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FOOTPRINTS

Pregnancy and Infant Loss Support, Education and Remembrance

# **Helping Families Cope With Perinatal Loss And How to Practice Self Care**

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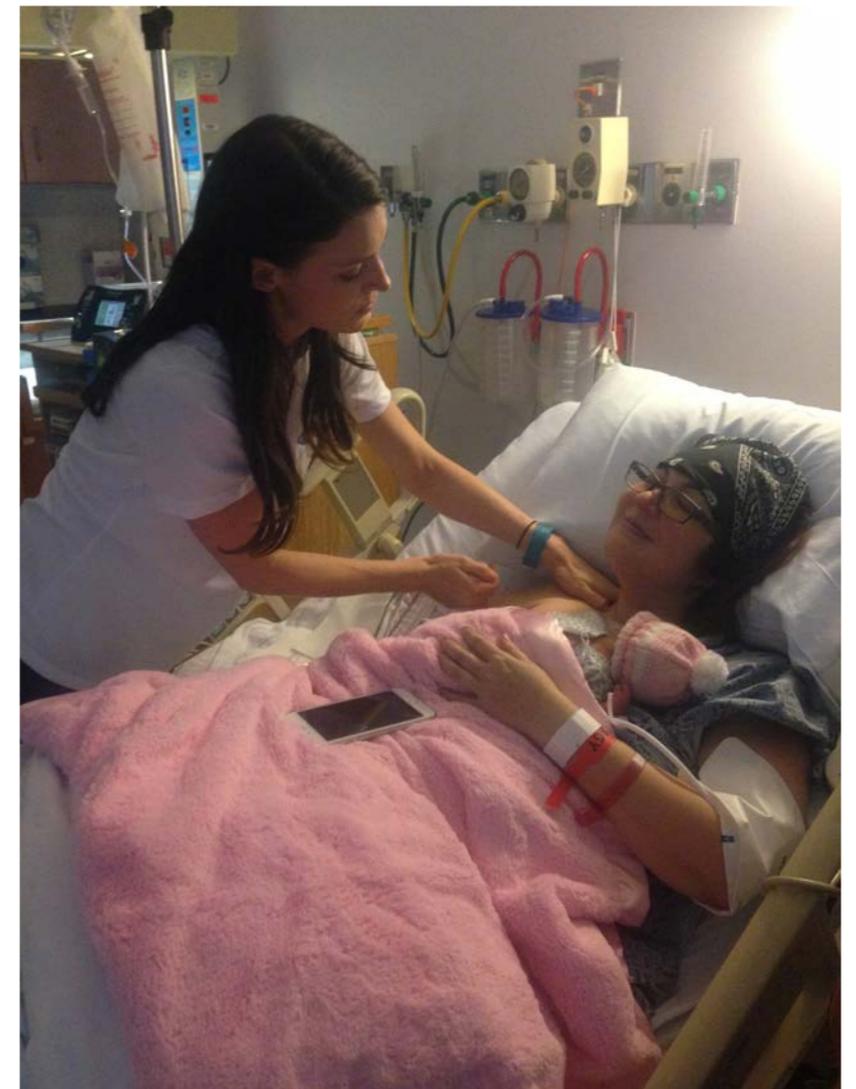
What is Forever Footprints?

Who do we serve?

What do we do?



***“Bereaved parents never forget the understanding, respect, and genuine warmth they received from caregivers, which can become as lasting and important as any other memories of their lost pregnancy or their baby’s brief life.”***



# How to care for patients with perinatal loss

- There is no “right” or “better” way for a parent to react to the loss.
- The parents’ experience is often misunderstood. It is generally minimized and invalidated by others.
- There can be health concerns to the mother that can cause fear, grief and anger.
- A vaginal delivery or D&C may be necessary.

# How to care for patients with perinatal loss

- In most cases, there is no explanation as to why the baby died.
- Parents need information to help with the guilt that accompanies this loss.
- Parents are dealing with the cruel violation of their expectations.



# Types of Perinatal Loss

## NEWBORN DEATH

“Every time we walked in and saw him, we prayed God would take him; and every time we walked out, we would pray God would let him live.”

- Parents are generally overwhelmed by the decisions and activity they are faced with (in NICU, etc.) and generally need extra time to make decisions. Consider using verbal AND written communication.
- Parents need to spend time with the baby. They need to “parent” the baby regardless of the baby’s condition.

# Types of Perinatal Loss

## LOSS IN A MULTIPLE PREGNANCY

“We are grieving and loving at the same time...but it’s not like pulling and tugging. It’s more like ripping and tearing.”

- If the surviving baby is ill or in the NICU, the parents will usually put off their grief. The focus is on the child that survived, and getting that child into a “safe zone.”

# Types of Perinatal Loss

## BABY WITH A LIFE-LIMITING DIAGNOSIS

(formerly known as “Condition Incompatible with Life”)

“I really have peace that we carried her to term. I know in my heart that I have given my daughter all that I could and loved her every day of her life.”

# Types of Perinatal Loss

## LIFE-LIMITING DIAGNOSIS

- It is common practice to give parents a choice about the pregnancy (i.e. terminate or continue with the pregnancy).
- The choice is very personal and individual.
- There is no right or wrong way to proceed.

# Grief Reaction - Psychological

## Psychological Symptoms

Preoccupation with thoughts of the baby

Irritability

Restlessness

Anxiety

Fear

Yearning

Hopelessness

Confusion

# Grief Reaction - Physical

## Physical Symptoms

Shortness of breath

Tightness in throat

Fatigue

Sighing

Crying spells

Empty feeling in abdomen

Sleeplessness

Change in appetite

Heart palpitations

# Points to Keep in Mind

- The death of their baby may be the first death they have had to deal with.
- The death of their baby will likely be the biggest trauma they have ever experienced in their lives.
- Perinatal loss is always Traumatic Grief.



## **Cheryl Beck, 2004 examined PTSD after childbirth**

- The patients replayed the traumatic birth, nightmares, flashbacks
- Women frequently used the image of “losing their souls”
- Seeking to have answers to their questions regarding the birth
- Anger towards clinicians, family members, baby and themselves
- Anxiety, panic, OCD
- Depression and suicidal ideation
- Isolation from the world of motherhood-dreams shattered

# Guidelines for Helpful Communication in the Hospital

“I am so sorry”

“This must be hard for you”

“It is OK to talk about how you feel”

“This was not your fault”

“There is no right or wrong way to grieve”

“Your reactions and feelings are normal”

“Making these decisions (photos, visitors, etc.) is caring  
for/parenting your child”



# Communication in the Hospital

Use the Baby's name

Try to find something positive to say about the baby – event when there has been a lot of trauma or injury.

“Billy's eyes are beautiful. They look just like his Mom's”

“Janie has so much pretty blond hair”

“What cute feet Billy has”

“What a sweet little baby”

# Communication in the Hospital – What NOT to Say

“I understand”

“You are young, you can have other babies”

“You have an angel heaven”

“I know someone who was farther along than you when their baby died”

“It was just a miscarriage”

“I know how you feel”

# What NOT to Say (continued)

“This happened for the best”

“At least you have other kids at home”

“Everything happens for a reason”

“It’s better to have lost the baby before you got to know him”

Saying nothing at all

# Improving Patient Care

## During the Loss

- Acknowledge – What the mother/family is currently going through. They news they have just been given. Use the baby's name because he/she did exist.
- Sympathy – “I am so sorry.” Comfort using touch, giving a hug.
- Patience – Initial reaction most likely will be shock, crying.
- Compassion – “I am here for you.” Offer to call significant other or family member if the mother is alone.



# Improving Patient Care

- If a diagnosis of “incompatible with life,” inform the family of their options:
  - Forever Footprints Journey to Remember program
- “Code Joseph” – If the mother has just delivered a stillborn or the baby died shortly after birth, clear the hallways of other mothers in labor and mothers leaving the hospital with healthy babies.

# Improving Patient Care

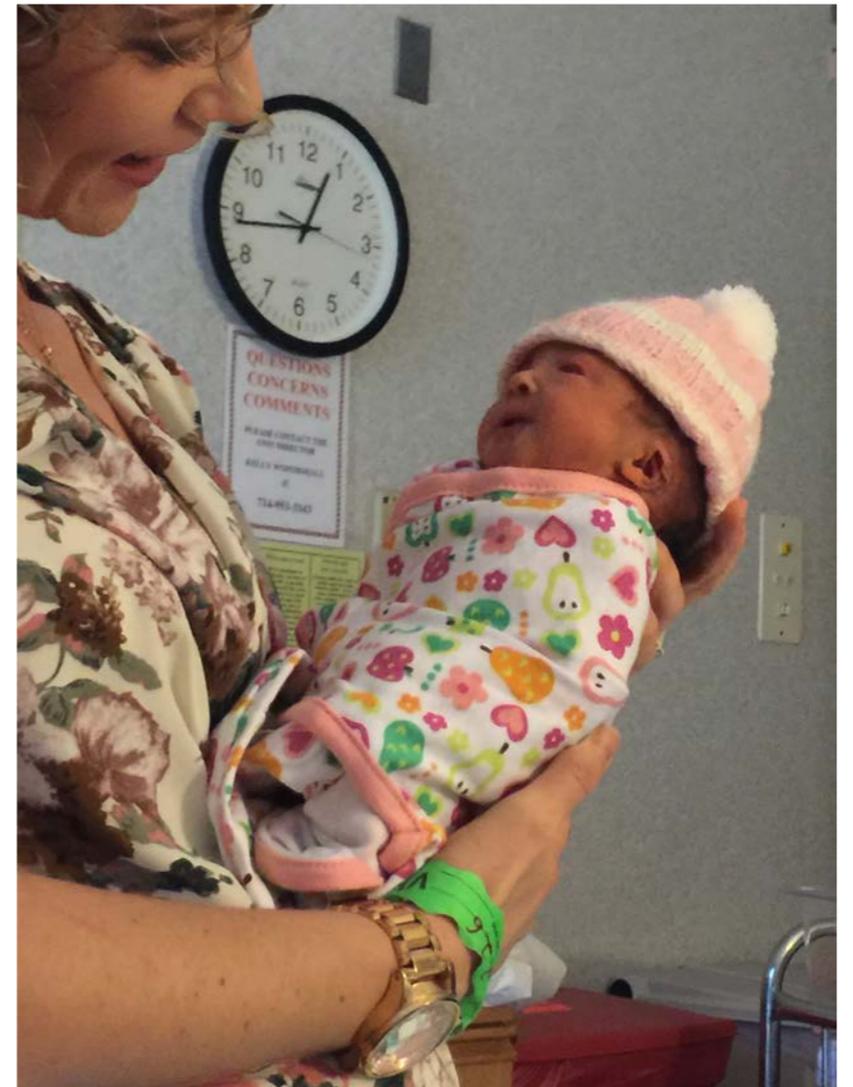
## After the Loss

- Encourage the family to see, hold and spend time with the baby.
- Provide the family with memory items: ultrasound photos, photos taken of the baby before and/or after the baby has passed, memory box, lock of hair, hand and footprints
- Follow up medical care – Schedule doctor's visit after hours, during lunch time or the very first appointment in the morning or after lunch hour. If unavailable, bring mother back into exam room right away so as not to spend time in the lobby with new mothers and their babies.
- Remember – Send a card to the family. Arrange a call from a nurse or social worker a week or two after the loss occurs

# Improving Patient Care

## After the Loss (continued)

- Reassure – Remind parents that their grief is normal. Men and women grieve differently.
- Allow the parents to talk, tell their story.
- Assess current support from partner, family and friends.
- Contact Forever Footprints – We can assist in finding a local support group and/or therapist.



# Improving Patient Care

After the Loss (continued)

- Lactation
  - Donate milk in memory of the baby to CHOC NICU
  - Don't bind breasts, instead wear supportive sports bra to keep from getting plugged ducts and mastitis
  - Sage Tea can decrease supply and help dry up milk. One full cup every 6 hours should dry up milk quickly. Found at most health food stores.
  - Cabbage Leaf Compresses – Rinse and dry plain green cabbage. Remove base of hard core vein and gently pound leaves. Wrap around breast and areola, leaving nipple exposed. Change every 30 minutes or as needed.

# How Nursing Staff can Help with Couples Communication

Encourage couple to talk and CONSULT with each other about ANY decision that needs to be made.

Holding the baby or not, and for how long

Pictures

Clothing and other keepsakes

Blessing / Baptism

Who should come to visit in the hospital (family/friends)

Funeral, burial, cremation

# Helping Couples with Communication (continued)

- One parent may want to try to make all the decisions as a way to protect the other from painful feelings.
- This is almost always a mistake and causes deep regrets and resentments.
- It is one of the issues that comes up later in therapy.

# How Therapy Can Help

- It can help both partners to have more understanding and compassion for the other.
- Understanding different styles (schemas) of grief helps increase empathy for the other partner – and maybe even begin to value the differences.
- You learn you are not alone in your tragic loss.
- You learn others have survived and you can too.

# How to practice self care after patient loss



# How to practice self care after patient loss

- There is no “right” or “better” way to react to the loss.
- Create a safe space for staff to discuss their feelings of the loss
- Prioritize yourself
- Find activities that bring comfort and happiness
- Seek professional help when needed

# Tools to practice self care

- Breathing
- Meditation
- Hugging
- Sleep, drink water, eat healthy, exercise
- Take a bath. Take a Nap. Take a Walk.
- EFT Technique with Amy St. Hilaire



# Perinatal Loss - Resources

Forever Footprints – <http://www.foreverfootprints.org>

- Forever Footprints support groups
- Memory boxes and sibling backpacks
- Annual OC Walk to Remember and IE Walk to Remember
  - Helps parents memorialize and remember their baby with other bereaved families and supporters.



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