

"May I offer my care and presence unconditionally, knowing it may be met with gratitude, indifference, anger or anguish."

May I see my own limits with compassion, just as I view the suffering of others.

May I be present and let go of expectations

May I forgive myself for mistakes made and things left undone. "

- Cynda Rushton

Self-care and education is the starting point of good bereavement care. We encourage you to own what is difficult for you about perinatal bereavement work, seize the challenges that bereavement care presents, and look for ways to connect with co-workers about your own physical and emotional responses when you are faced with loss. It will not be enough to take three deep breaths or take a bubble bath when you get home—you may face experiences where it will be essential for you to talk to others so that you can share the pain and sadness you've witnessed and, that you yourself have experienced as a witness. It is our hope, here at Empty Arms, that an important first step to keeping yourself strong as a provider is a combination of feeling capable and feeling strong in your ability to offer yourself and your compassion to the families you serve.

In this course, we go over best practices, dive into *why* we do those things, and learn about what means the most to families. All of this is rooted in the stories of real families. We hope you will learn to help families to get what they will ultimately need to heal and grow after a loss. In the process, we honor that this experience will change you, too.

We want you to become more fluent in this socially awkward, medically dreaded situation. We want to inspire conversation and encourage expertise. Research has consistently shown that one of the antidotes to trauma is compassion. Thank you for joining us on this journey.

The 11 Tenets of Companioning the Bereaved by Alan Wolfelt, Ph.D The Center for Loss and Transition

- 1. Companioning is about being present to another person's pain; it is not about taking away the pain
- 2. Companioning is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.
- 3. Companioning is about honoring the spirit; it is not about focusing on the intellect.
- 4. Companioning is about listening with the heart; it is not about analyzing with the head.
- 5. Companioning is about bearing witness to the struggle of others; it is not about judging or directing these struggles.
- 6. Companioning is about walking alongside; it is not about leading or being led.
- 7. Companioning means discovering the gifts of sacred silence; it does not mean filling up every moment with words.
- 8. Companioning is about being still; it is not about frantic movement forward.
- 9. Companioning is about respecting disorder and confusion; it is not about imposing order and logic.
- 10. Companioning is about learning from others; it is not about teaching them.
- 11. Companioning is about curiosity; it is not about expertise.

Quick Tips for Interacting with Parents

- 1. Express that there are no words for something this difficult. First, say: I'm so sorry for what you're going through. Then stop and let those words sit. After a few minutes, say: I'm going to be here with you to support you in whatever way I can. I want you to know that I'm going to do my best, but I'm going to need your help. If there's something you want or need, please tell me and don't be afraid If there's something I'm doing that you don't like, please say so. I want to support you and be here for you in a way that feels safe and good to you.
- 2. Recenter yourself around caring for this FAMILY emotionally as well as caring for the patient's physical needs as you would with any birth. Remember that this is going to be predominantly a social-emotional experience for the parents no matter how the birth happens. **Offer thoughtful, intentional care to the family unit**.
- 3. Check yourself for any biases you may have and commit yourself to providing the best possible care for this patient and her family, no matter who they are, and no matter how you perceive them to be. *This is a time to be actively non-judgmental and exceedingly compassionate.*
- 4. If labor has not started, or the patient is early on, use this time to make statements about what families normally do. Don't say these all at once, rather, insert them into conversation at different moments in time so families are able to process their options:
 - 1. Most people spend time with their babies
 - 2. Most people photograph their babies
 - 3. Many people like to bathe or dress their baby.
 - 4. Most people appreciate being able to introduce their baby to family members, such as siblings, grandparents or to friends.

It's OK to say something like, "These things may sound strange to you right now, and you don't need to decide anything until after your baby is born. I just want you to be familiar with some of the things that other families have done that have brought them comfort"

- 5. The only thing that must be determined before birth is whether the parent will hold the baby immediately. I usually offer first:
 - 1. "When your baby is born, I can put her right into your arms, or if you'd feel more comfortable I can wrap her in a blanket and then bring her to you"
 - 2. ONLY IF parents refuse both of these offers do you open the option that baby can go elsewhere. If they indicate they do not want to see the baby, say, "Some people need some time to feel ready to meet their baby. We can take care of her for you until you feel ready". This leaves the option to see baby wide open while respecting their options.

- 6. When the baby is being born, honor this birthing person's parenthood: They are doing a very brave thing. Treat them like any other birthing person, with love and care and encouragement.
- 7. If you have reason to believe the baby's skin or appearance may be compromised, calmly prepare parents in a gentle, safe way before they meet. For example, "Because of the gestation, we can expect that her skin will be pretty translucent, and we often see some bruising and some small skin tears in these situations. I just want you to know that all of this is normal, and she will still be beautiful and perfect to us
- 8. When the family is together, make every effort to keep the baby in the parents' arms (**See** *instruction card for Cuddle Cot*). Many parents express deep regret for the time when they were not holding their child and could have been. Make sure parents are told that they should keep their baby wherever they feel most comfortable, and that there are no limits on their time together. We find it helpful to say something like, "Your time with your baby is whatever feels right to you. For some families, after a few hours they feel overwhelmed and are ready for a break, while for others they are snuggled up in bed together for days. Many people are somewhere in between. What is right for you is something you'll feel in your heart, and know that as your nurse I have no expectations—I just want you to do what feels right."
- 9. It is VERY important to establish the NORM of holding their baby and spending time together. Say things to reinforce their time together: She looks so beautiful in your arms, you are such beautiful parents to her. Remind them on multiple occasions that this time belongs to them: say, "I hope you will spend as much time with her as you can".
 - 1. If there is hesitation to see the baby, offer the option for one parent to see the baby in one room while the other parent stays in a separate room (if possible).
 - 2. If both parents decline to see the baby, DO NOT SEND THE BABY TO THE MORGUE. The baby should be kept ON THE FLOOR and the parents should be told, "We will keep your baby here on the floor as long as you are here, and we'll take care of you until you feel ready to meet her". You always want to leave the door open for them to change their mind. Every couple of hours, ask them if they have thought some more about the possibility of meeting their baby. If they continue to decline, you can say something like, "I do want you to know that I am hearing your answer, and I respect your right to say no. I'm revisiting this issue with you simply because I know this is your only opportunity to meet your daughter (or son), and I have seen parents start to feel differently over time. I want to make sure that you leave this hospital with no regrets"
- 10. Continue to offer any and all experiences and mementos available. For example:
 - 1. Offer a variety of clothing if parents don't have their own so they can **choose an outfit** and dress their baby
 - 2. Offer hand and foot casting with dental alginate and stone
 - 3. Offer hand and foot print molds
 - 4. Offer ink prints of hands and feet
 - 5. Take lots of photographs. If they have a cell phone encourage them to take photos, also ask if you can use their phone to take photos of the family together. Take hospital photos even if the family has taken their own photos. Families are ALWAYS delighted to find out there are more photos. You can be part of giving them one more memory of their baby.

- 6. Offer the family to help bathe the baby. It's nice for them to see their baby's hair clean and fluffy, so if you notice that baby is caked with vernix, make sure to help with that!
- 7. Cut a lock of hair if possible.
- 8. Clip fingernails and toenails and put clippings in a bag for them to keep
- 9. Make sure to give them blankets, diapers and washcloths that were used for their babyeven ones that are soiled
- 10. Talk through what religious ceremonies might be desired, if appropriate/desired call in clergy
- 1. When it's time, help the family determine how to say goodbye. What can help this awful moment feel somewhat easier? Some parents wish to say goodbye to their baby at the time of discharge, and they may wish to walk out leaving baby tucked in a bassinet, or in the arms of their nurse. Other parents might ask to have their baby taken before they leave. Knowing that all of these options are painful to imagine, help the family determine what feels right. Some things that have helped parents in the past have been:
 - 1. Putting baby in a new outfit at goodbye-time, so they can take the outfit baby was wearing during their time together straight home with them
 - 2. Wrapping baby up in Mom or Dad's t-shirt so baby will take some of them with her
 - 3. Writing a note and putting it with baby, which will travel with baby to morgue and funeral home.
 - 4. Anything else creative that can make a tie between baby and family

A few more tips for giving the best care possible...

- 1. Remember that all families, no matter what the circumstances, and no matter how many other children they may have, grieve deeply for their babies who have died. Even if the baby looks unattractive or even grotesque to you, it is very important for parents to see and hold their children. Your interactions with the parents and their baby have an enormous impact on their ability to bond with their baby, and then grieve. Even if it feels difficult, find a way to compliment the baby, or to point out something amazing about their body. Use the baby's name. Never assume that because it's difficult for you to see the baby, it will be difficult for the parents.
- 2. Never ask parents about their motions or actions prior to the birth. Innocent statements such as, "Did anything happen the day before he died that could have caused this?" or, "How long had it been since you'd felt movement" can feel accusatory and as if the parent has done something wrong.
- 3. Let parents decide who will be with them, and when you are in the room, if there is extended family there, address EVERYONE. Under such circumstances assume that anyone who is there is a treasured part of the support network. Thank them for being there to be with the parents and acknowledge that this baby meant something to them, too.
- 4. Remember that this situation is not "just as hard for everyone". Biologically, human bodies crave their babies and will mourn them similarly, but some families face external challenges such as poverty, past trauma, systemic racism, homelessness, lack of social support, and more. Each of these layers complicates the grief process. Everybody grieves, and grieves hard for their baby. Some people just have less time to do that.

5. *It's OK to make mistakes and not to be perfect at this.* Even if you've worked with dozens of people or even hundreds, each family is a new set of humans and will have different feelings and needs. If you listen really carefully and greet each patient with an open heart and a compassionate mind you are bound to do your best work.

A Crash Course in Caring for the Bereaved

By Carol McMurrich, Empty Arms Bereavement Support

For some of you, this will all be a review. For others, it will be something you grab and read to prepare yourself for what you think might be the worst night of your life.

But the thing is, if you take the time and do it right, you will change a family's life forever. This feels good. Being a caregiver for a family whose baby has died gives you a unique opportunity to develop a caring, empathetic relationship with the baby's parents. The tools that you are able to provide them with to make the most of the brief time they will have with their baby mean that instead of leaving the hospital completely empty handed, they leave with some memories and some mementos. Most parents, in their state of shock and confusion, would not think to do any of the things that have proven, over time, to be the most helpful experiences to give a grieving family. I urge you to think of yourself as a gift to a family. You can sit with a family, in their darkest moment, as they are paralyzed with shock, and guide them through a birth and beyond. You can help them to create something out of nothing, so that years later they can look back on the memory of a baby and feel love. This can happen, with your help.

In the past few decades, much research has been conducted internationally with similar results. Across borders and cultures, it has been found that the loss of a child results in more intense and prolonged grief than the grief associated with the loss of a spouse, parent or sibling (Stroebe and Schut, 2001). The parents in your care have a lot of work ahead of them. Some guidelines have been established which I will summarize here for you.

- 1. Establish a relationship with your patient. LEAD WITH THE LOSS. First, say, "I'm so sorry this is happening to you", and then STOP TALKING. This is the most important thing you can do. Avoid the urge to tack on "but" or "at least"..... Just let the tragedy be what it is, for the moment. Then, sit down with them. Make eye contact and let them know you will do everything you possibly can to support them on this journey. Hold their hand if they don't mind. Don't be afraid to shed a tear with them. These moments of seeing a care provider show emotion are over and over the most treasured memories that bereaved parents have. Talk to parents about what their baby meant to them. Remember that they are still parents with the same love in their hearts for their baby as those who deliver a live baby. Find out what they feel most afraid of. Become somebody they can trust. Do not be afraid of what you don't know. With each interaction, you can ask the family if what you're doing feels comfortable to them. When you are constantly explicit about your intention and desire to help in every way possible, it becomes much more difficult to "say the wrong thing". Establish yourself as an emotional support person, as well as one who will be keeping a close eye on the physical safety of the birthing person.
- 2. In the context of this relationship you are establishing, **begin the open ended conversations** with these stunned, in-shock parents about what they may or may not do when their baby is born. Do not fire out all of these at once. Carefully, over time, weave these statements/thoughts into your talk with them. I always start with just "weaving the norms" into conversation. I am really explicit—I say, "Most families, when faced with this sudden news, are completely overwhelmed by the thoughts of what might happen and what they should do. So, when I'm getting to know new families who are facing a loss, I always like to just offer some thoughts on what other families in the past have done, so that you know what others have found helpful. But you should know, as I'm talking to you, that for each family this journey is different, and you should choose the path that feels most comfortable to you."

Examples of such statements might be:

-Most people spend time with their baby after he or she is born. People are often surprised at how much they cherish holding and spending time their baby, even though before the birth this concept can seem strange.

(Then stop talking)

... then, later on, say: Tell me about how you feel about meeting your baby. You had probably imagined this moment a thousand times... but not like this. How is it feeling now?

-It's common for people to invite their families in to meet their baby. (Then stop talking)

..... then, later on, say: Have you thought about asking anybody to come to meet your baby?

-Many families find that their photographs of their babies are their most treasured mementos. (Then stop talking)

.... then, later on, say: How do you feel about having pictures taken of your baby?

- -You should know that you will never have to make any decisions right away. Your baby will always be available to you as long as you are here. You don't have to decide anything right now.
- -Wait until after birth to discuss the fact that families will have to "make arrangements" for their baby... i.e. decide whether they want to bury/cremate their baby and where. This is an awful topic to have to raise, and it almost always comes as a kind of shock to the family. I always end up apologizing profusely for having to talk about it, recognizing that what they REALLY want to do is bring that baby home to the nursery.

Let them know this is something that you will be talking about with them later.

With statements like these, you:

- -Establish some norms around what families usually do when a baby dies (although people can't/don't articulate this, everyone needs to know what is normal)
- -Get people talking a little bit so you can get a sense of what they are comfortable with and what your next steps might be
- -Begin the process of making them aware of all their options and the continued availability of their baby and option to change their mind at any time. Before their baby is born, many people will find many of these options to seem morbid or just too weird-- such as photography or inviting in their family. However, many parents will change their mind so making them aware of the fact that they are more than welcome to do so at any time is of the utmost importance.

3. The Labor and Delivery

a. If the parents have made it clear that they are comfortable seeing and holding their baby, proceed as if with any delivery. Providing the mother with a "real" birth gives her a memory to cherish. Follow a birth plan if she has one. Respect her wishes whenever possible. If the baby was meant to be given directly to the mother at birth, you can ask if she would still like this to happen.

-Something to keep in mind is the anticipated condition of the baby's body based on how long it has been since the baby has died. If the baby has been gone for more than a couple of days, it is important to prepare the parents gently that they may see some bruising, discoloration, or peeling skin. Most bereaved parents are able to overlook such things to see the beauty of their baby but they should be prepared for what they might see in a kind, gentle manner. Offering to clean/wrap the baby first is often a good option in such situations and YOU demonstrating that YOU are comfortable with the baby and see her beauty will help the parents to cope with their concerns in this area.

b. If the parents are still undecided about whether they would like to see or hold their baby, ask the parents if it is acceptable to them that the baby be taken across the room to be cleaned and swaddled by the nurse. If they agree, the baby can be wrapped and placed in the bassinet. You can then approach the parents, sit on the side of the bed, and say something like, "You have a beautiful baby girl. Can I bring her to meet her mom and dad?" This kind of personalization encourages bonding.

- c. If the parents are reluctant to see their baby, and upon revisiting this option still feel that they do not want to see the baby, after the baby is cleaned/wrapped the baby can be taken from the room and the parents told where the baby will be. It can be helpful for the parents to know that you (or somebody else) will be caring for their baby even if they feel it is too difficult for them to do.
 - i. The baby should always be dressed/transported in a respectful way. Do not let the parents see the bassinette draped with a blanket. Make sure baby is swaddled in a blanket and wearing a hat. No matter what the gestation, this is a baby, not a medical specimen.
- d. In situations b. and c. it is important for the providers to model their own comfort with handling the baby and to model compassion and love for the infant in the way they speak of the baby (by name, if appropriate) and handle the baby.
- e. If parents are still reluctant to see their baby, respect this. Each time you check in with parents, talk to them about how they are feeling. Sometimes modeling for them or demonstrating that you have seen their baby is helpful. Saying, I just want you to know that I've bathed your baby and dressed her in a white outfit and wrapped her in a blanket. This way even if they do not hold their baby themselves, they know their baby was treated with love and respect by you. This can help to alleviate some of the guilt that parents feel about not having done these things at the time of the birth. If parents do not wish to see their child, explain the hospital policy about taking photographs to be kept in a file in case parents change their mind. Then, take as many photographs as you can—hands, feet, face, etc. so that if/when the parents retrieve the photos you will have given them something to work with. You can also take hand/foot molds and collect any other mementos you can to keep with the photos for the situation where the family changes their mind.

4. When the parents are spending time with their baby, offer gentle, personal guidance.

-Normalize this experience by demonstrating your own comfort holding the baby (even if you don't feel comfortable, act comfortable!!) and by talking to the baby and about the baby as you would any newborn baby. Point out ways in which the baby resembles parents and find some things to compliment the baby on-- cute nose, adorable feet, etc.

-Guide the parents through their time with baby -- but not all these things in a bullet point list. *One thing at a time!* Give them time to think, be alone, and explore their baby. Revisit options over the duration of their hospital stay. Always make it known that the baby is available to them again even after they have said goodbye.

- -How about if I bring you some things so that you can bathe her?
- -Encourage the parents to take time to see their baby's whole body. Many parents have expressed regret that they did not take off baby's clothes or diapers. Of course, every parent of a living child knows every inch of their child's body and these parents should be no different. Giving parents this permission and encouraging them to take time alone with their baby to get to know him/her is really important.
- -Could we dress her? Either in clothes you brought or I could get you some to choose from? If the family does not have clothing, offer the family a wide range of options to choose from)
- -Do you have any traditions in your family that we could honor with (baby's name) while you're here? I know that has meant a lot to some other families I've worked with... Find out if baptism/naming ceremony/other religious tradition is desired
- -I want you to think about who was really hoping to meet (baby's name) and let's figure out if we can get them in to meet her today or tomorrow. Find out if there are friends and family they would like to bring in. Normalize this, and if they are hesitant, encourage... this is their only chance.
- -Be creative about an experience they might have with their baby. A meal from a favorite restaurant? Painting baby's toenails? Getting a guitar and playing her a song? If parents seem open, remember that the more experiences they have, the more they have to work with on the difficult grief journey ahead.

5. Before parents leave, make sure:

- -That somebody has discussed funeral/memorial services with them, and that they are clear on what their next steps are (put in writing if possible, as newly bereaved parents are rarely clear headed).
 - -That the family has all the support materials from the bereavement drawer.
- -That lactation has talked with the mother about what to do when her milk comes in. There is an Empty Arms brochure which goes over this. Read it and become familiar with what to tell the mother. This is a very traumatic experience for EVERY bereaved mother and it is unfair to send her home without talking to her about it. **Do not encourage breast binding.**

-That you have connected the family with support outside of the hospital-- a peer, a support group, or a therapist. Offer to make phone calls FOR THEM to arrange these things. Most bereaved parents find it very difficult to reach out for support even when they feel desperate.

Mementos to Offer

Anything you normally give to a living baby: crib card, bracelet, name tag, hat, etc.

Photos-- as many as possible (even if family is not interested in photos-- you take these and hold them for the family if/when they want them, and most do eventually)

- -Whole body
- -Individual parts-- hands, feet, ears, hair whorl, fingers, etc.
- -Photos with family together and individual members holding baby, if they are willing
- -Dressed and undressed
- -Photo documentation of bathing, dressing, baptism, etc. if applicable

Even if you see the family photographing themselves, offer to do this for them so they can all be in the picture.

Footprints and Handprints- with ink and paper. If there are siblings at home, make some where the prints are to the side and sibling prints can be added after the fact.

Dental Stone casts of hands and feet

- -3-D versions of hands/feet using dental alginate and dental stone cast in deep containers like cups or bowls
 - -Press hand/footprints into plaster for imprints (3D footprints)

Lock of hair, fingernail clippings (in a plastic bag)

Blanket baby was wrapped in (if possible- both the hospital issue blanket AND a beautiful handmade one) Even if blanket has blood or stool on it, it should still go home.

Clothing—ALL BABIES SHOULD BE DRESSED after some skin to skin time unless the parents specifically state that they do not want their baby dressed.

- -If family has brought clothing for baby, invite them to diaper/dress baby
- -If not, *offer choices*, both what might be available or have somebody go and buy something for the baby to wear if appealing
 - -Even if family wants you to dress the baby, offer a choice of outfits so they will be happy with it

Anything that has touched the baby (cloth diapers, hats, blankets, washcloth, etc)

Certificate of Life

-In Massachusetts, we can give family application for "certificate of birth resulting in stillbirth" so they can get something legal (you can request this from the department of vital statistics)

Creative projects- with siblings, parents or grandparents:
Footprint or handprint art on paper
Painted rocks or a stepping stone for garden
Footprints on a flowerpot or other ceramic item
Handprint on a ball or baby's name written on other significant item

Something nice to put it all in a pretty box, a cloth envelope, etc.
Three Minute Forced Debrief: Write and Share
Here are three things I am feeling good about:
1.
2.
3.
One thing that is linguing for majo

One thing that is lingering for me is...

Something I'll carry forward with me from this experience is:

Something I'm feeling grateful for is: