## Dealing with Miscarriage, Stillbirth and Neonatal Death



## -An Empowering Guide for Medical & Nursing Staff-

"Help Heal Patients Emotionally, As Well As Physically"

# by **Lori Martini**

This document has been prepared in loving memory of Bryce Neily Martini (Full-Term & Stillborn on November 30, 2004 due to Placental Abruption)
"Forever a part of our Family, Forever our Son, Forever Loved"

Lori & Toby Martini

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# "Healing From The Start" A Coaching Manual for Medical & Nursing Staff

By

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Very sadly, the shock that parents feel, after their baby has died, often leads to their making decisions concerning their child that are regretted later on.

It is a reported fact, that the way that parents are dealt with, by medical & nursing staff, following the diagnosis and/or death of their baby **will** very much influence their grieving process. Whether it be that caregivers give extremely compassionate, supportive guidance or sadly when the opposite occurs (and staff is not very supportive to the parents, and possibly even neglectful to the family... due to their lack of grief training & experience.)

The bottom line is that how families are cared for & guided in the moment of their loss & afterwards makes a huge impact on how they go about spending time with their baby...and in their continued grief journey. Parents, who receive exemplary emotional support from their caregivers generally come to terms with their loss more easily and are able to carry on with their lives more peacefully as well.

By staff providing an extremely compassionate & supportive (as well as enlightening) experience, during such a devastating loss, this tends to allow newly bereaved parents to have much more quality time to mindfully integrate their grief into their lives.

One of the most important efforts that medical & nursing staff can do to support newly bereaved parents effectively would be to help **gently guide** them in **spending quality time** with and **creating keepsakes** of their baby who has just died. Sharing with them what they have learned from past bereaved parents, as well as, sharing the many beautiful stories of what other parents did in spending time with their babies...**helping to normalizing the idea of 'why' spend time with a baby that has died** (or is going to die soon.) Helping to empower these parents...

By applying the suggestions in this coaching manual, staff can *help heal patients emotionally*, as well as physically.

If any medical or nursing staff member is assigned to a family who is experiencing a perinatal loss and that staff member feels that they are 'too' uncomfortable with the situation to help effectively, then a 'seasoned' staff member should be assigned instead. Although, it is highly recommended that the 'uncomfortable' staff member assists or shadows during the care with the newly bereaved family. This way they can learn hands on from the 'seasoned' caregiver on how to give above and beyond compassionate grief care to these very deserving families during their 'one-and-only' opportunity to spend time and make memories with their precious baby.

Medical & nursing staff is highly advised to consult this manual every time they are preparing to take care of a family who is experiencing a loss. This brief guide can help to gently remind and empower staff on 'how to' go about taking care of their patients/parents with confidence. By applying the following suggestions (which comes directly from past bereaved parents) staff will feel more confident that what they are doing/saying is a good thing...even though emotions may be at their most heightened right now.

#### What You Can Do To Help

A gentle way to start would be to simply & sincerely say to the family; "I am so very sorry for your loss, we are here to support you..." "We will get through this together...you don't have to do this alone" "We will help guide you in meeting & spending precious moments with your baby..." Etc...

After the family has had a little bit of time to make calls and/or absorb 'some' of the shock of what is happening, you can then give them pamphlets & books on the subject of dealing with the death of a baby...as well as show them a video...slowly starting to prepare them for what is to come (as long as the mother is no danger...and there is no rush to deliver right away.)

Compassionately & sensitively let the families know what decisions they might have to face right away, how to prepare for delivery & recovery, what it might be like spending time with their baby, what other bereaved families have done in the past that was comforting & healing, what support people & organizations can help them while **still** at the **doctor's office**, while at the **hospital** and once they are back at **home** as well. All of this competent & caring guidance can help the bereaved parents to feel fully supported and 'somewhat' more empowered in this very out of control time.

Some excellent books to have on hand to help guide & prepare families in the moment are; "When Hello Means Goodbye" by Pat Schwiebert and "Empty Arms" by Sherokee Ilse. Then have staff go one step beyond just handing the book to the family to read. With the parent's permission, open it up with them and read the important parts...things they need to consider right now! (Then you can encourage the parents to read it over again by themselves.) The rest of the book can be used by the parents as their grief journey unfolds and/or once they are back at home.

If a language is spoken, other than English, try to have a caregiver who can speak their language or at least find someone to come in to interpret **accurately** all that needs to be said.

If possible, provide a bereaved patient with a private room. If this is not possible, then offer a private room on another floor. Help them to understand the pros and cons of choosing which floor/department mom will be in.

If the patient decides to move to another floor, make sure they are not ignored and receive the same high quality care as other parents on the maternity floor. Possibly having a Labor & Delivery Nurse check in on the bereaved family now and again...

Have the room and patient's chart flagged in a sensitive way that lets all staff members know that this family's baby has died.

Let the patients know that they can have a "Peer Support Parent" come in (this is a bereaved parent that has integrated their grief into their life and can now provide guidance to newly bereaved parents prior to their loss, during and afterwards.) Other options for support are Perinatal Loss Doulas, Midwives, Perinatal Hospice, a Bereavement Counselor, Social Worker, Chaplain or Specially Trained Nurse to come in **immediately** to help them with this emotionally devastating loss. This includes prior to the baby's death and afterwards too.

Limit **sedative** use for bereaved patients (or don't use them at all...if it's truly not necessary.) Sedatives can interfere with crucial decision making, which may lead to regrets later on by the parents. It can also cloud the memory of mom's one-and-only time with her baby (a regret that has been reported by many bereaved mothers.) And sedatives can also stall the grieving process...

Highly encourage parents to name, hold, bathe, apply scented lotion, diaper, dress, touch, smell, rock, sing to, talk to and kiss their baby who has died. This offer to hold and touch their baby should remain open for the entire time that they are in the hospital (although the parents do need to be informed about how their baby's body will change over time.) It is important to explain to the parents 'WHY' do these things, since they probably never thought about this in their life. They should be encouraged to say, "Hello" before they are rushed to say, "Goodbye."

Personalize the parent's loss by referring to their baby by his or her given name. If the parents have not yet named their baby, ask if they have a nickname they have been using. **Do** encourage the parents to **highly** consider naming their baby...since this will help make their child, who has died, more real to everyone (validating his or her life) especially to relatives and friends who might not know how to respond to this tragedy.

Relatives and friends might think such things as; "Is it a person who has died? Or more like a surgery to remove a tumor...basically, something that the parents will be getting over quickly??" Of course, the baby who has passed away is a cherished & loved family member. And unless relatives & friends have seen the baby this time after the baby is gone can get confusing. Society does not generally get trained in how to support parents who have had a baby die...

Before the parents see and hold their baby for the first time, staff should describe the baby's body temperature and condition in realistic, but not overly negative words (even when the baby's condition is poor.)

If a parent is too afraid to hold their baby, staff should offer (and model for the parents) their help in showing them how to handle their baby's body. Many bereaved parents from the past have let it be known that they found the courage to hold their deceased baby simply by seeing others holding and snuggling their child. Besides guiding the parents to hold their baby, also help them to examine his or her body (the nose, the toes, the eye color, the fingers and the baby's backside... maybe even uncovering these parts one at a time. Ask whose toes or nose their baby has; Dad's? Grandma's?)

Offer the parents the option to bathe and dress their baby in a special, handpicked, outfit (assisted or unassisted by staff.) If the parents do not want to do the bathing themselves, then offer them the option to watch their baby being bathed and dressed by either medical & nursing staff or by another family member. Explain to the family that bereaved parents from the past have taught the medical community that caring for their baby in this manner can be very comforting and healing. It is a chance for the parents to create a special forever memory with their child. Bathing and caring for their baby's body is a form of parenting their child...even though their baby has died. Also, getting many pictures and a video keepsake of this beautiful parenting ritual can bring much healing & comfort to the families after their baby is gone.

With the parent's permission, encourage the presence of friends and family members (including their other children) to see their baby. **Not just the parents...** 

Offer each family member time (individually) **alone** with their baby to say their private goodbyes. Having alone time can allow people to truly express what they need & wish to express...without having to worry about what other people might be thinking or feeling about what is being said.

Even when the family says that they are done saying their final goodbyes, **gently** offer the parents the option to take more time (and let them know that this has been known to be one of the **major regrets** of bereaved parents...**not having spent more time.**) If you share this fact with the newly parents, they just might spend that extra time with their baby and help cut down on regrets.

If the parents insist that they are done saying their goodbyes accept this request, but remind the family that they can change their minds and have their baby brought back later. Let them know that many parents have changed their minds and have had their baby's brought back to them. You might also pass on to the family that some parents have even decided to keep their baby with them in their room the entire time that they are at the hospital. If they choose this option, do prepare the parents for what changes they can expect to see in their baby's body.

Medical & nursing staff should share their feelings with the parents openly. Parents have expressed that they appreciated it **tremendously** when staff showed their emotions and even cried. This shows the parents that their baby's lives had an impact on others as well as their own. It validates their baby's life as being an important one...

**Strongly** inform the newly bereaved parents that past grieving parents have expressed that gathering mementoes of their baby can be a very healing and beautiful thing to do. **Verbally** explain to the parents that **it isn't morbid**; it actually is a way to honor their child's short life. It is a tangible/visible way to keep their baby's **memory** alive (proof of their child's cherished existence.)

Inform newly bereaved parents that; "We know of no parent who has ever regretted spending time with their baby or taking & keeping mementoes of their child...but an OVERWHELMING number of families have regretted NOT haven taken any." This can be a very powerful statement for parents to hear, who are in shock and confused as to what is 'ok' or 'not ok' to do.

Keepsakes help tremendously with the grieving process; they can provide much comfort to the families in the days to come. They even provide validation that their child even existed (which is very, very important to a lot of bereaved parents.) Caregivers might want to share this fact with the parents who are not sure if they want any keepsakes at all...it might make all the difference in the world!

Keepsakes can include, but are not limited to the following: memory boxes, memory books, perinatal loss pamphlets & books, ultrasound pictures, hospital certificates, **many pictures** of their precious baby after being born, **ink** (feet & hand prints,) **clay** (feet & hand prints,) hospital bracelets, the soap & lotion that was applied to their baby, toys that were intended for their baby, meaningful jewelry, a cross, tape measure, traced outline of baby on paper, special blanket & clothing worn by their baby (and yes, with the baby's blood still left on it,) meaningful music, a video of the time spent with their baby, scented oils that were used on their baby, condolence cards (signed by all of the caregivers,) a lock of hair and a crib card (with their baby's name, date of birth, weight and measurements.)

Be mindful/respectful of **cultural and religious differences** in grieving and taking keepsakes. For example, not all cultures would allow such things as taking pictures of deceased family members. Offer the pictures & keepsakes to **all** bereaved parents, explain **'WHY'** they might consider doing these things, what it has meant to past bereaved parents...but do respect their wishes if they say their culture or religion does not allow it.

Offer to take pictures of the **entire family (including siblings)** and **individual pictures** with their baby. These pictures will likely be all they have for the rest of their lives and can provide much healing. Advise the parents that even though it may feel uncomfortable or somehow inappropriate to take pictures of their deceased baby, grieving parents from the past have said that **pictures** are one of the **top most cherished keepsakes** that they had after their baby was gone. Help normalize this process of taking pictures to the bereaved families. It's ok to take pictures, it's a healthy thing to do and it's normal.

Remind the parents this is a loved baby/family member who happens to have died – still loved who will need to be remembered. **Pictures** will help that over time. **Take many pictures**, clothed, unclothed, being held by mom, dad, with siblings, relatives, friends, caregivers, clergy and family group photographs as well. You can also include pictures of their baby being bathed, dressed, kissed & caressed, rocked, sang to, during ceremonies & rituals and with items of special meaning next to their baby (the parent's wedding rings, a cross, a stuffed animal etc...) With digital options so available now there is no film cost and no disadvantage to taking literally hundreds of pictures.

Advise the parents that these are special pictures; they don't have to necessarily look at the camera and pose. Just have the parents surround their baby with love, hugs, kisses etc. and let the photographer capture the memory/moment.

If there are twins or higher multiples be sure to take pictures of them all together, especially if some live and some have died. It can warm a parent's heart to see the siblings snuggled together...just like they were in the womb.

Besides staff doing digital pictures with the hospital camera, highly recommend that the family do pictures with their own camera and possibly even a **video** camera (so they can better remember their time spent with their baby and hear what's being said.) Include close up shots of their baby's face, full body shots, nude shots from all angles (backside included,) they might even consider doing some pictures in black & white.

If the family is not up to taking their own pictures, staff can offer to use the patient's camera for them. Or they can have other relatives and/or friends to take the pictures...

Special items, such as a toy or stuffed animal, can be placed next to their baby in the picture. This can remind parents later on the actual size their baby was when born.

With the parent's permission, **and as soon as possible**, staff should call a professional hospital photographer and/or a professional photography company in to take pictures of their baby ...and the baby with the family members. "**Now I Lay Me Down to Sleep**" is one such wonderful organization.

Inform parents that the nationwide non-profit organization, "Now I Lay Me Down To Sleep," offers FREE Infant Remembrance Photography. Their website has a section that lists which photographers in their city would come to do such special photography. The website address is: <a href="https://www.nowilaymedowntosleep.org">www.nowilaymedowntosleep.org</a> (If the parents do agree to have N.I.L.M.D.T.S. come to the hospital, inform all staff that the volunteer photographer 'is' to be allowed into the family's room to take pictures ASAP!) Timing is crucial on getting quality pictures!

If the family does **not** take the pictures of their baby home with them, it is very important that before the family is discharged from the hospital that the staff gets current phone numbers, email addresses and mailing addresses of the bereaved family. This will ensure that the pictures will make it to the parents without any problem.

Approximately one month after the birth, contact the family to let them know that their pictures are available if they chose **not** to take the pictures with them when they left the hospital (right after birth some families say they don't want pictures, but frequently then change their minds once at home.) By calling the families one month (or later) after birth this gives them extra time to decide if they want their baby's remembrance pictures or not. If the parents, once again, choose **not** to get the pictures let them know how long the hospital will store them for...should they change their minds and decide they want them after all.

Offer Naming & Blessing Ceremonies, Baptisms, Kaddish or other rituals to the parents. If a family chooses to have no ceremony, honor their decision (however, share with the parents what these rituals have meant to past bereaved families and how it helped in their grieving processes.)

If the cause of death is known, offer families a detailed **verbal and written report** (using layman's terms...no medical jargon) concerning the cause of their baby's death.

Otherwise, if the cause of death is **not** known, offer an **autopsy or pathology exam** to be done on their baby. Do explain how long it will take to get the results back since this becomes a worry to bereaved parents and seems forever...especially if they have not been forewarned.

An organization called "Bereavement Services – Resolve Through Sharing" has a very good autopsy brochure to give the parents to teach them why consider having an autopsy on their baby. <a href="http://bereavementservices.org/index.asp?pageID=products&CompID=44&action=ViewProduct&ProductID=5469&CategoryID=372">http://bereavementservices.org/index.asp?pageID=products&CompID=44&action=ViewProduct&ProductID=5469&CategoryID=372</a>

Let parents know about their rights in getting a **birth certificate** (or **stillborn certificate**) and a **death certificate**.

Provide **complete verbal and written** information on **burial** and **cremation** options for the parents. Let the newly bereaved families know what other bereaved parents have done in the past when their babies died. Share the **Pros** & **Cons** of each choice (which can be learned from past bereaved parents and funeral directors.) Make sure to let the families know how long they have to decide, so that the parents don't feel rushed into a decision that they may regret later on.

Even though the following offer may be shocking to some...medical & nursing staff **can** sensitively offer the parents **the right to take their baby home with them** (funeral homes can help implement this option.)

# Reasons behind this offer to take their baby home are many, but here are just a few examples of why some parents may choose to do this:

- **A)** The families **(including siblings)** can spend time and make memories with their child in private...and not feel rushed into saying goodbye in a hospital environment with strangers around.
- **B)** The parents can show their baby around their house/rock their baby/sing to their baby/cry in private, etc.
- C) Talk to their baby about how much they are loved and what they had wished for him or her.
- **D)** Have pictures taken with the baby in their own home with family members & close friends.
- **E)** The bereaved parents can have an in home memorial service with their baby present. This would allow parents to do something special for their child and would make the loss more real for friends, relatives and co-workers (by them actually getting to see the baby it makes the loss more real. This is truly a family member that has died.)

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If the parents chose not to take their baby home, verbally prepare the families for physically & mentally **leaving the hospital without their baby**. Inform them that their reactions and what they are feeling are completely normal. Also, advise them on how their baby will be cared for after they have gone home from the hospital...as this is a big concern for a lot of parents.

Remember to go over 'thoroughly' with the parents & extended family members all of the resources that are in their grief package. Pointing out baby loss grief books & opening it up with them, support group information (in their community...as well as online) It is important to provide grief resource information (both verbally and in writing) because each bereaved parent absorbs information in very different ways from each other (such as, seeing, hearing, reading, etc.)

If the option of acquiring a "Peer Support Parent" wasn't offered by Medical & Nursing Staff to the newly bereaved parents (or wasn't accepted by the parents) prior to delivery or afterwards let the family know that they can connect them with one now that they are leaving the hospital. A "Peer Support Parent" can provide 'one on one' emotional support, a listening ear, coping suggestions, resources and hope to the parents when they get back home. Helping to guide the families in the intense grieving months yet to come. "First Candle," "Healing From The Start," "SHARE," and "Babies Remembered" are a few such resources that can connect newly bereaved families with volunteer Peer Support Parents.

#### Here are their links:

<sup>&</sup>quot;First Candle" - http://www.firstcandle.org/contactus/contactus.html

<sup>&</sup>quot;Healing From The Start" - http://healingfromthestart.com/support-for-bereaved-parents

<sup>&</sup>quot;SHARE" - http://www.nationalshare.org/parents.html

<sup>&</sup>quot;Babies Remembered & Wintergreen Press" - http://www.wintergreenpress.com/

HIPPA LAW - With the parent's permission, staff can contact Perinatal Hospice, a Perinatal Loss Doula, a Peer Support Parent (and/or) a pregnancy & infant loss support group for the families. This is allowed under the HIPPA Law – the key is to get the parent's permission on a consent form and keep it in their file...in case there is ever a question in the future.

Make **follow up calls** and send (**condolence**/'how are you holding up?') notes to the parents after they are discharged from the hospital. Also, important dates to remember the families on are their **due date**, approximately **4-6 months** after their loss and on the **one year** anniversary. Ideally, staff could also send a follow-up questionnaire (gentle, soft, inviting the parents to share what went well and what did not so they get to 'vent' and compliment. And medical & nursing staff can learn what needs to be improved, as well as what to feel proud about.)



### \*\*\*Closing Thoughts\*\*\*

Two of the most crucial things to keep in the forefront of one's mind...that caregiver's can do for newly bereaved families:

1. Slow things down and 'Openly Communicate'... with the parents all that is to be considered right now. As you are offering the families options for spending time and making memories with their precious baby, consistently check in with them on how they are feeling about these options. What are they thinking about? Why did they flinch when you offered them the option to hold their baby? Do they have any questions or concerns? Etc... This open dialogue will give the parents the freedom to express their fears, confront them and hopefully overcome them with your help. Generally, when newly bereaved parents see that their caregivers are comfortable openly talking about what's going on, they will more than likely mirror this openness. This could very possibly cut down on regrets that the parents may have had if they weren't given the opportunity to speak openly.

# -Healing From The Start\*\*\*Closing Thoughts - continued\*\*\*

2. Convey to the bereaved parents the 'WHY's' & HOW's... Explaining 'WHY' you are offering them the option to spend time and make memories with their baby who has died or will die soon. Explain to them what other bereaved parents have done in the past. What was helpful to them...what was not. What are some consistent regrets bereaved parents have shared with staff (such as not spending enough time with their baby or wishing they had MORE pictures & keepsakes of their baby, etc...)

Then go on to explain 'HOW' this can be caringly done (with the support of the Staff...with the support Peer Support Parents...Perinatal Loss Doulas...Volunteer Remembrance Photographers, etc...) Caregivers need to also make sure that they give an explanation of what they are doing & why (every step of the way) during the memory making process. The state of mind of most newly bereaved parents is that of pain and mass confusion. The parents can be offered a whole list of things to do with their baby (hold, name, kiss, take pictures etc.,) but if no explanation of 'why' do these things goes along with these offers, then many parents might 'not' choose to make these once in a lifetime memories...and there is not going back in time. If the WHY'S and HOW'S are not conveyed to the parents effectively & compassionately by the caregivers, the result could be huge regrets by the parents and a stalled grieving process that otherwise could have been avoided (or at the very least lessened if explanations were given.)

Knowledge can be very empowering to the parents! The more they know, the more in control they might feel during such an out of control and horrific time in their lives...

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<u>'Try' not to be offended by emotional outbursts from distraught parents</u> – Remind yourself, that it's not really you that they are upset with. They are angry that their baby has died and they understandably want their baby back!

<u>Do not be afraid of tears and emotions</u> - By not being afraid of and by viewing emotions & tears as completely healthy (yours and the bereaved families) you can be an extremely effective part of the parent's emotional healing process.

Do not let feeling uncomfortable or awkward around the bereaved parents to 'stop you' from communicating with them openly. Accept 'feeling uncomfortable' as being completely normal, a part of the process and do it anyways!! - You have so much to offer, give the bereaved parents your very best and feel proud of yourself for having made a profound difference for someone else during their darkest moments. Keep in mind...the more you learn from past bereaved parents, the more time you take to train on Perinatal Bereavement Care, the more empowered you will feel in doing this very sensitive part of your job. Empower yourself and you will not only be more effective, but you also just might feel less uncomfortable and less awkward (if in fact you are feeling this way at all...every caregiver is different in their comfort level. And however you are feeling as a caregiver...it's all okay.)

Consider this...someday YOU will be a griever (not necessarily from having had a baby die though.) It's not a matter of if you will ever be a griever.....it's when! Wouldn't you want an above and beyond grief caregiver to give you their very best in order to support you fully in your moment of tremendous need? Take a minute to really ponder the above statement. And choose to give of yourself to newly bereaved parents in the same compassionate way that you would want for yourself...or someone else you love dearly if they had someone die (or is going to die.) Truly think about it...

#### **Summary - Medical & Nursing Staff Check List:**

- When possible, provide bereaved patients/parents with a private room. Please don't ignore or avoid them.
- Tell the family; "I am so very sorry for your loss, we are here to support you...."
- Flag the patient's room and chart that their baby has died so that all staff is aware.
- If a language is spoken, other than English, try to have a caregiver who can speak their language (if not bring in an accurate interpreter.)
- Offer books and supportive written materials to the families especially those books that provide guidance about how to make good decisions immediately! (Suggestions are: "Empty Arms" by bereaved parent Sherokee Ilse or "When Hello Means Goodbye" by Nurse Pat Schwiebert.)
- Don't just hand a closed book, such as Empty Arms, to the parents. Instead offer
  to read a small portion with them on the immediate decisions that have to be
  made now! This will help them to take the first step of opening up such a book.
  You can also have a relative read to them during the quiet moments to help them
  prepare for what is to come.
- Make the parents aware that they can have a Peer Support Parent, Perinatal Loss Doula or Midwife, Perinatal Bereavement Counselor, Social Worker, Chaplain or Specially Trained Nurse come to assist them before and after the death of their baby. Offer to call for them.
- Limit sedative use for patients. This interferes with decision making and grieving.
- **Highly** encourage the parents to name, hold, touch, smell, talk to and kiss their baby (explain to the families 'WHY' consider doing these things and 'HOW.')
- Let the families know that we know of no parent who has ever regretted naming, holding, touching, kissing, taking pictures and having keepsakes of their baby, but an OVERWHELMING amount have shown huge regrets of <u>not</u> having done these things.
- Describe the baby's body temperature and condition before letting the parents see
   & hold their baby. Don't be overly negative in your description though.
- Refer to their baby by his or her given name.
- Extend the offer to check their baby's eye color (if possible.)
- Assist the parents in holding their baby's body (with the parent's permission.)
- Offer the parents the option to bathe, diaper and dress their baby in a special outfit.
- With the parent's permission, encourage all family members to see & hold their baby.
- Offer each family member alone time with the baby.
- Share your feelings openly with the parents. This validates their loss.
- Don't be afraid of tears and heightened emotions (the parents or your own) it is completely healthy and vital to the grieving/healing process.
- Offer to take pictures of their baby (alone and with family members.) Close up shots. Nude shots. All angles (including backside.)

### **Summary Continued:**

- Explain to the parents 'WHY' consider taking pictures, videos and gathering keepsakes of their baby.
- Let the parents know that having keepsakes of their baby can be a way of honoring his or her life and has been known to give great comfort to parents later on. It is <u>not</u> a morbid or wrong thing to do.
- Encourage parents to use their own camera as well as a video camera. (Pictures
  have been proven to be highly cherished by bereaved parents in the
  coming days...when the severity of their grief starts to lift somewhat,
  keepsakes can provide much comfort & validation of their child's life.)
- Let the parents know if the hospital will do professional photography and how they go about getting these pictures.
- Inform parents about FREE professional remembrance photography offered by the non-profit organization called "Now I Lay Me Down to Sleep." (Offer to call for them if they are not up to calling themselves.)
   www.nowilaymedowntosleep.org
- If possible, offer the parents a memory box for them to put their baby's keepsakes in.
- Ask the parents if they would like to have soft, soothing music playing in the room while they spend time and make memories with their baby (It is completely a personal preference, but it can be a healing thing to do.)
- · Honor Cultural & Religious preferences.
- If possible, do both (ink & clay) feet and handprints.
- Offer to get a lock of their baby's hair as a keepsake.
- Put the baby's crib cards, comb, diapers, tape measure, baby's weight & measurements in the memory box.
- Put the baby's hospital bracelet, blanket, hat & special outfit worn (or intended for their baby to wear) in the memory box.
- Offer Naming & Blessing Ceremonies, Baptisms, Kaddish or other rituals to the parents (which can be videotaped as well.)
- If cause of death is known, offer a detailed verbal and written report to the parents (using clear layman's terms.)
- If cause of death is **not** known, offer an autopsy or pathology exam to be done on their baby. Consider giving them "Bereavement Services" very sensitive & informative autopsy brochure:
  - http://bereavementservices.org/index.asp?pageID=products&CompID=44&action=ViewProduct&ProductID=5469&CategoryID=372
- Let parents know about birth certificates, stillborn certificates and death certificates.
- Inform the parents of their right to take their baby home for quality (hello/goodbye) time in a non-rushed home environment and to possibly have a memorial service etc... (Funeral homes can help accommodate such wishes.)

### **Summary Conclusion:**

- Provide (verbally & in writing) detailed information on burial and cremation options. Let the parents know what past bereaved parents have done. How long they have to make their decision, so that they don't rush into anything.
- Prepare the families emotionally on what to expect when leaving the hospital.
- Advise the parents on how their baby will be compassionately cared for after they
  leave the hospital (also, let the parents know if they can have a funeral director
  come to directly to pick up their baby...so their baby won't have to stay in the
  hospital morgue.)
- With the parent's permission, call a "Peer Support Parent" (Peer Support Parents can provide guidance to newly bereaved parents before delivery, during delivery and/or afterwards as well.)
- Inform the parents (verbally and in writing) of pregnancy & infant loss support
  groups in their area, as well as online. You can even call for them if they are
  interested in this option, but just not up to calling for themselves.
- Make a follow up call to the parents after they are discharged from the hospital.
- Send timely condolence notes to the family (due date, 6 months & 1 year.)
- If the hospital offers an annual memorial service to bereaved parents, inform them when it will be and how they will be notified.
- Most Important: Openly communicate with the bereaved parents every step of the way & Explain 'WHY' you are offering and doing what you are doing. And then gently move on to the 'HOW TO's...
- Even though this is an extremely heartbreaking time for the bereaved parents and staff, it can also be a cherished, loving and healing time spent with their baby (with the proper compassionate encouragement of medical and nursing staff.)



# "Why Make Memories?" By Lori Martini

"Why am I offering my patients the option to make memories with their baby who has died?"

What should I say when a bereaved parent asks me; "WHY are you suggesting that I spend time with, make memories and take mementoes of my baby who has died?" Or when the parents just aren't saying anything at all...

Yes, what does a medical staff member say to a newly bereaved parent when they need to explain the "WHY" and the "HOW?"

Logically, if medical and nursing staff don't truly understand some of the reasons behind the "why" (and also the major healing benefits behind spending time with the deceased baby) then how could they possibly be expected to ever convey "effectively" the reasons to a newly bereaved parent...who is more than likely in shock, not thinking clearly and very much needs someone to competently & compassionately assist them in spending time with their baby (and in making important life-changing decisions.)

If any medical or nursing staff member that is taking care of a newly bereaved family has never personally experienced having had their baby die, then it can be "very" difficult to truly understand the "whys." Especially in the actual moment of the loss when the mood is quite intense and could feel very disturbing and uncomfortable to all involved.

\*\*\*\*\*

Below you will find just a 'brief' sampling of what some of the reasons could be...which hopefully will allow for a little more understanding Do take the time to continually learn what other reasons might be...there is definitely something to be learned from every bereaved parent who has experienced the death of a baby (their grief journeys are all truly unique and very enlightening.)

Why Read to the Parents the "Important Parts" of a Perinatal Loss Book (Such As "Empty Arms" by Sherokee Ilse?)

If the bereaved parents could read "the important parts" of a perinatal loss book or have it be read to them by a staff member, friend or a relative (that is, if they are not up to reading it themselves right now.) Then the family could learn immediately about what other bereaved parents have done when their babies had died. This could cut down on major regrets and give the parents a sense of control during this very traumatic time. Learning about what they need to know immediately can also add to the parent's **confidence level** in proceeding to spend precious time with their baby and collecting keepsakes (just by simply knowing that other bereaved parents have done such things, can let them know that it is **okay and normal** for them to do it too.) In addition, this kind of a book can **validate** that what they are feeling right now is normal, helps them to see that they are **not alone** in their loss, as well as, providing them **resources** for getting support in the days to come. Finally, it can help inform the parents of their **options** and **rights** in regards to their baby...something they never thought they would have to learn about, but who very much need to know now.

#### Call in a "Peer Support Parent" (a Perinatal Loss Doula or Perinatal Hospice Person:)

A recent study has shown that the majority of newly bereaved parents said that they wish that in the moment of their loss that they were offered to have a past bereaved parent (who has integrated their grief into their lives) come to help support them. Prior to birth, during and once at home. And with **Waiver Forms** for the newly bereaved parents to sign, OB/GYN offices and hospitals can now open their doors to this option without fear of liabilities. A "**Peer Support Parent**" is not there to make decisions for the parents. They are there to provide a listening ear, a shoulder to cry on, to help guide the parents in making memories with their baby, explain **why** consider doing such things, be an advocate to help carry out the parent's wishes, offer bereavement resources and to inspire hope (...for they are an immediate example that one **can survive** and go on to **thrive** after such a horrific loss.) Having a **Peer Support Parent** at the hospital can also help support staff in this very difficult, but rewarding, part of their job (a job of providing compassionate & competent grief care.) **Perinatal Loss Doulas & Hospice** can provide similar services...without having necessarily experienced the loss of a baby.

#### Naming Baby:

This is a family member who has died (**not a medical non-event.**) Naming a baby not only honors their precious life, but it also validates their life (people have names...whether they are still living or not, people have names.) However short their life...they still matter!

#### **Take Many Pictures and Videos of Their Baby:**

Memories fade over time...and by having pictures (and perhaps even videos of baby) these can provide the parents a very comforting visual reminder for them to cherish always. Pictures and videos enable the parents to keep their baby's memory alive; it is proof to the outside world of their child's existence and also allows them to remember the **true**, **specific details** of their baby's features (Mom's hair color? Dad's fingers? Grandmom's nose? Etc...) And if they choose to do a video as well, they will also be able to **hear** what's being said by themselves and others during their precious moments with their baby.

#### Why Put Special Items Next to Their Baby in The Remembrance Pictures:

By adding the parent's wedding rings, a cherished cross or a special toy that was intended for their baby, etc. it can add special meaning to the picture once their baby is gone. By having these special items next to their baby, it can personalize the picture, the families can see & remember the true size their baby was, and allow for added healing by providing the parents the opportunity to forever see and hold the same object that was next to their baby in the photo taken.

#### Take Pictures with Multiple Babies Together (Especially When Some Have Died):

It can warm a parent's heart to be able to see the siblings that were bonded in the womb, to be forever portrayed in a picture together. And when the surviving sibling gets older it can allow them to see what their sister or brother looked like (which has been reported to be quite healing for the sibling as well.)

What's the Urgency in Getting a Professional Photographer to Take Pictures Right Away? The harsh reality is that when a baby is stillborn, or has died shortly after birth, the baby's skin coloring can change very rapidly. It **must be** a priority to get pictures done, as soon as possible, in order to create the highest quality pictures for the parents to cherish (and heal from...)

#### Hold, Touch, Smell, Caress & Kiss:

Holding their baby can be very healing. It creates a forever 'touch' memory of time spent with their child. It's their "one and only" chance to do what any parent would normally do with a baby who had lived. Really see what features on their baby resembles the Mom, Dad, siblings and Grandparents etc... As well as, it's a time to bond with and get to know their baby's body (bonding has been shown to be more healing to the grief process than avoiding the bond.)

#### Talking & Singing To:

Can be a time to express thoughts & feelings to their baby. Parents can tell their baby that they are loved, what they had wished for their baby, their pain, their hopes, introduce family & friends to them...and sing lullabies or songs that they had always envisioned being able to sing to their baby, if they were to have survived.

#### **Bathe, Diaper and Dress:**

This is a time to parent their baby and create a lasting memory. It's not pretending that their child is alive; it's simply a way to spend precious one-on-one time caring for their baby. If the parents had picked out a special outfit for their baby, prior to knowing that he or she had died, they can still dress baby in the same outfit or have a relative go get a new, handpicked, outfit for their baby to wear. Making decisions and choosing options for their baby is still a form of parenting their child, even though the baby is not living. After bathing their baby, the family can use a scented oil or lotion to put on baby (or on the baby's blanket, if the skin is too fragile.) Bathing, diapering and applying lotion is another way for the parents to be able to explore their baby's body. And with the left over lotion or oil, the family can bring it home with them, which they can smell later on to remind them of their special time with their child...creating a 'scent' memory or bond. It can be a very loving, comforting memory.....

#### **Rocking Baby:**

Rocking their baby is a very soothing movement and loving thing to do (it can create a comforting feeling within the parents.) It is yet another parenting memory for them to look back on lovingly when the pain is not quite so intense in the future.

#### **Have Music Playing While Making Memories:**

Many families have reported that when they spent time with their baby who died, the room was overwhelmingly quite, which added to it feeling somehow disturbing and wrong to spend time with their baby. Gentle music playing in the room, while a family is spending precious moments with their baby, has been reported to add to the quality and peacefulness of spending time with their baby. One family said they even chose to bring in a few gospel singers from their church...which they expressed brought them much comfort & peace.

#### Why Call in a Professional Counselor:

A counselor that "specializes" in perinatal bereavement issues can provide very helpful professional support. It is highly recommended to find a counselor with the specific experience of having supported many bereaved parents after the loss of a baby. A counselor who **does not** have this background might not be able to provide as sensitive emotional care.

#### Call in a Clergy Person:

A clergy person may perform religious ceremonies/blessings/rituals and services that can provide great comfort to families. **Even if someone is not religious**, having a clergy person do a non-religious service can validate (even further) the reality that this was a precious life that has ended. No matter how small the baby is, they still are a person who died and needs to be honored in some meaningful way to the family.

#### Limit Sedative Use...or do away with it all together:

Sedatives can interfere with decision making and **cloud a bereaved person's judgment & memory.** If altered by drugs, the bereaved parent might make decisions that they otherwise would **not** have made. And they may not be able to fully remember the beautiful details of their time spent with their child (and might have major regrets later on because of this.) Sedatives can also stall the grieving process...

#### **Recommend Their Other Children Spend Time With Their Deceased Sibling:**

Never force a child to be a part of spending time with their deceased sibling, but offering this option is highly recommended for many reasons. It will allow the sibling to feel included in the family, it cuts down on the confusion level of the child by being involved, helps with their own grieving to be surrounded by those they love & trust...and makes the loss more real for them. As well as, allowing them to truly understand that it was not their fault in any way (younger children sometimes come to this conclusion falsely.)

#### Invite The Parent's Family & Friends To See Their Baby:

When newly bereaved parents are surrounded by family & friends, this could help them to feel more supported in their loss. Also, by family & friends being allowed to actually see the parents baby this can make the loss more "real" for them too. They will then be able to see with their own eyes that this is a family member that has died. Sometimes, because the bereaved parent's friends & family have not actually seen the baby, it is very easy for them to view this as an unfortunate event and not like a cherished loved one who has died. When viewed as a "medical non-event", friends and family can't possibly fully support the bereaved family properly during the vital up and coming months of intense grieving. Seeing is believing, for a lot of people...

#### Have a Ceremony/Funeral/Memorial Service:

This gives the bereaved parents an opportunity to **publically** parent their baby. A chance to do something special & meaningful for their baby, to be surrounded and supported by family & friends, as well as creating a 'new' memory of honoring the very real life of their baby that has ended too soon.

#### **Creating Mementoes and Keepsakes:**

This helps the parents to keep the memory of their baby alive. Allowing them to feel forever connected to their baby once he or she is gone. For example, having a lock of their baby's hair enables the parents to remember exactly what color hair their baby had, to have ink prints would remind the parents of the true size of their baby's feet & hands. And by creating clay impressions of their baby's hands & feet this would enable the parents to run their fingers over them, which has been reported by past bereaved parents to "almost" feel like they can still touch their baby.

# Offer an Autopsy and Pathology Exam - Then Explain the Findings Clearly and Thoroughly With Parents:

Bereaved parents usually want to get an answer as to why this happened to their baby. Was it a developmental problem? Was there a disease or infection of some sort? And finding out the "why" could allow the parents to get a better idea of what the chances might be of this happening to them again in a future pregnancy.

"Bereavement Services – RTS" has a very compassionate, sensitive and informative perinatal Autopsy Brochure that can be given to the parents to help them decide:

http://bereavementservices.org/index.asp?pageID=products&CompID=44&action=ViewProduct&Product&ProductID=5469&CategoryID=372

#### Offer Birth, Stillbirth and Death Certificate:

This legally **validates their baby's existence**. It is written proof to the entire world, as well as to themselves, that they are parents of their much loved baby that happens to of died...and always will be. This written proof is just one more way of helping the family move forward in their grief journey.

#### Why Stay on the Maternity Floor?

To receive compassionate care from nurses that are very familiar with the needs of a woman after birth...especially after the loss of a baby. Some mothers, who have just had a baby die, actually demand to stay on the maternity floor. Their feelings are that **they are still mothers** (which they very much are) who have just given birth, just like all the other women on the maternity floor. The only difference is that the other women get to keep their babies...

#### Move to a Different Floor?

Some bereaved mothers choose to move to a different floor, so that they can avoid seeing happy parents with their newborns. As well as to avoid hearing the sounds of babies crying.

Why Consider Taking Baby Home: A) The families can make memories with their child in private and not feel rushed into saying goodbye in a hospital environment. B) They can show their baby around their house/rock their baby/cry in private. C) Sing & Talk to their baby about what they had wished for them. D) Have pictures taken with the baby in their own home with family members. E) They can have a memorial service with their baby present- this would allow parents to publically do something special for their child. F) And a memorial service would make the loss more real for friends and relatives (by allowing them to actually see the beloved baby.) If it's seen as a 'real' loss (which it is) of a cherished family member, by relatives & friends, they tend to be more supportive to the grieving family in the tender days to come.

# Recommend a "Perinatal Loss Support Group" for the Bereaved Family to Go to After They Have Gone Back Home:

By parents attending a support group, this can allow them to really know that they are far from alone in this type of a loss (which can help them to feel less isolated throughout their entire grief journey.) The newly bereaved family can learn about what other bereaved parents have been feeling, experiencing, thinking about, how they are coping and moving forward in life. These compassionate groups can also give the parents a chance to get their feelings out in a safe/supportive environment, providing them with coping techniques, hope for the future, as well as, offering them other perinatal loss resources. Support groups can be of great comfort to the grieving parents.....by allowing them to simply be surrounded by others who "truly" know some of what they are going through.

#### \*\*\*Please note there are many, many more reasons "WHY"\*\*\*

Do consider taking the time to learn what they might be...so that you can **not only** be more empowered in your job, but you can also make a profound impact on the quality care and beginning grieving process that you are helping to implement for your bereaved patients.

Truly the more you understand the, "Why Make Memories" and the "How Tos," the better you will be at compassionately guiding the newly bereaved parents in their decision making process (these are decisions that the parents never thought in their wildest dreams that they would have to consider... and they very much need to be supported and sensitively educated at this shocking time. They truly need your help and guidance!!)

Fully explaining the "Whys" & "Hows" to the parents could help minimize their regrets of what they chose to do (or not do) with their baby...and, as we all know, there is no going back in time for "do-overs!"

By minimizing regrets, bereaved families tend to be able grieve in a healthier manner, integrate their loss more effectively and reinvest themselves in living...in honor of the love & forever bond they will always have with their baby who died.

From the bottom of our hearts, **we bereaved parents** (from the past, present & future) thank you for all that you do and all that you give of yourselves. You truly make an astounding difference during such a heartbreaking time in so many families' lives. It's very admirable, inspiring & heartwarming indeed! **Thank You...** 

"Dare to reach out your hand into the darkness, to pull another hand into the light." - Norman B. Rice



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-Help us to help grieving families and support the caregivers that serve them-

No bereaved family should have to endure alone this life changing trauma of having their child die (this includes prior to birth, during and afterwards.) And no caregiver should have to support a grieving family without the proper training and guidance.

Often, bereaved families, caregivers and friends of "Healing From The Start" who have received our help, coaching, resources and support materials want to know what they can do to help. Your generous donations can help us to continue our mission to reach out to others. Healing From The Start is currently 'not' a non-profit organization; it is funded through the kind donations of our supporters. Donations are accepted at: www.HealingFromTheStart.com securely online through PayPal.

Thank you for caring and helping us to make a profound difference in the lives of many broken hearts. Hearts that, with your help, will learn to thrive and once again have hope...

This document has been prepared in loving memory of Bryce Neily Martini (Full-Term & Stillborn on November 30, 2004 due to Placental Abruption)
"Forever a part of our Family, Forever our Son, Forever Loved"

Lori & Toby Martini

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