A Baby Dies…
Dealing with Perinatal Loss

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

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

Talia Gates
Early Pregnancy Loss
- <20 weeks

Stillbirth
- After 20 weeks

Neonatal Death
- <28 days of life

Attachment

Grief is experienced in relation to the significance of the attachment.
Attachment/Bonding Concepts

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

Tasks of Pregnancy

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

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.


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

Four Phases of Bereavement

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


Strategies for Care
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.

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

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.
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?”)

Laboring Your Patient

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

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)
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

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.

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?”
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

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

What Families Remember

- Being close, body contact
- Honest appraisal of the baby’s condition
- Privacy
- Being able to assist with care
- Pictures
Planning a Special Goodbye

Funeral Options

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

Funeral Options

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

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

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

"Every baby has a purpose; and this baby fulfilled his purpose perfectly."
Typical Responses to Perinatal Death

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

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”.

Some may avoid contact.
Detrimental 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.”

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”.

Supportive

- “I’m sorry.”
- “I’m here to listen if you need to talk.”
- “Tell me about………”
- Listening attentively
How You Can Help

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

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

Community Outreach
Follow Up

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

Follow up Guidelines

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

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

National Pregnancy and Infant Loss Awareness Month

- Established in October, 1988 by President Reagan
- Actual Day is October 15th
- Commemorated by Walk to Remember

Walk to Remember
Christmas Memorial Service

- Tree trimming with personalized ornament
- Candle lighting ceremony

A Message to Caregivers

- 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

Cardinal Rules of Support
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

Helpful Suggestions

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

Rules of Life

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

- Resolve Through Sharing (RTS)
  - www.bereavementservices.org

- Share Pregnancy & Infant Loss Support, Inc.
  - www.nationalshare.org

- Pregnancy Loss and Infant Death Alliance
  - www.plida.org

- Centering Corporation—Grief Publications
  - www.centering.org