



# Caring for Patients Experiencing Perinatal Loss

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# Agenda

OK Laws

Attachment/Bonding

Grief

Guidelines for Care

Making Memories

Taking Photos

Final Disposition

Resources



“Miscarriage and infant loss are different because you lose potential – not the person they were, but the person they could have been.”

- Talia Gates



# Oklahoma Law – Ashlen's Law 2015



- Addressed definitions related to live birth, fetal death and stillbirth
- $\geq 12$  weeks requires a stillbirth certificate

# Oklahoma Law – Lily’s Law 11/2021



- “Live Birth”
  - complete expulsion or extraction from mother the products of conception at any gestation age and which the POC breathes or shows any other evidence of life such as beating heart, pulsation of umbilical cord or definite movement of voluntary muscles whether the cord has been cut or not
- “Fetal Death”
  - complete expulsion/extraction of POC at any gestational age that does not show any of above signs of life
- Addresses parents right to direct final disposition and requires hospitals to notify parents of that right and give them a copy of the hospital’s policy on final disposition of remains

# Attachment/Bonding Concepts

- Planning the pregnancy
- Confirming the pregnancy
- Accepting the pregnancy
- Feeling fetal movements
- Accepting the fetus as an individual

# Developmental Tasks of Pregnancy

- Pregnancy Validation
- Fetal Embodiment
- Fetal distinction
- Role Transition



Loss of baby 75%  
versus  
Part of life 25%

- In a study by Marie Allen, PhD and Shelly Marks, MS (1993) they found that the majority of women in their study had a profound emotional response to their loss
- They also found that some did not




# Stages of Grief

- Denial/Shock
  - Survival mode, helps to minimize the overwhelming pain of the loss
  - Slows down the process due to the overwhelm of grief
- Anger
  - Working to adjust to new reality, more socially acceptable to be angry than scared
  - First feeling as we release emotions related to loss
- Bargaining
  - Comes from a feeling of helplessness, desperation
  - Willing to do anything to fix it, to relieve the pain
- Depression
  - Start to feel the loss more abundantly
  - The loss feels more present and unavoidable
  - Normal but can feel isolating
- Acceptance
  - No longer resisting the reality of the situation
  - Still feel the loss but emotional survival no longer relying on denial, bargaining, anger



# Attachment



Grief is experienced in  
relation to the  
significance of the  
attachment

# What does it mean



- Don't make assumptions about how a mother should be reacting or how she should grieve
- Don't make assumptions based on gestational age of the loss, how many children they have, etc
- Everyone grieves differently

The suddenness and unexpected nature of the loss

The way infant death is socially defined in our culture



Why perinatal death can be so hard





## General Care

Caring for patients experiencing perinatal loss is a standard of care

We know that acknowledging their loss is an important part of care

Supportive, compassionate care that addresses the needs of the patient and her family/support as well as partners

# Common Patient Feelings/Comments



- Feeling helpless (“There’s nothing I can do”)
- Guilt (“Did I do something that caused this?”)
- Hope (“He will be ok”)
  - Is there a chance for survival
  - Maybe baby isn’t really dead
- Bitterness (“Why did this happen to me”)

# Responses that are not helpful from staff, family, friends


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- Some may avoid contact with patient
- Some may avoid talking about the baby believing it is kinder
- Some may believe it is or should be 'finished business' and not understand the family's/mother's grief
- At least you never knew the baby
- You can always have another baby
- At least you have children at home
- You should (or can) get pregnant again/put this behind you
- It was for the best, something was likely wrong with baby
- God must have wanted a little angel in heaven
- If you had taken better care of yourself...
- I don't understand why you keep talking about it, if you get busy/go back to work, you will forget
- I understand how you feel, my friend lost a baby to SIDS (and other stories to try to relate)
- Calling baby 'Fetus' or 'It'



# What do I say?

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- Call baby by name or say “baby”
  - “I’m sorry....”
  - “I’m here to listen if you need to talk...”
  - “Tell me about..... “
    - Examples: ...your birth experience, ...how you picked her name, ...what support you have at home)
  - Listen attentively, be sincere
  - Don’t be afraid of silence
  - **It’s OK to Cry**
  - Sit down when speaking to them if possible





# General Guidelines for Care



# Guidelines for Care



Labor	Preparing for Delivery	Communication	Time with Baby	Other
<p>Strive for a positive labor experience</p> <p>Explain options</p> <p>Provide appropriate pain management</p>	<p>What to expect at delivery, during recovery, what baby might look like</p> <p>Discuss options for immediately after delivery for viewing/holding</p>	<p>Use silence cautiously</p> <p>Give options but limit choices to avoid overwhelm</p> <p>Don't overload with information</p> <p>Provide written and verbal information when possible</p>	<p>Provide options for baby to stay with them</p> <p>Give unlimited time with baby</p> <p>This is the only time they will ever have</p>	<p>Respect privacy but don't avoid them</p> <p>Include information for family/friends</p> <p>Handle baby carefully, place in an appropriate container/basket or blankets.</p>

## Seeing Baby

- Approach slowly, are they reaching out, do they seem hesitant
- Be nearby, but not with them unless they request you to stay, Point out positive traits of baby

## What Families Remember

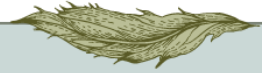


- Being close, body contact
- Honest appraisal of baby's condition
- Privacy
- Being able to assist with care
- Pictures

## Making Memories

- Give options for them to be involved in care
  - Bath
  - Photos
  - Dressing/undressing
  - Timing of when baby goes to funeral home

# Making Memories



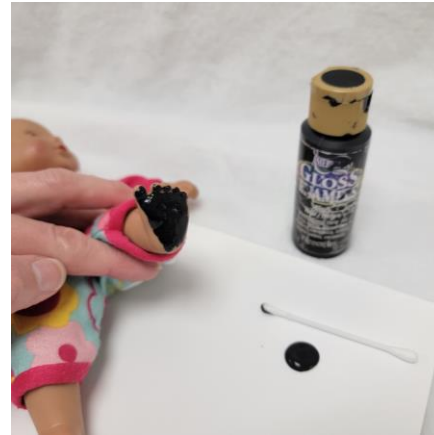
- Photos
- ID band/cribcard
- Baptism/blessing
- Baby ring/bracelet
- Stuffed animal/bear
- Hand/footprints
- Hand/food mold or imprint
- Lock of hair (always ask)
- Blankets/clothing used with baby sent home with them
- Weighted bear/animal
- Ornament

# Making Memories

## Hand/Footprints and Jewelry



Ornaments and  
paper for prints



Use acrylic craft  
paint for early  
gestation prints



Clay and mold  
kits



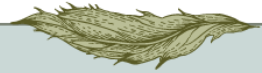
Matching bracelet  
sets





# Stuffed Animals/Bears

Gives her something to hold/hug





# Making Memories Clothing and Blankets



Bridget's Cradles, Labor of Love, Holy Sews





# Rooming In







# Taking Photos



# Set up for success

Most nurses are not photographers and we don't have time. A few tricks can upgrade the photos we provide

Set the stage:

Backdrop can eliminate background issues

Find a place with good lighting

Develop a routine for yourself

Collect your supplies



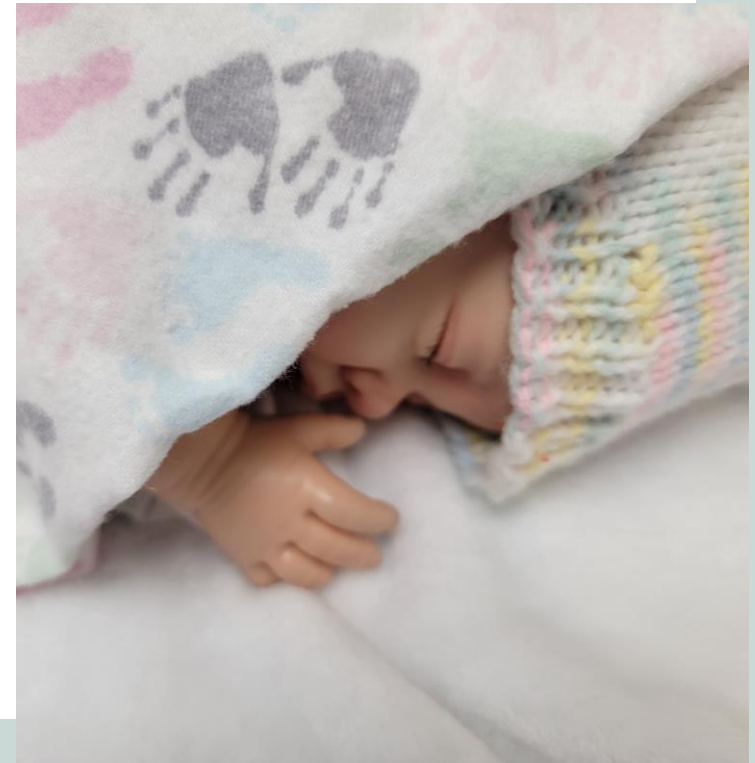
- If you feel comfortable offer to take photos in the patient's room
- Offer a few photos of them and their baby

## Posing Baby Side Lying





# Posing Baby Stomach



# Posing Baby hands, feet, details





# Posing Baby Challenges

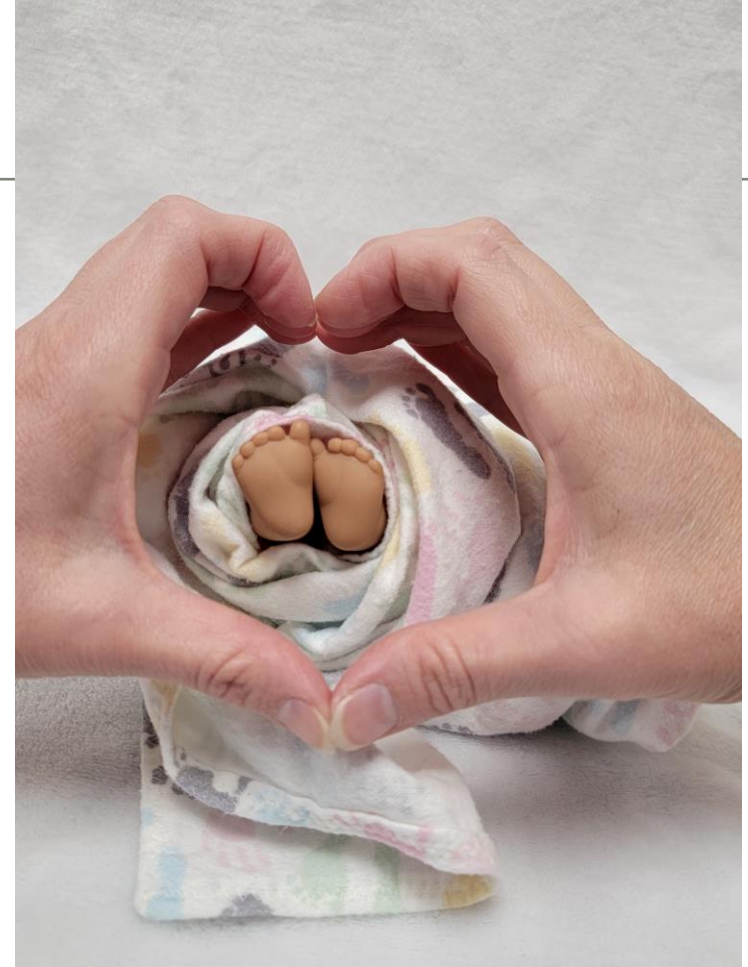




## Posing Baby Memory Items



# Posing Baby Family





# Posing Baby Black and White





# Final Disposition-Planning a Funeral



Parents don't plan to bury their babies and they are typically not prepared to make these decisions



Some facilities may have burial options up to a specific gestational age or for all POC



## Final Disposition

- Bringing up burial/funeral services
  - Social services or Pastoral care assist with these tasks at some facilities
- Do they have a funeral home their family used for other family members?
- Do they have a close friend or family member who would assist them with contacting/planning
- Low-cost burials or low/no cost cremation available at some funeral homes-takes calling around to find them

# Discharge Planning



- Lactation
- Resumption of activities and returning to work
- Postpartum teaching
- Community and perinatal grief/loss resources
- Follow up appointments



# National Pregnancy and Infant Loss Day



October 15<sup>th</sup> every  
year  
Wave of Light at  
7pm in all time  
zones, all over the  
world

[www.october15th.com](http://www.october15th.com)

Other memorials may be happening  
in your area. You can search online  
for options. Hospitals may offer  
annual memorials.





## Caring for yourself




## Common responses experienced by caregivers

- Feeling drained
- Feeling sad for family
- Feeling inadequate, overwhelmed, guilty
- Wanting to say the ‘right’ thing
- Fearful of causing more pain
- May bring up our own experiences/feelings from loss of our own loved ones



## Other resources

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- Resolve through Sharing (RTS)  
[www.bereavementservices.org](http://www.bereavementservices.org)
  - Share Pregnancy and Infant Loss Support, Inc [www.nationalshare.org](http://www.nationalshare.org)
  - Pregnancy Loss and Infant Death Alliance [www.plida.org](http://www.plida.org)
  - Kids Joining Eternity in OKC  
<https://kidsjoiningeternity.org/>
  - Jaxon Kade Foundation in OKC  
<http://www.jaxonkadefoundation.org/>
  - **Big thanks** to Lisa Pendleton for the powerpoint and teaching me so much about caring for these patients



Thank you



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