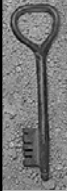


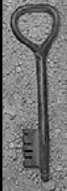
When a Baby Dies

What to do



Write a note in the chart

- ◆ Date and time of death
- ◆ Resuscitation if any/description of terminal events (be very, very brief, too much detail here leaves loopholes)
- ◆ Autopsy permission given/not given (it's our policy to ask for an autopsy)
- ◆ Disposition of the remains two options only (Public Health law)
 - Children's Hospital disposal (cremation, common burial, or parents may contact Family Services and request the ashes).
 - Funeral Service if known, if not – talk to Social Worker, or use yellow pages. Most funeral homes do babies at cost/non-profit/Children's is cheapest (cost needs basis, Little Angels program).
 - If undecided after 30 days ashes go to ME for common burial.
- ◆ Who was there specifically
 - You
 - Family
 - Nurse
 - Surgeon
 - Social Worker
 - Clergy/Ethics Forum consultant
- ◆ Sign legibly, put your 4-digit pager number below signature



Fill out "Death Pack" from bottom left file drawer at the Unit Clerk's desk

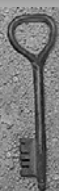
- ◆ Death Certificate Worksheet
- ◆ Authorization for Autopsy
- ◆ Government of D.C. Dept. Human Services Anatomical Gift Act/Uniform Disposition Form

This drawer

Computer

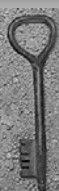
FAX

			X		
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Death Certificate Work Sheet

<p>1. Decedent's Name: _____</p> <p>2. Date of Death: _____</p> <p>3. Hour of Death: _____</p> <p>4. Was Case Referred to Medical Examiner/Coroner? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p>5. Contact Washington Regional Transplant Consortium (WRTC) (703) 641-6100 Spoke to: _____ Print Name _____ Date: _____ Time: _____ Accepted as potential candidate? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p>If No, reason given by WRTC: _____</p> <p>PART I: Enter the disease, injuries or complications that caused death, do not enter cardiac or respiratory arrest, shock or heart failure. List one cause on each line. IMMEDIATE CAUSE: _____ INTERVAL: _____</p> <p>a. _____</p> <p>b. _____</p> <p>c. _____</p> <p>d. _____</p> <p>PART II: Other contributing conditions: _____</p> <p>6. PRINT: _____ First Name _____ PRINT: _____ Last Name _____</p>	<p>Answer is No, unless death unusually fast after admission, or otherwise suspicious, eg trauma/shaken baby</p> <p>Usually unacceptable for organ donation if very premature, or if suspected sepsis on antibiotics</p> <p>We do not discuss or consent for organ donations</p> <p>Usually none</p> <p>Attending only, usually STEPHEN BAUMGART</p>
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Causes of death

- ◆ The coroner is looking for a time-line, tell them a logical story in sequence.
- ◆ Do say:
 - Pulmonary hypertension (due to)
 - Septicemia (due to)
 - Necrotizing enterocolitis (due to)
 - Extreme prematurity (idiopathic)
- ◆ Do not say:
 - Cardiac arrest (due to)
 - Septic shock (due to)
 - Sepsis



Authorization For Autopsy

- ◆ When I speak to parents about an autopsy, I begin by saying "it's our policy to offer you an autopsy for your baby [first name],"
- ◆ I go on to say there are only three reasons why you might want one performed:
 - If you have any doubts or uncertainties how or why this baby died, an autopsy may reveal the reasons.
 - If there might be any genetic cause that might affect future pregnancies, an autopsy may reveal this; better yet, a skin biopsy from the umbilicus can culture fibroblasts [payor is billed], also a limited autopsy for pulmonary or heart valve cultures are good post-mortem [hospital pays for this].
 - If there's any good to come, or silver-lining for this bad event, we the doctors and nurses may learn more about caring for other babies in the future with these types of conditions



Authorization For Autopsy

DATE: _____ ADDRESS: _____

I, _____ hereby authorize Children's Hospital, its employees, agents, and representatives, to conduct a post-mortem examination upon the body of the deceased, including the removal of such organs and tissues as may be deemed proper by the examining physician in the interest of determining the cause of death and advancing medical knowledge and progress.

LIMITATIONS OR SPECIAL WISHES (IF THERE ARE NO RESTRICTIONS, WRITE "NONE")

#1. NONE.

Signature: _____ Parent or Person (if deceased) _____
 Signature: _____ Legal Guardian (if deceased) _____
 Signature: _____ Party Responsible for disposal of remains (if deceased) _____

#2. Print name, signature and print of the physician obtaining authorization.

#3. Print name and print of second physician to contact together with the physician.

STATUS OF DEATH CERTIFICATE PERMISSION AND EXAMINATION (check for affirmative answer)

1. STATUS OF CONSENT (To be completed by attending physician, medical, or biologist)

Consent Requested Please call ext. 2051 to notify administrator for autopsy.
 Consent Granted Leave patient's name and physician contact information.
 Consent Refused Explain.
 Consent Pending Explain.

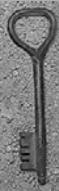
Additional Remarks: I spoke with Janice to confirm autopsy requested.

Original - Medical Records Yellow Copy - Pathology Revised 4/9/06

Call Pathology at 2051 to confirm autopsy will be done, document to whom you spoke at bottom of this form.


Please print limitations, even if "none."

Please print legibly, with 4 digit pager ###



Government of the District of Columbia Department of Human Services Anatomical Gift Act/Uniform Disposition Form

- ◆ **WRTC: Washington Regional Transplant Consortium**
 - Tel. Be-a-donor = 866-232-3666, record name of person you talked to.
- ◆ **We do not discuss or consent for organ/tissue donation.**
- ◆ **Fill out only the very bottom section of this form:**
 - ◆ **Donor Outcome**
 - Donor
 - Non-donor
 - Medically Unsuitable: Reason
 - Usually the reason is too premature, too small, or suspected sepsis.




When a Baby Dies; Basics of Neonatal Bereavement

Christina Lloyd, RNC, MS
Dec. 2007

Occurrence of Perinatal/Infant Loss

In the United States in 2004, 27,995 infants died before reaching their first birthday, an infant mortality rate of 6.8 per 1,000 live births. 4.6 occurred during the 1st month of life (*ie* neonatal mortality) 18,938.



Most common causes: birth defects; prematurity/low birthweight; sudden infant death syndrome; maternal complications of pregnancy and respiratory distress syndrome

Definitions of Loss

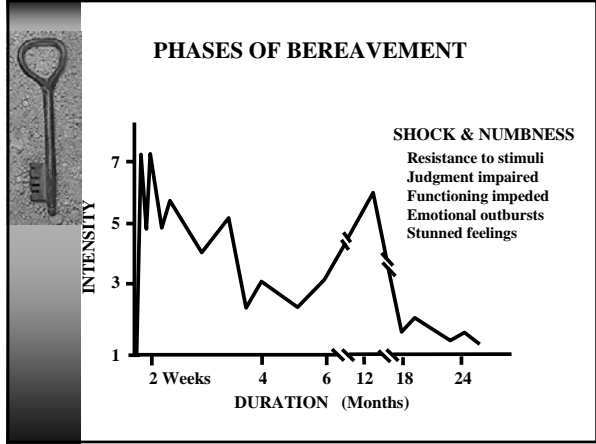
Pregnancy Loss

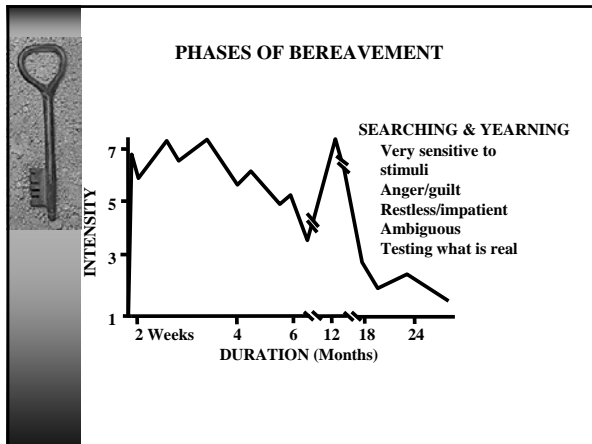
- Ectopic Pregnancy
- Blighted Ovum
- Molar Pregnancy
- Miscarriage
- Medical Interruption

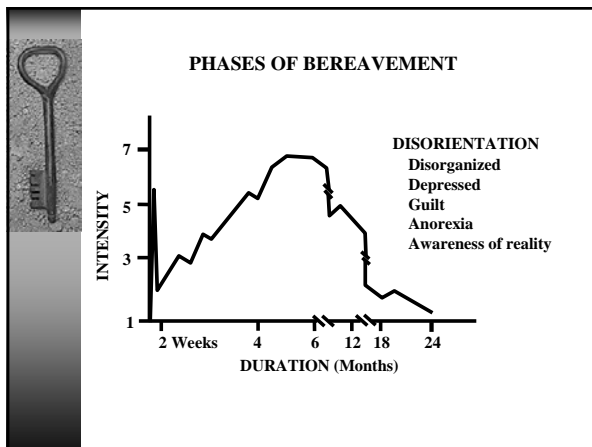
Stillbirth

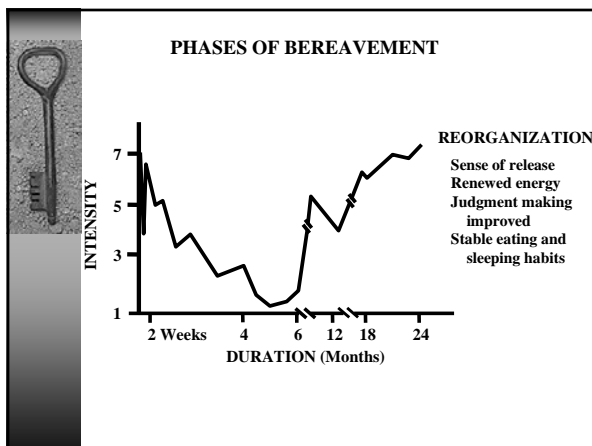
Newborn Death

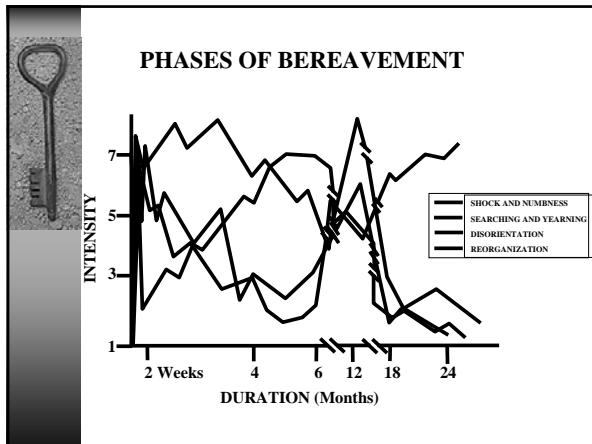
Sudden Infant Death
















When a baby dies

- ◆ Shock denial, numbness (overwhelmed parent by input)
 - May be viewed negatively by caregivers
- ◆ Reality: intense suffering and pain (effort to deal with loss)
 - This is very hard for empathetic caregivers
- ◆ Guilt
 - Be careful what you say
- ◆ Anger (advocacy, search for control, passion)
 - Might be directed against you – you’re an easy target
- ◆ Withdrawal (effort to regain emotional stability and self protection)
- ◆ Intrusiveness (seeking parental role, passion to participate in care)
- ◆ Fear
 - Going crazy
 - Strange rituals




What Not to Say

- ◆ **“You can have other children.”**
- ◆ **“You have an angel in heaven.”**
- ◆ **“This happened for the best.”**
- ◆ **“At least it happened early.”**
- ◆ **“Thank God you have another one”**
- ◆ **“You are young.”**



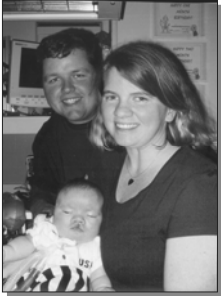
What You Can Say


- ◆ “I’m so sorry that this has happened.”
- ◆ “This must be hard for you.”
- ◆ “I just don’t know what to say.”
- ◆ “How are you doing with all of this?”



Here are some things that work

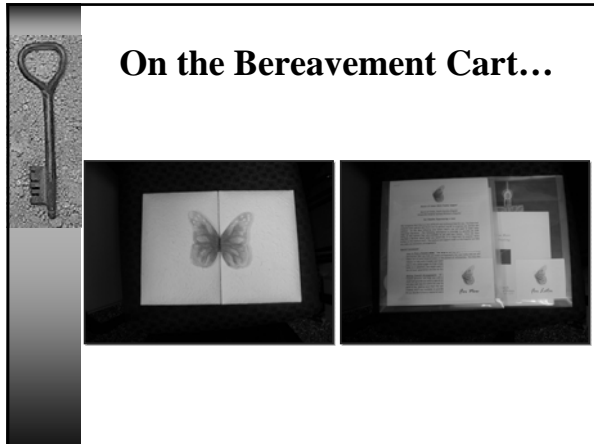
- ◆ **Decrease confusion**
 - Validate their understanding
 - Avoid jargon
 - Give clear information
 - Provide immediate care
- ◆ **Be with their grief**
 - Let go of “doing” more
 - Just listen,
 - Hear their story
 - Sit, understand helplessness

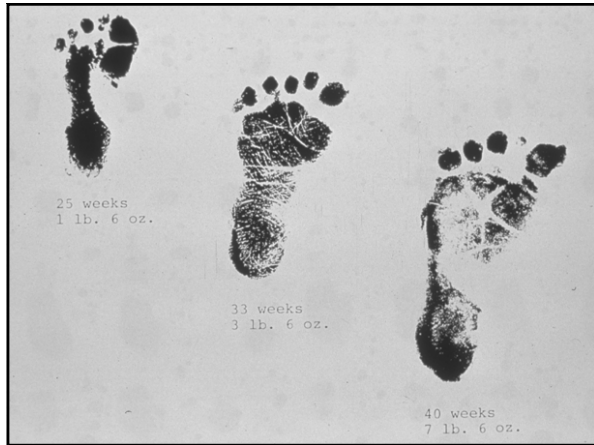




Some things that work (cont)....


- ◆ **Mementos- all in bereavement cart**
 - Whatever they want
 - foot prints
 - bathing
 - rings
 - crib items
 - molds
 - diapers
 - Privacy time in parent room with entire family
 - Pictures







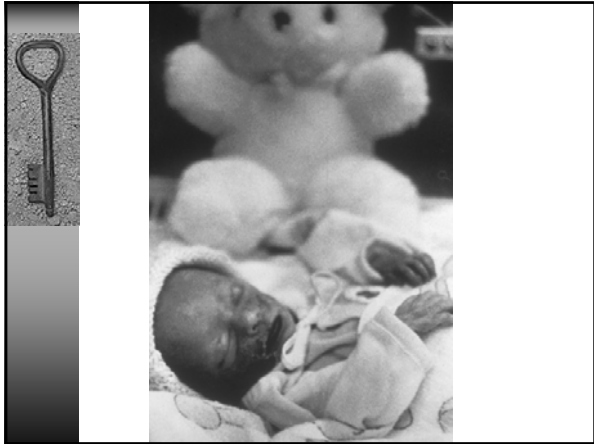




Some things that work (cont)....

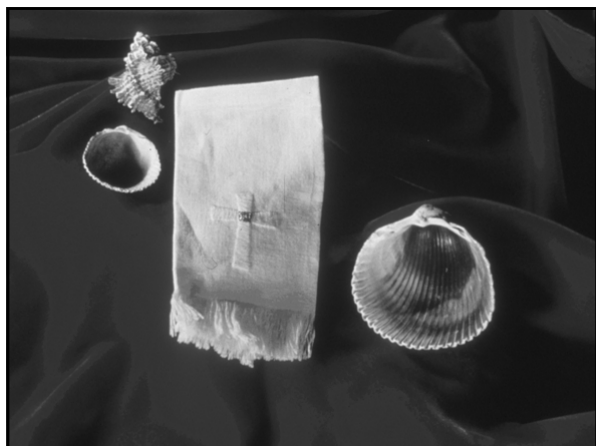
- ◆ **Photographs**
– Some ideas ...

















Some things that work (cont)....


◆ Other Support Services

- Privacy time in parent room with entire family
- Clergy/social services/child life
- Be considerate regarding autopsy/funeral arrangements, don't rush (some families hold the body for several hours, it's OK)
- Written information about funeral services
- Record the name in the bereavement cart so that we can make follow up phone calls




Normal Caregiver Responses

- ◆ **Feeling overwhelmed**
- ◆ **Being fearful of causing more pain**
- ◆ **Feeling guilt that you couldn't do more**




3 Types of Caregiver Responses to Perinatal Death

- ◆ **Avoidance**
 - Two types of house officers, those who run toward the problem and those who run away. Ask for company to go in to see family with you.
- ◆ **Insensitive or moralizing**
- ◆ **Supportive [appropriate]**




Helpful Approaches

- ◆ **Care for yourself**
 - Know your limits/get help from co-workers
 - Refill/debrief
 - Know that you make a difference just by being present
- ◆ **Having a standard of care**
- ◆ **Sharing your feelings**
- ◆ **Attending care conferences**
- ◆ **Interdisciplinary team**
- ◆ **Guidelines for employee support**




Incongruent Grief Stereotypes


<i>Feminine</i>	<i>Masculine</i>
<ul style="list-style-type: none"> ◆ open expression ◆ sad, depressed ◆ empty feeling ◆ need to talk ◆ comforted by holding 	<ul style="list-style-type: none"> ◆ stoic ◆ aggressive, angry ◆ powerless ◆ task focused ◆ sexual intimacy ◆ needs partner to feel better



Cardinal Rules for Grief Support


- ◆ Silence is OK
- ◆ Admit our own helplessness
- ◆ Be genuine
- ◆ Be with the person in grief
- ◆ Don't judge another's grief
- ◆ Be clear about your issues on death
- ◆ Know your limitations
- ◆ You do not want to add to the pain
- ◆ Know that you cannot take the pain away






Being With

- ◆ Being there
- ◆ Conveying availability
- ◆ Sharing feelings
- ◆ Not burdening




Enabling

- ◆ Informing/explaining
- ◆ Supporting/allowing
- ◆ Focusing
- ◆ Generating alternatives
- ◆ Validating




Doing For

- ◆ Comforting
- ◆ Anticipating
- ◆ Performing competently/skillfully
- ◆ Protecting
- ◆ Preserving & respecting dignity




Offering Choices


◆ Select a name	◆ Having support when “bad” news is given
◆ Blessing or baptism	◆ Being with the baby at the time of death or knowing that our staff was there
◆ Autopsy, genetic studies	
◆ Disposition/funeral options	
◆ Holding baby/kangaroo care	



***Facilitate Emotional
Relocation of the Deceased***

- ◆ Follow up phone calls
- ◆ Memorial services
- ◆ Help reminisce positive memories
- ◆ Facilitate helping parents find a new place in their life for the baby
- ◆ Discuss meaning of subsequent pregnancy






The Most Important concept

A family will remember you forever if you were caring, even though the child was lost.

They will also remember you if you were not there/did not make time.




Twin and Higher Order Birth Loss

Parents Appreciate:

- ◆ seeing/holding babies together
- ◆ photos of babies together and separately
- ◆ input about surviving baby (separate id's) identification
- ◆ combining ceremonies







Condolence Letter (Bereavement)

- ◆ I usually wait a few days, then write the family a personal condolence note.
- ◆ I use personal note stationary for this purpose.
- ◆ It's short, I use the baby's 1st name and I also use the word "died".
- ◆ I sign it, "With my Sympathy, "
- ◆ I find this helps me deal with the death and the families universally have been pleased to receive these commemorations.
- ◆ Call me any time you need to.

