

A Baby Dies...  
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Dealing with Perinatal Loss

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Lisa Pendleton, BSN, RNC-NIC has no real or perceived conflicts of interest for this presentation.

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

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## Loss by Definition



☞ Early Pregnancy Loss

☞ <20 weeks

☞ Stillbirth

☞ After 20 weeks

☞ Neonatal Death

☞ <28 days of life

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## Attachment

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Grief is experienced in relation to the significance of the attachment.

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## Attachment/Bonding Concepts

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

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## Tasks of Pregnancy

- ☞ Validation
- ☞ Incorporating fetus into mother's body
- ☞ Fetal distinction
- ☞ Transition from pregnancy to motherhood

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## Common Feelings in Early Pregnancy Loss

"Loss of a Baby" -75%  
Vs.  
"Part of Life" -25%

- ☞ Allen and Marks found that the majority of women in their study had a profound emotional response to their loss.
- ☞ Some women did not.

Limbo, R. & Wheeler, S. (1986). Women's Responses to the Loss of Their Pregnancy Through Miscarriage: A Longitudinal Study. *Forum Newsletter*, 10(4).

Research conducted by Marie Allen, PhD & Shelly Marks, MS in Miscarriage: Women Sharing From the Heart, 1993

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## Why Perinatal Death Can Be So Hard

- ☞ The suddenness and unexpected nature of the loss
- ☞ The way infant death is socially defined in our culture

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## Four Phases of Bereavement

- ☞ Shock and numbness
- ☞ Searching and yearning
- ☞ Disorientation
- ☞ Reorganization/Resolution

Davidson, G.W. (1984). *Understanding Mourning*. Minneapolis, MN: Augsburg Publishing House.

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## Strategies for Care

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## Why do we provide special care in these situations?

- ☞ In the past we thought that we were protecting the woman if we did not acknowledge her loss.
- ☞ We have learned that ignoring the loss can complicate the grief the family is experiencing.

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## Why do we provide special care in these situations?

- ☞ Healthcare workers address all the needs of a patient. Caring for patient with perinatal loss is a standard of care.
- ☞ Standard of care recognized by ANA, ACOG, AAP, AWHONN, NANN, The Joint Commission

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## General Guidelines for Intervention

- ☞ Be cautious about assigning anyone who is pregnant to their care.
- ☞ Be aware of who to include as their support people.

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## Anticipatory Grief



- ☞ Chance for survival
- ☞ Parents feel helpless ("There's nothing I can do")
- ☞ Guilt ("Do I have bad genes?")
- ☞ Hope ("He'll be OK.")
- ☞ Bitterness ("Why did this happen to me?")

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## Laboring Your Patient



- ☞ Use silence cautiously
- ☞ Strive for positive labor experience
- ☞ Use praise
- ☞ Explain options

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## General Guidelines For Intervention



- ☞ If you don't know how they are feeling, refer to the "pregnancy loss" rather than to the "baby".
- ☞ Listen
- ☞ Offer appropriate reading material
- ☞ Offer options (e.g. seeing, holding, pictures)

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## General Guidelines for Intervention



- ☞ Let them know that some choices can be made later (e.g. blessing service)
- ☞ Respect privacy and amount of time spent with baby
- ☞ Offer options more than once
- ☞ Provide information (verbal or written) about incongruent grief
- ☞ Include information on family and friends

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## When Hello Means Goodbye



- ☞ Parents need to be able to say "hello" before they can say "goodbye."
- ☞ Hospital time is the main opportunity they have to "parent" their infant.
- ☞ Opportunity to make memories.

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## Showing Families Their Babies



- ☞ Approach slowly with the baby
- ☞ Wait to see if their arms are outstretched
- ☞ Say "Shall I unwrap her or would you like to be alone with her for a while and do that yourself?"

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## Showing Families Their Babies



- ☞ Be nearby, but not with them unless they request your presence
- ☞ Help families identify positive traits
- ☞ Take photos of parents holding baby if they wish
- ☞ Provide option of seeing and/or holding again



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## Examples of Memory Making



- ☞ Opportunity to see and hold
- ☞ Photos
- ☞ ID band/crib card
- ☞ Baptism/blessing
- ☞ Baby Ring
- ☞ Stuffed animals (props)
- ☞ Hand/footprints
- ☞ Lock of hair
- ☞ Participating in bath/dressing
- ☞ Clothing
- ☞ Christmas Ornaments
- ☞ Planning memorial/funeral service

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## What Families Remember



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

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 Planning a Special  
 Goodbye

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Funeral Options  


- Burial or cremation
- Viewing the baby
- Family involvement
- Music/poetry
- Flowers
- Pictures

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Funeral Options  


- Self transport
- Obituary
- Hospital chaplain/Chapel
- Funeral/Gravesite service
- Burial with relative
- Specific area for babies in cemetery

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# Funeral Options



- ☞ <20 weeks gestation, there is no standard or law regarding burial.
- ☞ State law requires burial >20 weeks - parents responsibility

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Resurrection Memorial Cemetery  
 7801 N.W. Expressway  
 Oklahoma City, OK 73132




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"Every baby has a purpose; and this baby fulfilled his purpose perfectly."

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☮  
Typical Responses to  
Perinatal Death

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☮  
“When a person is born, we rejoice. When they are married, we jubilate. But when they die, we pretend nothing happened.”  
Margaret Mead

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Avoidance

- ☮ Some may avoid contact.
- ☮ Some may avoid talking about the baby, believing it is kinder.
- ☮ Occasionally some may believe it is, or should be, “finished business”.

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## Insensitive or Moralizing Responses

- ☞ "At least you never knew the baby."
- ☞ "You can always have another."
- ☞ "You should (or can) get pregnant right away and then you can put this behind you".
- ☞ "It was for the best; the baby probably would have been abnormal anyway."

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## Insensitive or Moralizing Responses

- ☞ "God must have wanted a little angel in heaven."
- ☞ "If you had taken better care of yourself, this might not have happened."
- ☞ I don't understand why you keep talking about it. If you would get busy, you could forget and feel better."
- ☞ "I understand how you feel. My friend lost a baby to SIDS."
- ☞ Calling the baby "fetus" or "it".

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## Supportive

- ☞ "I'm sorry."
- ☞ "I'm here to listen if you need to talk."
- ☞ "Tell me about....."
- ☞ Listening attentively

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## How You Can Help



- ☞ Listen
- ☞ Touch
- ☞ Cry (if it comes naturally)
- ☞ Be sincere
- ☞ Power of presence

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## It's Time to Go Home



- ☞ Discharge plan should include information on:
  - lactation
  - after pains
  - sexuality
  - nutrition
  - exercise
  - signs and symptoms of complications
- ☞ Provide written instructions

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## Community Outreach



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## Follow Up



- ☞ Conveys concern
- ☞ Allows for asking/answering questions
- ☞ Offers support

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## Follow up Guidelines



- ☞ Early pregnancy loss
  - ☞ Within 1 week
  - ☞ Between 3 weeks and 4 months
  - ☞ Due day or anniversary date

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## Follow up Guidelines



- ☞ Stillbirth or Newborn Death
  - ☞ Within 1 week
  - ☞ 3 weeks
  - ☞ 4 months
  - ☞ Due date
  - ☞ 6-10 months
  - ☞ Anniversary date

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## Support Groups



- ☞ Groups are available in person or online.
- ☞ P.R.I.D.E—Parents Responding to an Infant Death Experience
- ☞ Share- Pregnancy and Infant Loss Support Blog

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## National Pregnancy and Infant Loss Awareness Month



- ☞ Established in October, 1988 by President Reagan
- ☞ Actual Day is October 15<sup>th</sup>
- ☞ Commemorated by Walk to Remember

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## Walk to Remember



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## Christmas Memorial Service



- ☞ Tree trimming with personalized ornament
- ☞ Candle lighting ceremony




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## A Message to Caregivers




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## Cardinal Rules of Support



- ☞ Silence
- ☞ Admit Our Helplessness
- ☞ Be genuine
- ☞ Be with the person in grief
- ☞ Don't judge another's grief
- ☞ Be clear about your own issues on death
- ☞ Know your limitations

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## Common Responses Experienced by Caregivers



- ☞ Feeling drained
- ☞ Feeling sad for the family
- ☞ Feeling inadequate
- ☞ Wanting to say the "right" thing
- ☞ Feeling overwhelmed
- ☞ Fearful of causing more pain
- ☞ Feeling guilty

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## Helpful Suggestions



- ☞ Have policies/protocols in place
- ☞ Perinatal loss checklist
- ☞ Delegate tasks
- ☞ Share your feelings
- ☞ Interdisciplinary team
- ☞ Say no
- ☞ Take care of self/others

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## Rules of Life



- ☞ People will forget what you said.
- ☞ People will forget what you did.
- ☞ People will never forget how you made them feel.

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## Resources



- ☞ Resolve Through Sharing (RTS)  
☞ [www.bereavementservices.org](http://www.bereavementservices.org)
- ☞ Share Pregnancy & Infant Loss Support, Inc.  
☞ [www.nationalshare.org](http://www.nationalshare.org)
- ☞ Pregnancy Loss and Infant Death Alliance  
☞ [www.plida.org](http://www.plida.org)
- ☞ Centering Corporation – Grief Publications  
☞ [www.centering.org](http://www.centering.org)

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