain, MN 55359 (612) 476-1303 www.Wintergreenpress.com

> **Perinatal Loss** 2116 N.E. 18th Ave. Portland, OR 97212 (503) 284-7426

ICEA Bookmarks P.O. Box 20048 Minneapolis, MN 55420 800-624-4934

life is Eternal

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength and I stand and watch her at length until she hangs like a speck of white cloud just where the sea and sky come down to mingle with each other. Then someone at my side said: "There! She's gone."

Gone where? Gone from my sight – that is all. She is just as large in mast and hull and spar as she was when she left my side, and just as able to bear her load of living freight to the place of destination. Her diminished size is in me, not in her; and just at the moment when someone at my side says, "There! She's gone," there are other eyes watching her coming and other voices ready to take up the glad shout, "There she comes!"

Author unknown



M.F.N.DPage 14

$M. \sqsubseteq . N. D.$ is a

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E-Mail: Rebekah@mend.org Sharlene@mend.org

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P.O. Box 1007 Coppell, TX 75019.

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[&]quot;... that we can comfort those in any trouble with the comfort we ourselves have received from God" (2 Corinthians 1:4)