

Supporting Parents at the Time of Perinatal or Infant Loss

Tending Grief

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Disclosure

I have no actual or potential conflict of interest in
relation to this program / presentation

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Birth and
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Perinatal
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Loss



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Trauma
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Bereaved
Parent

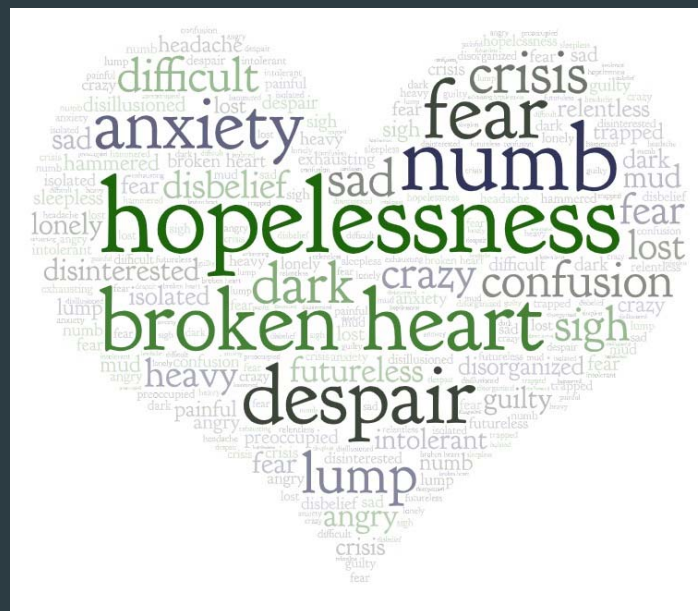
Learning Objectives

- Summarize grief related needs of parents experiencing perinatal or infant loss.
- Identify three ways to verbally support parents experiencing perinatal or infant loss that will support them on the trajectory of healing.
- Identify three ways to practically support parents experiencing perinatal or infant loss that will support them on the trajectory of healing.
- Describe the unique role health care providers have in supporting parents at the time of loss.

*begin to take the tiny steps
toward healing.*



*75% of families losing even an early pregnancy referred to the woman as "mother" and the products of conception as "baby." ¹





Perinatal and Infant Loss Bereavement Care

A Real Need²

A Public Health Issue³

A Responsibility

A Difference Maker

Working Towards a “Good Outcome” at Discharge



EXPRESSES
FEELINGS



UNDERSTANDS
CHOICES



RECOGNIZES
IMPACT OF
GRIEVING PROCESS



PARTNER IS
INCLUDED



MANAGES TASKS OF
DAILY LIVING



HAS CONTACT
INFORMATION



SUPPORT PLAN
AFTER DISCHARGE



KNOWS WHAT TO EXPECT:
FUNERAL HOME, AUTOPSY
RESULTS, FURTHER
CONTACT

It can be hard and uncomfortable.

It can push on our own pain.

We can say or do the wrong thing.

We can say and do better things.

THE TRUTH ABOUT SUPPORTING THOSE EXPERIENCING LOSS

The Experience of Perinatal or Infant Loss is Unique

- ▶ They are parents, but there is no living baby
- ▶ Baby will not meet many people
- ▶ Taboo to talk about it in many places
- ▶ Few people understand



The Loss Itself is Unique



- ▶ Future hopes and dreams
- ▶ Parenthood
- ▶ Being pregnant/physical connection
- ▶ A sense of possibility

TALKING TO PARENTS

| Repeat | Communicate | Assure | Explain | Validate |
|--|--|--|--|--|
| Say what you are going to say. Say it. Say it again. | Speak to both parents, if possible, or find another person to be a listener. | Assure parents that you will stay with them. They will not be abandoned. This type of loss is survivable. | Tell parents what to expect <ul style="list-style-type: none">• How the baby may look• How family members sometimes react• What the overall process looks like | Validate the loss <ul style="list-style-type: none">• Use the baby's name• Point out memorable features |

WHAT DO I SAY???

HELPFUL

"I wish things would have ended differently."

"I'm sorry."

"You have a beautiful baby."

"We can talk later."

"Your baby is well loved."

"May I just sit here with you?"

WHAT DO I NOT SAY???

LESS THAN HELPFUL

"It was a blessing."

"You have other children to think about."

"It could be worse."

"Time will heal."

"At least ... "

"This is God's will."

"You need to ..."



HOW DO I TALK ABOUT THE BABY?

- ▶ Ask about the baby's name. How did you choose it? Was he or she named after anyone? When did you decide on a name?
- ▶ What did the baby like or dislike before she was born? Did you get a sense of personality? Tell me about him.
- ▶ Ask about the pregnancy. Tell me what it was like when you found out you were pregnant. Did you know the baby's gender? What was it like to find out?
- ▶ Who does the baby look like? "Does anyone else in your family have long fingers like she does?" "His eyes look like perfect little blueberries."

What Do I Do?



- ▶ Do not let your ideas about what parents need get in the way
- ▶ Give parents all the time they need
- ▶ Listen, listen, listen
- ▶ Honor parent(s)' need to be detached sometimes
- ▶ Support the presence of family, including siblings, grandparents, etc.
- ▶ Explain resources to parents

WHAT ELSE MAY PARENTS NEED?

- ▶ Help with extended family/ complicated family
- ▶ To say hard things out loud
- ▶ To prepare for talking to others, responding to questions
- ▶ Empathetic touch

WHAT ELSE MAY PARENTS NEED?

- ▶ Help curb negative self-talk
 - ▶ Interrupt the habit before it starts
- ▶ Help normalizing feelings
 - ▶ Fear/ Anxiety
 - ▶ Anger
 - ▶ Guilt/ Shame
 - ▶ Confusion
 - ▶ Isolation

So much of what connects parents
to babies they have lost is
searing pain.

Use the precious time you have with
them to help create memories that
are more than painful.

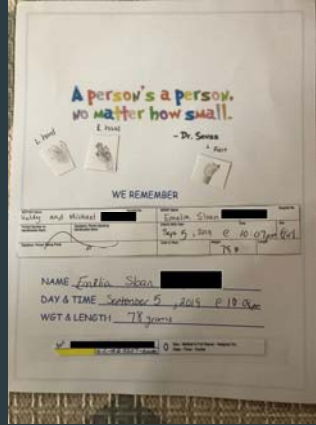
-Brigid Boyle



MAKING MEMORIES

- ▶ Suggest, discuss, help with photographs
- ▶ Support parents in helping to create mementos
- ▶ Assist parents in tending to baby- bathing, dressing, swaddling, reading, etc.
- ▶ Offer options, not orders
- ▶ Let go of your own agenda

OTHER OPTIONS FOR MEMORIES



Facilitate Holding and Spending Time with the Baby



- ▶ Be creative
- ▶ Demonstrate holding the baby
- ▶ Lay baby on pillow
- ▶ Have parent hold baby in a basket
- ▶ Make repeated offers, not demands
- ▶ Explain and offer Cuddle Cot, if available

100% of bereaved mothers who delivered macerated or malformed infants found that seeing and holding the baby after death was helpful. ⁴



Saying Goodbye

- ▶ Talk through options with parents
- ▶ Support their choices, even if they are not the choices you may have made
- ▶ Learn about their culture's customs, their personal beliefs
- ▶ Invite spiritual leaders- blessing, baptism, baby naming ...
- ▶ Grant privacy, but do not abandon parents
- ▶ Explain what will happen next, where the baby will go, etc.

Following Up

Essential to help maintain the healthy grieving they started in the hospital.

Ideally, the person who follows up should be a person who is most involved with the parents in the hospital.

The connection with someone who knew their baby is powerful and healing.

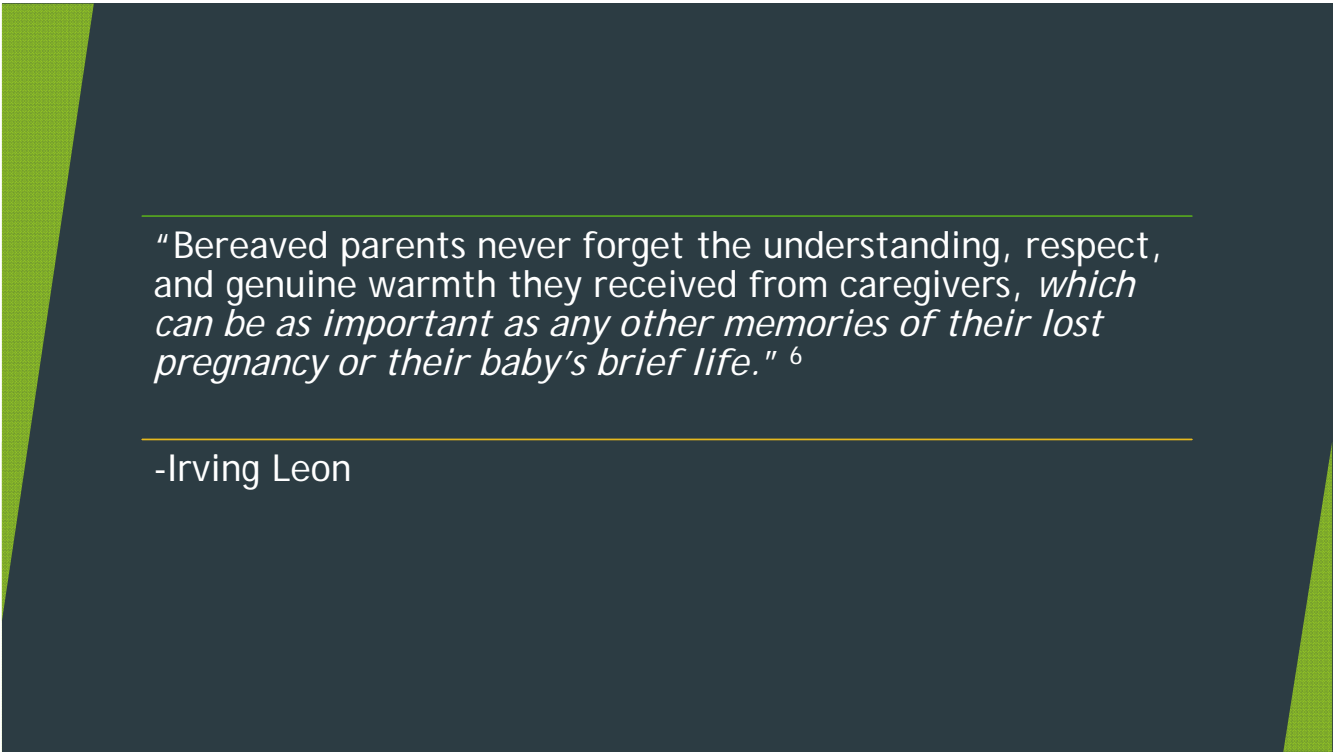
Allows for information regarding the final outcome for the parents, and can energize the provider moving forward.

Honoring and Remembering

- ▶ Post Partum Visits
- ▶ Opportunities for Reconnection
- ▶ Subsequent Pregnancies
- ▶ Visible Acknowledgment of Losses




*"The lost hearts.
This is our memorial to all the unborn children who unfortunately "lost" their hearts,
Hearts that stopped beating during pregnancy.
This is our way to remember all those babies that passed before birth.
Our thoughts are always with them and their parents.
So every time a loss of life is determined, we put a small heart in the glass jar as a symbol that they will never be forgotten."*⁵



"Bereaved parents never forget the understanding, respect, and genuine warmth they received from caregivers, *which can be as important as any other memories of their lost pregnancy or their baby's brief life.*" ⁶

-Irving Leon



Thank you to all those who care for families experiencing losses with comfort, wisdom, grace, and love.

Thank you to all the bereaved parents who generously share
their stories of heartache, loss, and profound love, and
especially to those who so willingly granted permission to
share photographs of their beautiful babies.

Michael
Isabel
Janie B
Kinslee
Brynn
Emelia
Oliver
Leo

PARENT PANEL



Emelia Sloan



Leo Joseph



Brynn
Ann

NOTES

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