Care and Compassion

End of Life Issues
When a Baby Dies
“When we bury the old, we bury the known past, the past we imagine sometimes better than it was, but the past all the same, a portion of which we inhabited. Memory is the overwhelming theme, the eventual comfort.

But in burying infants, we bury the future, unwielding and unknown, full of promise and possibilities, outcomes punctuated. The grief has no borders, no limits, no known ends, and the little infant graves that edge the corners and fencerows of every cemetery are never quite big enough to contain that grief.”

Thomas Lynch, The Undertaking: Life Studies From The Dismal Trade
Table of Contents

- Facts
- Swanson’s Five Critical Attributes of the Attentive Care Provider
- The Role of the Nurse
- Making Memories
- Photographing the Infant
- Cosmetic Problems
- Preparing for the Morgue
- Care for the Caregiver
Facts

- Pregnancy/childbirth was the leading cause of death of American women of childbearing age at the turn of the century.
- As late as the 1930’s every pregnant women knew that her life, as well as her infant’s life, was in danger.
- As medical care and medical facilities improved, pregnant women began to expect to deliver a healthy baby.
- Every year in the United States 15-20 % of clinically diagnosed pregnancies end in miscarriage.
- 30,000 babies are stillborn.
- 20,000 babies die as newborns.
- 800,000 elective abortions are performed.
- 120,000 infants are placed for adoption.
- 6 million women of childbearing age have problems with infertility.
- 60,000 infants are born prematurely; some end up with special care needs.
- 400 women die from complications of pregnancy, childbirth and the postpartum period.

From The Wisconsin Association for Perinatal Care position statement 2002
Swanson’s Five Critical Attributes of the Attentive Care Provider

Knowing
- A provider strives to understand an event as it has meaning in the life of another.
- A provider is sensitive and knowledgeable.

Being With
- Being with or emotionally present to another.
- Able to respond to parents’ grief and pain without hiding behind the cold, professional approach of ‘a job has to be done’.

Doing For
- Doing for parents what one would do for oneself. This includes collecting mementos, taking photographs, and encouraging private time with the baby.

Enabling
- Giving anticipatory guidance about events that may occur during the dying process or about memorial services.

Maintaining Belief
- Supporting the parents’ capacity to come through this event successfully and to face the future with meaning.

The Role of the Nurse

BEFORE DEATH

- Meet the family where they are in their grief.
- Find out the details of her history before you go in the room.
- Be quiet and respectful.
- Acknowledge family members.
- Father of the baby will be angry and may focus that on you.
- Tell them who you are let them know that you know the status of their baby.
- Explain what they can expect over the next hours or days.
- Be honest.
- Inform them of the procedures that will be performed. Patient may cry when you speak about the baby. Her husband will be upset with you for “making her cry”.
- Find out her religion and ask if there are any religious or cultural rituals that need to be performed.
- Give them some options. Choices at this time give the family some control back.
- For labor and delivery nurses find out gestational age from LMP.
- Give family member or husband a list of things they may want to bring to the hospital:
  - Camera still and/or video
  - Blanket, toy, or religious medallion
  - Video camera
  - Special clothing or blanket for baby
AS DEATH IS NEAR

- Now is the time for touch.
- Actual delivery confirms diagnosis.
- For labor and delivery nurses, mom will probably look at you just before the baby is born. Give her encouragement.
- For labor and delivery nurses, if at all possible, don’t drug patient just before delivery. This slows down her ability to grieve.
- Always look to see if the is any obvious reason why the baby died.

AFTER DEATH

- For labor and delivery nurses, look for anomalies, cord problems, anything that may have caused the baby to die.
- Bathe and dress baby. Involve family members.
- Collect keepsakes.
- Comment on characteristics.
- Call the baby by its name.
- Handle the baby gently and respectfully.

WHAT TO SAY

- Statements that express comfort and a willingness to talk about the death.
- "I'm sorry."
- "I know that this is a bad time for you."
- "Is there anything I can do for you?"
- "What's your baby's name?"
- "Tell me what happened as you remember it."
WHAT NOT TO SAY

- Statements that minimize the death and increase the feelings of guilt.
- "You're young, you can have other children."
- "It probably would have been abnormal anyway."
- "This was for the best."
- "At least you didn't get to know it."
- "It's over with now you can get on with your life."
- "Time heals all wounds."

NON-COMFORTING RELIGIOUS CLICHES

- "God took your child home because He loved him so much."
- "God is trying to teach you something."
- "You should feel privileged, not bitter, about your opportunity to lean on Him in faith."
- "Meditate on the blessings you still enjoy - at least you are alive."
- "You are undergoing a training regime - a chance to exercise your muscles of faith."
- "Don't worry. God will not test you beyond your endurance."
- "Someone is always worse off than you - look around."
- "Give thanks despite your circumstances."

SIBLINGS

- Children are excellent observers, but terrible interpreters.
- Parents need to give honest, simple explanations.
- Accept their child’s feelings.
- Show their child that they love them.
- Give their child permission to grieve.
- Be patient.
- Maintain household routines.
- Encourage their child to draw pictures or write stories about their feelings.
- Children who are allowed to participate in the death and mourning process with the family are able to proceed through bereavement easier and faster.
Phases of Bereavement

Grief is a process rather than a state. No two people will grieve in the same way. They do not follow a set timetable. This outline is a general guide only.

SHOCK AND NUMBNESS

PHASES OF BEREAVEMENT

Figure 1  Intensity of the characteristics of shock and numbness during the 2 years following the death of a loved one.


RTS Bereavement Services

SHOCK AND NUMBNESS - CHARACTERISTICS:

- Short attention span
- Stunned disbelief
- Denial
- Failure to accept reality
- Concentration is difficult
- Functioning impeded
- Time confusion
SEARCHING AND YEARNING

SEARCHING AND YEARNING - CHARACTERISTICS:

- Sensitive to stimuli
- Dreams / nightmares
- Testing what is real
- Weight gain / loss
- Preoccupation with the deceased
- Vivid dreams
- Time confusion
- Sighing
- Headaches
- Resentment
- Anger / guilt
- Restless / impatient
- Irritability
- Sleep difficulties
- Obsession to get pregnant again
- Bitterness
- Palpitations
- Lack of strength
- Blurred vision
- Aching arms

Figure 2: Intensity of the characteristics of searching and yearning during the 2 years following the death of a loved one.


RTS Bereavement Services
DISORIENTATION

PHASES OF BEREAVEMENT

<table>
<thead>
<tr>
<th>DISORIENTATION</th>
<th>INTENSITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISorganized</td>
<td>5</td>
</tr>
<tr>
<td>Depressed</td>
<td>4</td>
</tr>
<tr>
<td>Guilt</td>
<td>3</td>
</tr>
<tr>
<td>Anorexia</td>
<td>2</td>
</tr>
<tr>
<td>Awareness of reality</td>
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DURATION Months

1 2 3 4 5 6 8 12 18 24

Figure 3. Intensity of disorientation during the 2 years following the death of a loved one.


RTN Bereavement Notice

DISORIENTATION - CHARACTERISTICS:

Think 'I'm going crazy'

Social withdrawal

Disorganized

Weight loss/gain

Sense of failure

Exhaustion

Lack of energy

Difficulty in concentration

Forgetful

Depressed

Guilt

Insomnia

Anorexia

Sadness

Feels ill
REORGANIZATION/RESOLUTIONS - CHARACTERISTICS:

- Sense of release
- Renewed energy
- Able to make decisions more easily
- Eating and sleeping habits re-established
- Able to laugh and smile again
- Hope for the future

A PICTURE OF NORMAL GRIEF
Photographing the Infant

A PICTURE:

- Helps to confirm the baby’s existence
- Confirms the fact that the baby was alive and is now dead
- Helps parents remember what their baby looked like
- Gives the parents the ability to share their baby with others
- Helps to enhance memory and help to form a mental timeline
- Helps the mother form her birth story
- Try to have the pictures tell a story about this time

THINGS TO REMEMBER

- Be aware of what is in the viewfinder
- Have some type of backdrop
- Patient gown
- Blanket
- Wall
- Basket
- Family members in background
- Drape the warmer ahead of time
- Gather supplies
- If clothing is available, give the family a choice of several styles and/or colors

THINGS TO AVOID

- Garbage cans
- Dirty linen
- Bloody table or instruments
- Clutter
USE PROPS

- Basket
- Doll or bear
- Nurse’s, mom’s, or dad’s hand
- Religious medals and/or icons
- Special Blanket
- Take posed and candid pictures
- Take a picture of the baby without clothes
- If possible, zoom in instead of standing closer
- Take pictures with siblings and family members
- Take a family portrait
- If possible make a picture of multiples together
- Always avoid “up the nose” shots
- Stand above and over the baby
- Stand in a chair
- Put the baby on the bed and drop the level
- Put the baby on a chair or recliner
- Raise the baby’s upper body so that you are looking straight into the face
- Place baby on a draped bedside table
- Position baby in normal, healthy baby body position
- Take pictures of their feet and hands cradled in your hands to show the size difference
- Have two cameras loaded -- one with color film the other with black and white film
Making Memories

The memory keepsake given to the family:

- Gives the family something tangible to hold
- Helps to form memories to lay the groundwork for healing to begin
- Adds to the history of their family
- If parents have planned to involve family members and/or siblings ask each if they want to hold the baby.
- Make pictures of family and siblings with baby
- The interactions of the parents, siblings, and family members with each other and with the baby become memories
- Always be quiet, gentle and respectful
- Give one of the baby bracelets to the family
- Give the tape measure the baby was measured with to the family
- If the baby is tiny, trace the body on a footprint sheet
LOCK OF HAIR

FROM THE BABY

- Cut hair from the back of the head along the neckline
- Place on white paper
- Use clear tape across the top of the lock of hair to secure it to the paper
- Leave a small amount of hair below the tape so that mom will always have a part of her baby that she can touch

FROM THE FAMILY

- Cut a small lock of hair from family members
- Bind locks together with ribbon
- Place bound locks of hair in baby’s hand and tie around wrist with ribbon
- The baby will carry a part of her family with her

LIP PRINTS

- Paint lipstick on baby’s lips with applicator
- Use a small piece of white paper
- Lightly press paper to baby’s lips
- Lift paper off lips in one smooth motion
- Place lip prints in bag or envelope
HAND AND FOOTPRINTS

- Always bring the object that you are putting the prints on to the baby’s hand or foot
- Support the top of the foot and toes with your curved index finger
- Separate the toes/fingers as much as possible
- Try to move the hand or foot as little as possible
- If the ankle is slipping from your hand, wrap strip of paper towel around the ankle.
- Remove paper from heel of hand/foot towards toes/fingers
- Paint digit in rather than try to print it into the hand/foot
- Use alcohol or acetone to dry skin
- Paint ink on rather than blot
- Use alcohol or Vaseline to clean the ink from the baby’s foot
- Betadine solution may work when ink won’t
- Apply Betadine lightly and blot until it is almost dry
- Press the paper very lightly to the hand or foot
- The Betadine will spread a little and turn black on the paper

**Big toes and thumbs go to the middle.**
Cosmetic Problems

- Ask parents if they want a picture with the anomalies showing
- Cleft lip: Take a few pictures with the baby’s thumb in his or her mouth
- Before dressing the baby cover anything that may be leaking
- With an abdominal or back defect there may be secretions coming from the defect
- Wrap a diaper around the baby’s abdomen and back like an abdominal binder and secure it with tape. Then put another diaper on as usual and pull it over the chest

TONGUE THRUST

- Bathe the baby in warm water
- Gently push the tongue inside the mouth
- Place a paper towel roll under the chin
- If the tongue protrudes again, push it in, and adjust the paper towel roll if necessary
- As the baby cools, the jaw and tongue will set with tongue inside the mouth

MACERATION

- Trim loose or hanging skin
- Cover seeping skin with Vaseline and powder
- Use gloves or strips of chux to cover seeping areas
- Cool the baby as soon as possible
- Bathe the baby by placing the baby in the sink and swish the water around the baby.
- Soap a washcloth and squeeze soapy water over the baby.
- Use alcohol or Vaseline to gently clean vernix or meconium from the face and body
- Use a diaper that is too large to cover the chest and back
- Use gloves, clear plastic, or undershirt to protect the clothes from body fluids that may be seeping through the clothes
PACKING THE NOSE

- Inform family members what you are doing and why. They may not want to look.
- Gently suction nose and mouth of secretions
- Use the bulb syringe to gently blow powder up the nose
- Use a small amount of cotton ball as packing. Twist cotton and cover with Vaseline.
- Use applicator to twist and push cotton into nose
- Avoid tilting the head down that makes the nose seep more

PREVIABLE BABIES AND BABIES THAT HAVE FATAL ANOMALIES

- Babies can be born with a heart rate and can live for several hours
- Gestation age less than 23 weeks
- PROM with no accumulation of fluid
- PROM and infected
- Fatal Anomalies
- Warn parents before delivery that baby may be bruised due to their delicate skin
- Warn parents that baby may gasp
  - Gasing in a newborn is a reflex that is in response to low oxygen levels
  - Low oxygen levels cause the release of endorphins
  - Endorphins are morphine-like chemicals that decrease pain and cause calm feelings and euphoria
  - If a baby gasps, more than likely, it is calm and not hurting
- Encourage families to hold their babies while they are alive
- Take pictures of the baby while it is still alive
Preparing the Body for the Morgue

- If family members are present at this time give them the option to leave or stay.

- Wrap the baby in such a way as to preserve how the baby looks.

- Use blankets to support the baby’s body to preserve the appearance of the baby.

- Place rolls in the hands to prevent fingers from becoming mangled.

- Cover the face and lips in a thin coat of lotion or Vaseline to keep tissue from becoming dry.

- If the mouth is dropping open, place a paper towel roll under the chin and a folded washcloth under the head to tilt the head down on the paper towel roll, closing the mouth. Make sure the lips are straight and full.

- Use rolled blanket to keep the head in position, keep the arms and hands together and keep the blanket off of the face.

- Place the identifying bands and labels on the baby and the bag.

- How you “package” the baby’s body will greatly influence what condition the baby will be in when the family next sees it.
Care for the Caregiver

- When faced with a situation involving loss, emotions and memories from all previous losses come to the surface for:
  - The patient
  - Her family
  - The nurse

- Establish a habit of performing personal rituals to emotionally bring you to a safe, peaceful place after caring for families experiencing a loss.

- Personal Rituals also allow the caregiver to bring this experience to an end.

- Part visualization, part self-hypnosis, part prayer.

- Condition you to:
  - Relax
  - Become centered
  - Let go of some of the pain that you have experienced with a family
  - Go you a familiar, safe place after a stressful experience

- As with all other grief experiences, everyone involved is changed:
  - The patient
  - Her family
  - The nurse

“Memory is the overwhelming theme, the eventual comfort.”

As a caregiver, carry the change in you to the next family experiencing a loss and use that change to help that family begin to grieve for their baby. Use the change in you to help families make memories that will become their eventual comfort.
When someone you love becomes a memory

That memory becomes a treasure