**Bereavement Care after Perinatal Loss**

Attachment can happen very early in pregnancy, **regardless of gestational age.**

This is a unique loss, not only of a baby but also of a person’s identity as a parent.

**A parent’s experience in the hospital or clinic can make the difference in their grief and mourning**

Things often associated with attachment include:

* Planning pregnancy, confirming pregnancy, feeling fetal movements

Factors that do NOT influence how a person feels about a pregnancy

* Length of pregnancy, whether baby is planned/wanted or not

Perinatal Loss: **UNINTENDED** ending of a pregnancy at any time before or during birth, or death of a newborn in the first month after birth

Types of Loss

Miscarriage/SAB: <20 weeks

Ectopic Pregnancy

Stillbirth: >20 weeks and fetal wt 350g or more

Neonatal Death: death within the 1st 28 days of life

Things you can say when there is a loss:

I’m so sorry to have to give you this news, your baby is dead

I wish I had other news to give you

I wish things had turned out better

How are you doing with all of this?

What can I do for you?

Acknowledge your own vulnerability/your own feelings about this

Things you should NOT say:

At least it happened early

You’re young you can have others

This happened for the best

At least you have other children

I understand how you feel

Do not call the baby “fetus” or “it”

**What do bereaving families want from professionals after the sudden death of their child?**

BMC 2014: systematic review 52 studies, 25 quantitative, 20 qualitative, 7 mixed

3 themes came up throughout these studies:

* Be able to say goodbye
* Understand why and how their child died
* Feel supported by professionals

Summary of data on these topics from M&M on Perinatal Loss:

**Being able to say goodbye:**

* Conflicting evidence, small samples, mostly qualitative, mediating factors not accounted for
* Most qualitative data shows holding baby can be beneficial for bereaved parents
* We should give info about options and support parents to choose options that feel right for them
* Being coerced about decisions is detrimental
* There is an Important role of healthcare professionals in encouraging parents to see and hold their stillborn baby

**Understand why and how their baby died**

* Parents struggle to understand why their baby died
* Autopsy can help erase feelings of guilt, provide answers, help cope with death (ObGyn 2007)
* Parents report few choices during labor and delivery, inadequate communication on burial options and autopsy results

**Feel supported by professionals**

* Families don’t always receive the follow up care and meetings they need
* Parents want practical information about dealing with bereavement and professionals to remain in contact
* Only 13% parents had a scheduled meeting with any physician to discuss their child’s death (2007 Journal of Pediatrics)

**Memento Mori**

* Memorabilia important to parents
* Includes photographs, plaster casts of the child's hands and feet, or clothing that the child wore in the hospital
* Qualitative studies show parents without photos regretted not having them

**Early Pregnancy Loss – Bereavement Assessment <20 weeks**

Ensure parent understands management options

* Aspiration w/ general/deep sedation (operating room)
* Aspiration w/ local/moderate sedation (office-based)
* Medical (misoprostol +/- mifepristone)
* Expectant management
* Best choice reflects patient values and preferences
* **CRMC wiki 2011 Early Pregnancy Failure** for more detail– Ian Wallace, talks a lot about shared decision making

Listen for and assess the meaning of their experience

* 75% of parents will consider this a loss of a baby
* 25% of parents will consider loss of a part of life
* Try to assess: Is there a sense of loss of baby, loss of pregnancy, no sense of loss, cannot tell?

Why does this happen?

* 80% of all cases of pregnancy loss occur within the first trimester, 10% of all pregnancies
* 50% 1st trimester loss chromosomal abnormalities
* **A significant portion of stillbirths remains unexplained**
* Some risk factors: nulliparity, advanced maternal age, obesity, HTN, DM
* Women with diabetes prior to pregnancy have a two- to five-fold increased risk of stillbirth
* http://www.acog.org/-/media/Practice-Bulletins/Committee-on-Practice-Bulletins----Gynecology/Public/pb150.pdf

If a woman chooses expectant Management

* Explain what will happen
  + You can assess how much a woman wants to know, at least let them know in general that they will experience bleeding, cramping, will pass tissue
* Ask if they have thought about a plan for pregnancy tissue
  + Again, some women may not want to talk about this, but should be aware there will be tissue.
  + You can say “is it ok if I ask you whether you’ve considered what you may do with the pregnancy tissue?”
* Discuss pain management
  + SAB can be VERY painful. A woman in our perinatal bereavement training said it felt close to as painful as when she delivered a term baby.
  + Advise ibuprofen and consider a Rx for small amount of norco
* Discuss lactation (see below for details)
* Consider asking if they have any spiritual traditions, blessing ceremony, naming ceremony
* Up to 8 weeks expectant management is successful in achieving complete expulsion in approximately 80% of women

If a woman is in the emergency room with a SAB, you should discuss respectful disposition of remains

* Most tissue <20 weeks at CCRMC is put in formalin to prevent autolysing and sent to pathology for testing (whether POC/molar/infection/etc) after which they are discarded
* Ask if parent would like to have tissue buried after required tests are done
* Chromosomal testing can be done on POC if h/o recurrent SAB but must be approved by the pathologist. If this is the case ask parent if they would want this
* According to Dr. Das head of pathology, **if the fetus is intact it is possible to NOT be preserved in formalin, but you must call pathology to confirm this at the time**
* There is a form parents can sign “authorization for Contra Costa Health Services to use or disclose health information”
* **Tissue cannot be given directly to parents and MUST go through a funeral home**
* Some emergency rooms have “fetal demise kits” that parents can take home: gloves, chucks, hat. You could grab some of these things if you had time



Discuss grief process, make sure support information is given

* Remember, 75% of parents will see this as loss of a baby, **regardless of gestational age**
* CCRMC is in the process of creating a perinatal bereavement team with social workers who can follow up on mothers after a demise. As of now Sally is trained in this as is Tommie Tigh
* Contra Costa Counseling 1-800-837-1818
* http://nationalshare.org

**Lactation**

Mothers will still lactate after a fetal demise. Its important to talk to them about this

If breasts are firmly supported and milk is not expressed more than needed for comfort, milk supply will gradually decrease

* Wear a firm bra
* Use breast pads to soak up leaking milk
* Relieve pain/swelling of engorgement with cold compresses or cold cabbage leaves in bra
* If breasts feel too full, express a little milk but only enough to provide comfort
* Ibuprofen can help with pain and swelling
* Check in with lactation consultants, they are likely to have experience with this
* If a mother wants to donate milk, this can be done with Contra Costa Milk Bank 408-998-4550. They are based in San Jose. Call the number they will fax a form for MD to sign and fax back to the hospital. Mom has to go to quest lab for more blood tests. Milk bank will send a cooler

**Bereavement Assessment > 20 weeks: Stillbirth/Newborn**

* RNs have their own checklist and do most of this already, but I think it is good for doctors to be aware and part of the process as well
* Discuss options for delivery (will not go into this here)
* Once the patient is admitted flag the door – we have this on L&D with a leaf. **It is VERY important that people not walk into the room thinking this is a woman with a live baby which has happened**
* Offer pastoral care – we have volunteer pastors on call
  + Parents even without religious affiliation may find comfort in ritual/ceremony
  + Ask if they have any spiritual traditions, blessing ceremony, naming ceremony
* Offer option for parent(s) to spend as much time as they wish with the baby after delivery
  + Our policy at CCMRC is that a parent can see their baby for as long as they want. In between being with parent(s) the baby is taken by RN down to the morgue
  + RNs know to warm baby with blankets before being given back to parents
* Autopsies are possible, but depend on the situation. Check with an attending before discussing this with the patient
* Have parents name the baby if they’d like to, bathe/dress the baby if possible and desired (RN usually does this)
* RN will record baby’s weight, length and head circumference
* Genetic studies can be offered if there is a history of recurrent loss
* Offer mementos: RN has boxes on L&D in which blanket, lock of hair, baby clothes are placed
* Offer photographs
  + ***Now I Lay Me Down to Sleep*** is a volunteer professional photography service that will send a photographer to the hospital and provide free photographs.
  + <https://www.nowilaymedowntosleep.org/find-photographers/>
  + Nurses also have a digital camera as well as a large camera in the room where the blanket warmers are and can take photographs of the baby. **Its important that this is done by someone that feels comfortable taking these photographs**
  + **According to qualitative data, most patients wanted photographs of their baby**
* Discuss cremation/burial options
  + Babies born >20 weeks are kept in the morgue for 30 days, parents can spend as much time with them in the hospital as they wish
  + CCRMC will pay for cremation if parent wants this
  + If they want a burial, RN and SW has information on funeral homes that offer discounted services for demises. Baby must be released directly to a funeral home
* Discuss Laction (see above)
* Follow Up (see below)





Sample photos from Now I Lay me Down

To Sleep website

**Follow Up**

* Try to schedule mom a post partum appt with delivering or prenatal provider
* If not able to, send a message to the doctor to let them know in advance about the outcome and appt (there have been many incidences of people not knowing a woman had a fetal loss and congratulating them at the post partum visit
* Remember stillbirth counseling process has several stages:
  + At time of diagnosis
  + When making plans for delivery
  + At delivery and immediately postpartum
  + During the weeks after discharge and at the first postpartum visit
  + At "wrap-up" meeting when all laboratory and pathology results are available
  + When considering another pregnancy
  + According to qualitative data, **most parents WANT to be asked about their loss, discomfort in asking is often our own. You can always say “is it ok if we talk about the loss of (name of baby)”**
* Remember what parents want
  + Be able to say goodbye
  + Understand why and how their child died
  + Feel supported by professionals
* Follow up on grief/counseling services
  + CCRMC is in the process of creating a perinatal bereavement team with social workers who can follow up on mothers after a demise. As of now Sally and Tommie Tigh is trained in this
  + Contra Costa Counseling 1-800-837-1818
  + Fetal Infant Mortality Review: can provide follow up call. Make sure form was faxed in the hospital (usually done by RN)
  + http://nationalshare.org
* Things to check in about
  + Make sure they were connected with grief counseling/perinatal bereavement team
  + How are they doing? How was there experience in the hospital?
  + Are there any questions they felt were not answered?
  + Ask if they’d like to share any mementos such as photos with you (if you have time)
  + Lactation
  + Birth Control
* Why did this happen?
  + Around 80% of all cases of pregnancy loss occur within the first trimester, 10% of all pregnancies
  + 50% 1st trimester loss chromosomal abnormalities
  + A significant portion of stillbirths remains unexplained
  + Some risk factors: nulliparity, advanced maternal age, obesity, HTN, DM
  + Women with diabetes prior to pregnancy have a two- to five-fold increased risk of stillbirth
  + **Its ok to say that we just don’t know, and acknowledge how hard that may be**
* Will this happen again?
  + In low-risk women with unexplained stillbirth, risk of recurrence after 20 wks is 7.8 to 10.5/1,000 births with most risk < 37 wks (so around 1%)
  + After 37 weeks, the risk of recurrence drops to 1.8 per 1,000 (so < 0.2%)
  + Optimize their health prior to pregnancy – control BS, folic acid, control BP
  + When the cause of the prior stillbirth is unknown, there is no evidence that intensive monitoring in future pregnancies will make a significant difference in preventing stillbirth
* When can I get pregnant again?
  + Small observational studies show no benefit to delayed conception after early pregnancy loss
  + There is no convincing evidence on the optimum interpregnancy interval after a stillbirth
  + It is reasonable to advise women to delay conception until they feel they have achieved psychological closure of the previous pregnancy loss, which typically takes at least 6 to 12 months

Remember:

* This is a unique loss, not only of a baby but also of a person’s identity as a parent
* Their experience in the hospital or clinic can make the difference in their grief/mourning

**MORE RESOURCES**

http://www.glowm.com/section\_view/heading/Helping%20Families%20Cope%20with%20Perinatal%20Loss/item/417