

Websites:

The Compassionate Friends
www.compassionatefriends.org/

The Labor of Love
<http://www.thelaboroflove.com/prose/loss.html>

The MISS Foundation
<http://www.missfoundation.org/>

The Cope Foundation
<http://www.copefoundation.org/>

Remembering Our Babies - Pregnancy and Infant Loss
<http://www.october15th.com/>

Share - Pregnancy and Infant Loss Support
<http://www.nationalshareoffice.com/>

Breath of Hope's Listserv for Parents of Angels
[Breath of Hope Angels Listserv Forum](http://www.breathofhope.org/forums/)

<http://health.groups.yahoo.com/group/BreathofHopeAngels/>



www.breathofhopeinc.com

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This booklet was made possible by our families who are also parents of these precious CDH Heavenly Angels.

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In the Event of an Angel

A Reference for Babies Born with Congenital Diaphragmatic Hernia, who choose wings over feet



January 18, 2012

EVERY BREATH THEY TAKE IS OUR BREATH OF HOPE

MISSION STATEMENT:

Breath of Hope exists to raise awareness of congenital diaphragmatic hernia by working with parents, family members, and medical professionals to educate and support all who are affected by or want to learn more about CDH.

THE DEVASTATING NEWS

To hear your baby has died is the worst thing in life you will ever hear. There are no words that will help. This news is not what you hoped for, not what you expected even with the statistics of CDH – you had hope. There is still hope and it will come back to you but it takes time.

This may be the first time you have to experience grief of a loved one. The loss of a child, however, has been called the worst loss. It shakes the foundation of your esteem, your faith and your will. You will never be the same and this may frustrate you and others close to you. Sometimes family become like strangers and strangers become like family.

At the Hospital - Name your baby, take pictures, take foot prints, hand prints, ear prints, bathe and dress your baby and hold your baby. Do not be scared, know you can examine every inch of your beautiful baby. There are organizations out there that can come and take professional photos of you, your family with your baby. They will do so and capture the memories and the moments you have with them. The staff at hospitals can help with this. You can also have your baby baptized.

You can also keep the blankets your baby was in or on in the hospital, put them in a Ziploc bag with a piece of acid free paper – these blankets and clothing will always have your baby's scent. You can save a lock of hair, the bracelets the hospital used for your baby, baby's hospital card, any certificates the hospital gives such as: birth/death or baptism.

Parents have spent the whole day and night with their babies. They blocked out all else in the world so they could have those moments with their child. If you want to do something with your baby – ask if you can, they should be able to help you achieve your desires. These moments are about you and your child – your family.

Most hospitals will give you the names of the nurses who cared for you and your baby as well as support group information. If they don't, ask for it because it is their job to take care of you.

Help, Comfort and Hope After Losing Your Baby in Pregnancy or the First Year - Hannah Lathrop
Holding on to Hope - Nancy Guthrie
Safe in the Arms of God - John MacArthur
Gone but not Lost: Grieving the Death of a Child - David W. Wiersbe
Empty Arms - Sherokee Ilse
I'll Hold You in Heaven Remembrance Book - Debbie Heydrick

Heaven is for Real: A Little Boy's Astounding Story of His Trip to Heaven and Back
By Todd Burpo and Lynn Vincent

Our Heartbreaking Choices – Edited by Christie Brooks
Closer to the Light - Melvin Morse, Paul Perry, and Raymond A. Moody
Song for Sarah: a Young Mother's Journey Through Death and Grief - Paula D'arcy
Trying Again - A guide to pregnancy after miscarriage, stillbirth, and infant loss - Ann Douglas and John R. Sussman, M.D
Pregnancy after a Loss - A Guide to Pregnancy after a Miscarriage, Stillbirth or Infant Death - Carol Cirulli Lanham
Gone too Soon: the Life and Loss of Infants and Unborn Children - Sherri D. Wittwer
Waiting with Gabriel - Amy Kuebelbeck
After the Death of a Child: Living with Loss through the Years - Ann K. Finkbiener
When The Bough Breaks: Forever After the Death of a Son or Daughter - Judith R. Bernstein
The Worst Loss: How Families Heal from the Death of a Child - Barbara D. Rosof

For Children

Please note - some of these books are also good for parents too.

Mommy, Please Don't Cry, There Are No Tears In Heaven

- Linda Deymaz

We Were Gonna Have a Baby, But We Had An Angel Instead

-Pat Schwiebert and Taylor Bills

No New Baby - Marilyn Gryte

All Gods Creatures Go to Heaven - A.A. Nolfo and N.A. Noel

Helpful Resources

Now I Lay Me Down To Sleep – <http://nowilaymedowntosleep.org/>

Photographers in your area to take photos of your baby and your family – this is a free service.

Centering Corporation – Grief Books and resources for all
PO Box 4600, Omaha NE 68104
402-553-1200
<http://www.centering.org/>

SHARE, One of the first national organizations to provide support groups for parents. 800-821-6819

Butterflies:
Michael's Fluttering Wings, Route 1 Box 447A, Mathis TX 78368
512-547-5568

Mr. Butterflies
<http://www.mrbutterflies.com/>

Fragrant Acres' Butterfly Farm
<http://www.butterflyreleases.com/>

Vibrant Wings Butterfly Release
<http://www.vibrantwings.com/>

Books For Adults

Empty Cradle, Broken Heart: Surviving the Death of your Baby - Deborah L. Davis
Grieving the Child I Never Knew - Kathe Wunnenberg

The Death of a Child: Reflections for Grieving Parents - Elaine E. Stillwell
Chicken Soup for the Grieving Soul - Jack Canfield and Mark Victor Hansen
After the Darkest Hour, the Sun will Shine Again: A Parents Guide to Coping with the Loss of a Child - Elizabeth Mehren

Giving the news to family and friends. It might be best if you call just a few family and friends and have them relay the news to the rest.

You are in shock and disbelief and this is normal. There is a numbness that washes over a grieving parent which protects them from the pain of this grief. If you were to feel the true impact of this pain, you would not survive it. There is a reason for you to survive but there will be moments where you wish you wouldn't. Every parent who has had a child die has wished that they would also. This is not suicidal thoughts but thoughts of wishing they just wouldn't wake up. Wishing they could die. The pain is that intense. You are not alone.

Tears come very easily and sometimes you may be talking about something else and suddenly the tears flow. It is okay. You are grieving your baby and you are allowed to cry as much as you want and need.

Memorial Service / Funeral - This may be the first time you have to plan a memorial service or funeral. Take your time. The parents should make the decisions for this together – it is something that the parents can do for their baby. There is no set rule to the time frame a funeral must take place unless there are religious reasons for them to occur. You can turn something sad into the celebration of your precious baby's life.

Balloon releases for a funeral can be beautiful. If weather permits they can also have butterfly releases. There are some very beautiful poems out there that can be read at the service. Whatever you plan for you baby – will be perfect for you and your baby. Don't be afraid to take pictures or video tape.

You can have a viewing or not. You can also ask if you can dress your baby for the funeral. Be prepared that your baby may feel cool to the touch but they are still your child. If an autopsy was performed, the funeral director may insist on having a t-shirt on your baby to cover the incision. This is not to prevent you from seeing it but perhaps save you from seeing it.

If you choose cremation, you can choose a very nice container; one Mom chose a Peter Rabbit porcelain container used for keepsakes for her baby's ashes and keeps it beside her baby's picture. There are also necklaces which can hold a bit of the ashes in them to be worn over your heart – always.

You can also have your baby buried at the foot of a beloved grandparent or many cemeteries have Baby lands, or in your own family plots. Take your time with your decisions and some of them may come immediately. We do recommend that you take time before choosing the memorial marker. Many parents have told us making that decision too early – they wished they had waited.

Other children

If you have other children and wonder if they should be exposed to funerals or your baby, yes they should. Unfortunately this is their life too and death is part of our lives here on earth. They too will grieve and learning the rituals of a funeral and memorials for their little brother or sister is important. They may ask questions, so be prepared to answer them as honestly as you can and if you don't have the answer don't be afraid to tell them this but if it is a question that could have an answer find it for them.

After the Funeral / Memorial Service

Everyone leaves, the cards stop coming in the mail. The bills still come and the world still moves forward. You are grappling and hanging on by a thread trying to keep up or you might be just there not wanting to go forward. This empty feeling engulfs you. The feelings that come astound you. They are so extreme. From complete utter sadness to anger to denial. There are five phases we go through with grief:

Shock
Awareness of Loss
Conservation/Withdraw
Healing
Renewal

Hard and Difficult Feelings

Guilt is grief's ugly side-kick. It is a way to find answers to unanswered questions of WHY? It is a way to place and aim your anger. It is also a way to gain control and perhaps do over a minute that may have made a difference.

To turn this guilt to a positive, ask to have a meeting with your baby's attending doctor and find out everything you can about what happened to your baby. Buy a journal or notebook and write down your questions and the answers you receive.

Grieving as a Couple

"Take care of one another." A NICU Nurse told us this when we left the NICU for that final time. This is and will be the hardest thing to do and survive this. Your relationship is taking a major hit and if your relationship is valuable to you, it is the time now to nurture it, just as you nurtured your baby.

- Set aside time with your partner to check in with them about where they are in their grief and where you are too. No judgment, many times you both will not be at the same place in this journey.
- Relive your courtship with one another and times you had before this baby. Remember how you both fell in love and how far you have come.
- Hug every day.
- Always kiss each other good-bye in the morning.
- Go shopping for one another with just \$10 and see what you receive and will give.

You both shared this beautiful baby, you both are grieving not just this beautiful baby but all the hopes and dreams you had for this baby too. (Some of them might not have been the same but you both need to respect one another's dreams that were lost with this child.)

Know that there will be times where you both don't understand what the other is going through. This is the time when you need to communicate what you are feeling, what you need and what you don't need. Many times all you need is someone to agree with you that it wasn't appropriate for Aunt Sue to ask you when you were going to "have another baby". Aunt Sue has to keep her nose out of your reproductive plans if you have any because they are none of her business.

Men feel the need to fix everything and this can not be fixed. They feel they should but the fix is time and it never really is fixed but survived and accepted and embraced too. You will learn in time to accept your baby's death totally and also know that your baby is always in your heart and that love never dies. Parents of angels are special people.

If you laugh, it does not mean you have forgotten your baby and you are over your grief. When you laugh there is a chemical change that is healing. To take care of yourself is one of the best ways in honoring your child.

When you can, read as much as you can about grief. Attend at least one meeting of a parents support group. Grief is never easy and you deserve as much support as you can get.

Your Other Children

They grieve too. There are some wonderful resources for them. From coloring books to stories and books that could help them. If your other children are over the age of 7 – 8 they will grieve differently than younger children. Occasionally younger children who have a death of a loved one prior to the age of 7 – 8 will re-grieve at that age when they realize the true impact of the loss in their life. Children also do not grieve continuously as adults do in the first few months. They have to have breaks from grief with play and school. This does not mean they are not grieving.

Counseling

Do not be afraid to seek out a grief counselor for yourself and your family. It is not a sign of weakness if you need an outside individual to evaluate your emotional state. In fact, it will make you stronger in many cases. It can be a clergy person or a professional counselor. Be sure you are comfortable with them and do not be afraid to shop around for the right fit.

Anti-depressants or Anti-anxiety drugs

Some feel that they helped their grief; others felt they would only prolong their grief. This is something individual. Depression is part of the early parts of grief. Grief is sad. If this is too much for you and you are not able to feel like you are functioning, please feel free to consult with your doctor. It will not be an immediate fix because many of these drugs require a few weeks before they become effective. Some may not work. Be sure you know their side effects and adverse affects they might have to be alerted so you will know if you should contact your doctor and stop using them.

Your questions should be direct and you should expect honest answers but also be realistic. All of the questions you have are important. If you have a question, it needs to be asked because you need to know. It helps with your healing. An autopsy may help find answers, sometimes opening more questions be prepared to ask questions but also to truly listen to your baby's doctors and nurses. Also be prepared sometimes they don't have answers.

Keep a Daily Journal and write down your feelings. This will help you through your grief. Write a goodbye letter to your baby. Then write a letter back to you from your baby.

Anger – holding it in causes depression and a heavy feeling – talk to others about how angry you are. Express your anger in a way that can get it out through physical exercise or even a safe place to scream. Punch pillows or safely break glass wear. One Mom would throw it in a galvanized trash can the sound helped and there was no clean up.

Fear – write your fears down, ask questions and share your feelings with someone who will help with the answers to help diminish your fears. You may find that some of your fears are unrealistic and you will be relieved. These fears might surface in the future and they are part of you. Do not let your fears control you – you can control them.

Withdrawing or going into yourself – you might feel like crawling into bed and never coming out again. This is how we protect ourselves from further pain and also having our time to collect ourselves. This can also be healing and allow you to begin to recover and getting in touch with your feelings. Withdrawing too long can be self-defeating and lonely.

There is a time to reach out beyond you and there is a time to reach into yourself. Let people know when you need their support. You may reach out to your church and clergy. Prayer can be a source of strength. Be honest with your feelings with God. There are also points where your faith will be questioned by you and a time you might be angry with God. This is okay. Anyone who tells you this is wrong has never had a child die. It shakes our foundations.

If you are a single parent you may be told that this was “for the best” even couples are told this too. Others think they are comforting us and they are not. You will find that friends and family sometimes become strange or strangers and strangers become the best of friends. People say the stupidest things in tragic situations. “You can have another” is also a slap in the face, you wanted this child. You were prepared for this child and willing to take on any and all of the joys and issues that came with this child. Never let anyone tell you otherwise. Even if you made the decision to stop this child’s life support, this was done out of love.

Don’t let anyone tell you there is a time limit for your grief. There isn’t. If a child has their parents die, they are called an orphan. If a wife has their husband die, they are called a widow. If a husband has his wife die, he is called a widower. If a parent has a child die, there is no name for it. It is that lonely at times and that tragic. There are no words, so when others try to comfort us with words, it is just not acceptable. Sometimes what we truly need is to be hugged or allowed to be at peace with our thoughts.

Sometimes people even avoid us because they don’t want to be sad or see us in this new way. Well, the issue with that is that we will never be the same again and we are gradually moving to our new normal. This is a struggle for the grieving parent too.

Residuals

As the days go forward there may be some things that will surface that you may not have considered.

- You may receive free subscriptions to baby magazines
- Coupons for diapers, formula or baby food arrive in the mail
- Photographers may send their advertisements
- It will seem like every woman is pregnant or having a baby
- All commercials appear to be for baby products or have infants in them

Feel free to contact the companies sending you coupons and magazines and request to be removed. If they ask why – tell them. (Sometimes they need to be more sensitive.)

You also may find that you are hurt and jealous when you hear the announcements from friends and family who are pregnant. It is alright to feel this way.

You may also feel like no one else has a clue, not all pregnancies have happy endings, these people are clueless.

Memories and Remembering

Including your baby in celebrations can be helpful. On their birthday you can have a party with a cake. A candle can be lit on special occasions in your baby’s name. You can buy ornaments for Christmas, keep a chest or box with your baby’s things. You can create a website or blog in memory of your baby. You can release balloons or butterflies on their birthday or for celebrations.

It is also good to look back in your journal and see where you were, remembering and how far you have come over time. The feelings of grief for your baby will last a long time but it becomes easier with time.

Many parents compare it to being out in the ocean in a boat; a fierce storm has swallowed you up for some time and consumed you. Eventually the storm dies down and there are a few good days. As you travel through grief, there may be predictable storms that come up and some unpredictable. As you travel on the good days are more than the bad days. You never will stop remembering or loving your baby. It just becomes easier to do these things.

Taking Care of Yourself

This is the time to take care of yourself and being kind to you during this period. You will need all the strength you can because grief is hard work.

Moms may still be lactating and there isn’t much that can be done except for time. Cabbage leaves have been recommended and ibuprofen.

- Eat nutritious food and drink plenty of water
- Exercise, a walk to clear your head or get fresh air may help every day. Exposing yourself to fifteen minutes of sunshine also will help.
- Talk about your feelings and your baby as much as you need to.
- Take naps when you need them
- Love your pets or get one if you want one.
- Find a movie to make you laugh – sometimes laughter will help when there are no more tears to be shed for a while.