



**STAR LEGACY**  
FOUNDATION

# WHEN PREGNANCIES DON'T GO AS EXPECTED

LINDSEY J. WIMMER, DNP, CPNP, IPPE-C

# PERINATAL BEREAVEMENT



# PERINATAL BEREAVEMENT

Infertility

Miscarriage

Ectopic  
Pregnancy

Selective  
Reduction

Elective  
Termination

Stillbirth

Neonatal  
Death

# PERINATAL BEREAVEMENT

## Miscarriage

- \* Death of baby in utero before 20 weeks gestation
- \* 15-20% of all recognized pregnancies
- \* 750,000 – 1,000,000 miscarriages in the US/year

## Ectopic Pregnancy

- \* Fertilized egg implanted/growing outside the uterus
- \* 2% of all pregnancies

## Stillbirth

- \* Death of baby in utero after 20 weeks gestation
- \* 1/160 deliveries ends in stillbirth in the US
- \* 21,000 stillbirths in the US/year

## Neonatal Death

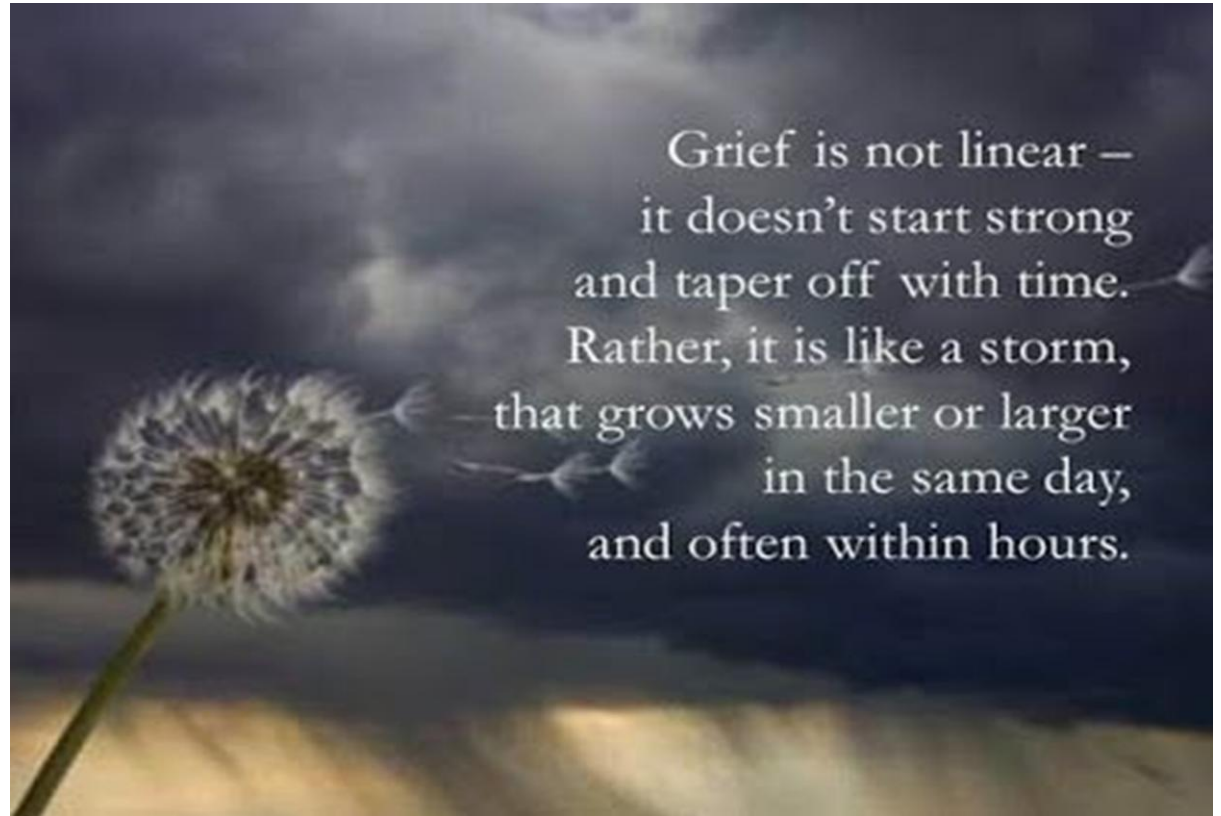
- \* Death of a baby after the moment of birth through 28 days
- \* Most common cause is complications from prematurity



# GRIEF CONCEPTS

## *NO ROADMAP FOR GRIEF*

- \* Rollercoaster of emotions
- \* Grief is not linear
- \* Grief is not predictable
- \* Grief is individualized



Grief is not linear –  
it doesn't start strong  
and taper off with time.  
Rather, it is like a storm,  
that grows smaller or larger  
in the same day,  
and often within hours.

(Black, 2020; Cacciatore et al, 2008; Capitulo, 2005; Leon, 2009; Miller et al., n.d.; Minton et al., 2022)

# GRIEF SYMPTOMS

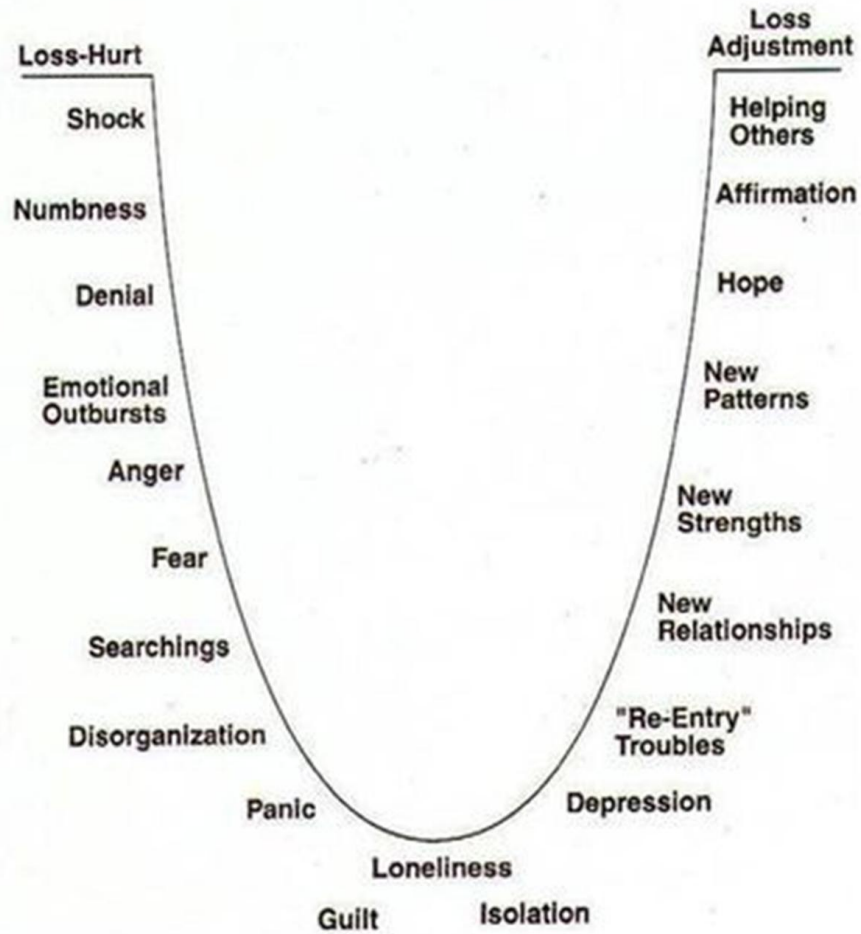
## EMOTIONS

- \* Shock
- \* Sadness
- \* Anger
- \* Irritability
- \* Anxiety
- \* Guilt
- \* Shame
- \* Helplessness
- \* Loneliness
- \* Powerlessness
- \* Jealousy
- \* Self-pity
- \* Vulnerability
- \* Poor self-esteem
- \* Sense of unfairness
- \* Easily distracted
- \* Denial
- \* Resentment
- \* Loss of control
- \* Fear
- \* Difficulty making decisions
- \* Withdrawal
- \* Depression
- \* Envy
- \* Hopelessness
- \* Lack of trust

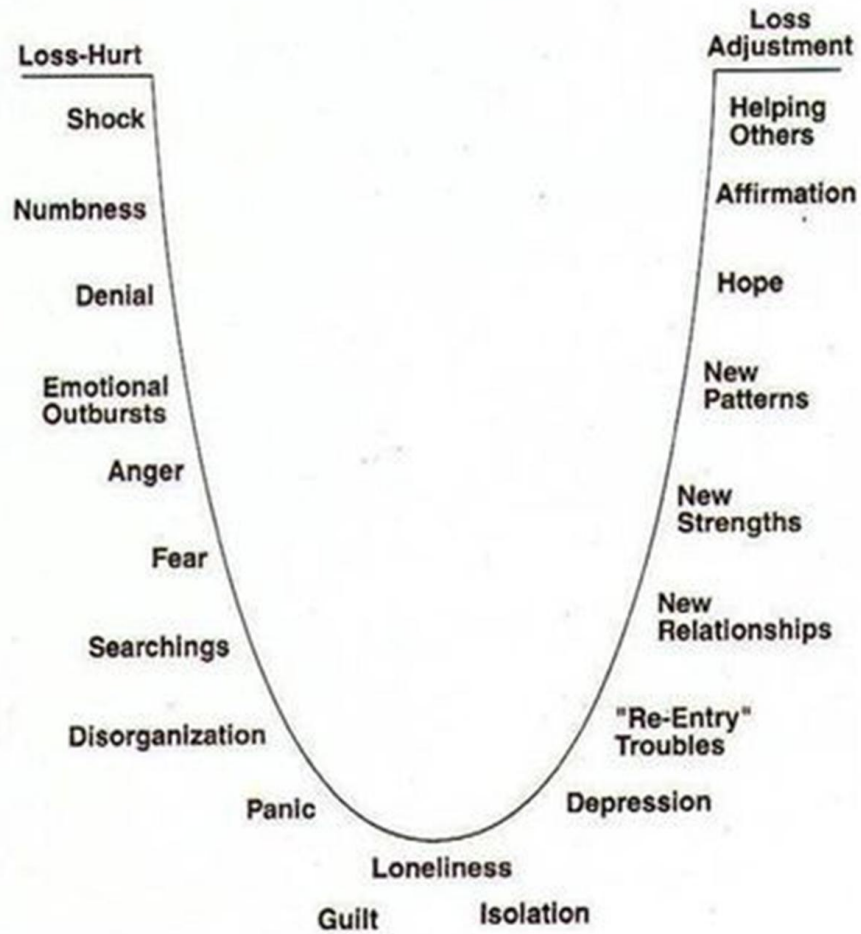


(Aggarwal & Moatti, 2022; Aiyelaagbe et al., 2017; Cacciato et al., 2009; Capitulo, 2005; Cena et al., 2021; Jones et al., 2021; Fenstermacher & Hupcey, 2019; Fernández-Basanta et al., 2020; Hendson & Davies, 2018; Koopmans et al., 2013; Krosch & Shakespeare-Finch, 2017; Leon, 2009; Markin & Zilcha-Mano, 2018; Murphy & Cacciato, 2017; Paraíso Pueyo et al., 2021; Pollock et al., 2020; Stillbirth: Information for Parents Whose Baby Has Died before Birth, 2012; Watson et al., 2019; Willer et al., 2020)

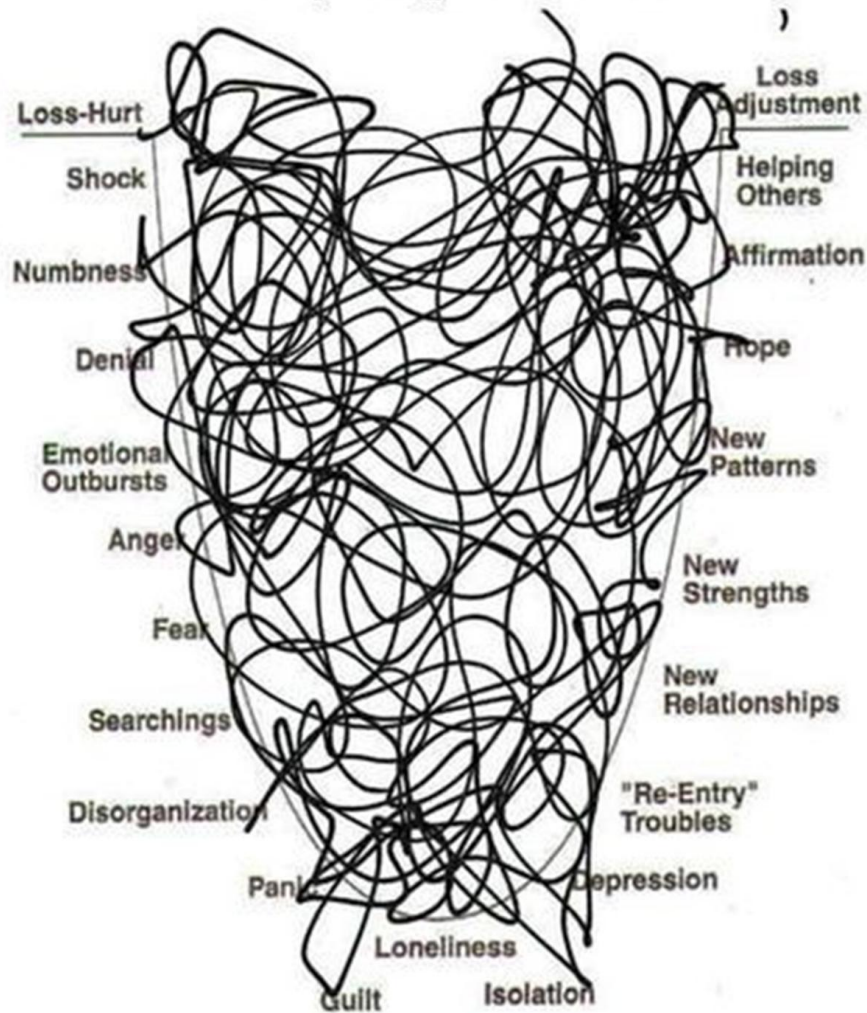
## STAGES OF GRIEF



## STAGES OF GRIEF



## My experience



# GRIEF SYMPTOMS

## PHYSICAL SYMPTOMS

- \* Nausea
- \* Headache
- \* SOB/chest pain
- \* Abdominal pain
- \* Arm aches
- \* Changes in heart/breathing patterns
- \* Throat tightness
- \* Appetite changes
- \* Sleep changes
- \* Fatigue
- \* Malaise
- \* Decreased concentration
- \* Memory lapses
- \* Physical illness
- \* Hallucinations/dreams/nightmares



(Aggarwal & Moatti, 2022; Aiyelaagbe et al., 2017; Cacciatore et al., 2009; Capitolo, 2005; Cena et al., 2021; Jones et al., 2021; Fenstermacher & Hupcey, 2019; Fernández-Basanta et al., 2020; Henderson & Davies, 2018; Koopmans et al., 2013; Krosch & Shakespeare-Finch, 2017; Leon, 2009; Markin & Zilcha-Mano, 2018; Murphy & Cacciatore, 2017; Paraíso Pueyo et al., 2021; Pollock et al., 2020; Stillbirth: Information for Parents Whose Baby Has Died before Birth, 2012; Watson et al., 2019; Willer et al., 2020))

# GRIEF CONCEPTS

## COMMON SEQUELAE

- \* Broken/changed relationships
- \* Chronic pain
- \* Chronic fatigue
- \* Mental health concerns
- \* Substance use
- \* Decreased productivity
- \* Employment difficulties
- \* Loss of social status
- \* Social isolation
- \* Financial difficulties
- \* Increased use of health services



(Bakbakhi et al., 2017; Beck et al., 2019; Burden et al., 2016; Cacciatore et al., 2009; Heazell et al., 2016; King et al., 2021; Leon, 2009; Pollock et al., 2020; Roberts et al., 2022; Shakespeare et al., 2020; Siassakos et al., 2018; Watson et al., 2019; Willer et al., 2020)

# GRIEF CONCEPTS



(Alvarenga et al., 2021; Leon, 2009; Marking & Zilcha-Mano, 2018; Miller et al., n.d.; Roberts et al., 2022)

# FAMILIES



- Fathers/Partners – Forgotten Mourners
- Children will grieve, too
- Grandparents have two losses

# MENTAL HEALTH

- \* 3-fold increased risk of depression, anxiety, and PTSD for both parents
- \* Perinatal loss also associated with sleeping disorders, complicated grief, risk of suicide, social phobia, panic disorder, substance use
- \* 25% of bereaved parents have significant psychological difficulties in the first two years after the loss



(Black, 2020; Burden et al., 2016; Cacciatore, 2010; Gold & Johnson, 2014; Herbert et al., 2022; Hollins Martin & Reid, 2022; Jones et al., 2019; Jones et al., 2021; King et al., 2021; Koopmans et al., 2013; Leon, 2009; Lewkowitz et al., 2019; Markin & Zilcha-Mano, 2018; Miller et al., n.d.; Navidian et al, 2017; O'Connell et al., 2016; Roberts et al., 2022)

*"I know when I bring up my baby, people around me are sad. Feeling sad is uncomfortable. Being depressed is uncomfortable. My baby dying is uncomfortable. It is easier for people to pretend these uncomfortable and terrible things do not exist. It is scary to face that we live in a world where tragic things happen. Many will choose to ignore it to protect themselves, and the result is that those of us who experience it end up feeling very alone."*

# GOALS

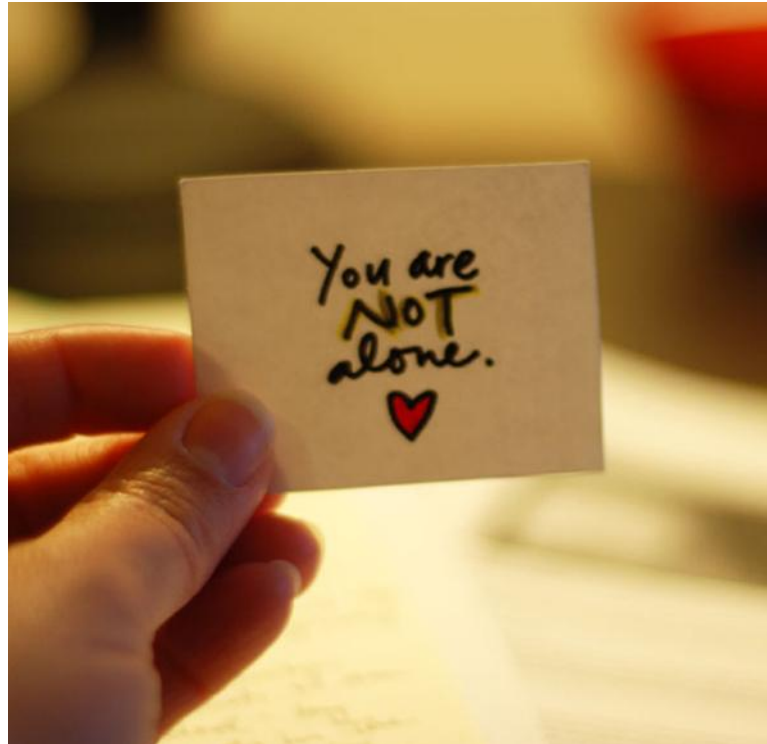


## PARENTAL GOALS:

- \* Regain control
- \* Be informed
- \* Feel prioritized
- \* Make good decisions
- \* Find their new 'normal'

;(Bakhtakhi et al., 2017; Beck et al., 2019; Boyle et al., 2020; Cacciatore, 2010; Fernandez-Basanta et al., 2020; King et al., 2020; Krosch & Shakespeare-Finch, 2017; Minton et al., 2022; O'Connell et al., 2016; O'Leary et al., 2011; Price, 2013; Watson et al., 2019)

# GOALS



## HEALTH PROFESSIONAL GOALS:

- \* Help families move *forward*, not *move on*
- \* Provide competent and compassionate care
- \* Adjust as the family's needs change over time
- \* Avoid adding further distress
- \* Minimize regrets

(Bakhabakhi et al., 2017; Beck et al., 2019; Boyle et al., 2020; Cacciatore, 2010; Fernandez-Basanta et al., 2020; King et al., 2020; Krosch & Shakespeare-Finch, 2017; Minton et al., 2022; O'Connell et al., 2016; O'Leary et al., 2011; Price, 2013; Watson et al., 2019)

# RESPECTFUL CARE



## MAKING DECISIONS

- \* Time to process their options
- \* Provide all the information
- \* Offer information multiple times
- \* Ability to change their minds
- \* Help them regain a sense of control
- \* Perceived staff attitudes influence decision making
- \* Recognize that the decision is not ours

(Aiyelaagbe et al., 2017; Beck et al., 2019; Boyle et al., 2020; Carter, 2007; Hendson & Davies, 2018; Koopmans et al., 2013; Leon, 2009; Paraiso Pueyo et al., 2021; Peters et al., 2015)

# CULTURAL CARE



## WORKING WITH FAMILIES

- \* Always ask about cultural preferences – No assumptions!
- \* Parents may avoid expressing their emotions if they feel unsupported
- \* Involve members of the community
- \* Be flexible
- \* Utilize spiritual care services

(Alaradi et al., 2022; Fernandez-Basanta et al., 2020; Henderson & Davies, 2018)

# RESPECTFUL CARE

## COMPASSION

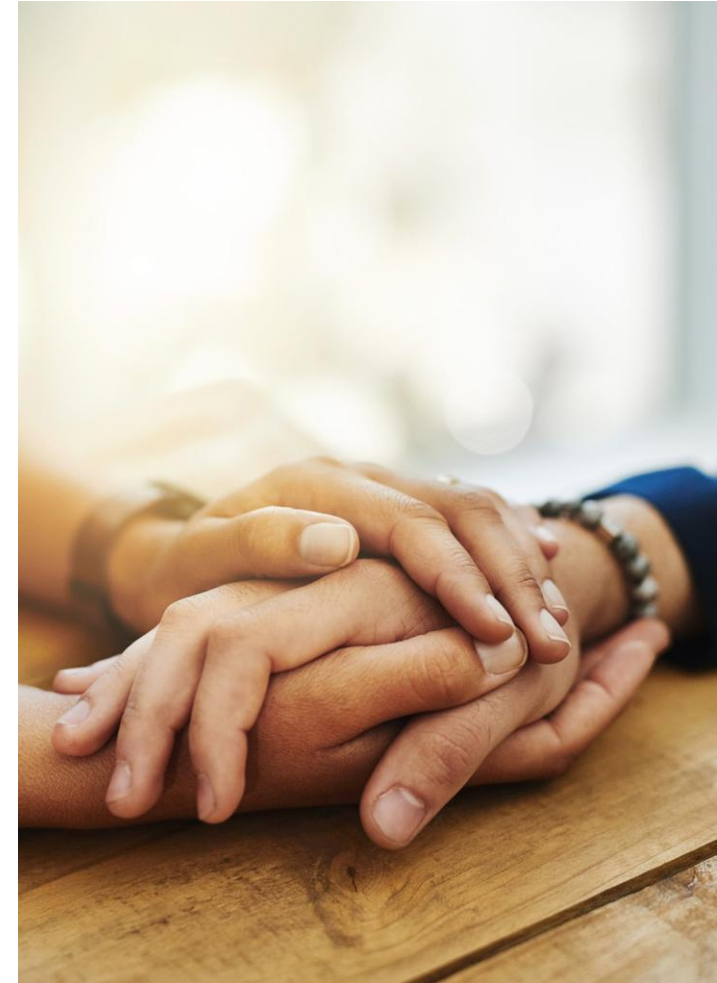


- \* Provide a hug
- \* Hold their hand
- \* Sit with them in silence
- \* Share information
- \* Listen
- \* Incorporate their values and preferences
- \* Help them create memories
- \* Explain actions in advance
- \* Privacy, not avoidance
- \* Be mindful of activity outside the room
- \* Find your own comfort level

# COMMUNICATION

## WHAT TO SAY

- \* “I’m sorry”
- \* “We’re here to support you”
- \* “Tell me about your pregnancy/baby”
- \* “This isn’t your fault”
- \* “I wish we had more answers”
- \* “How are you today?”
- \* “Some parents find it helpful to...”
  
- \* Use the baby’s name
- \* Validate their emotions
- \* Don’t hide your emotions



(Black, 2020; Ellis et al., 2016; Florescue, 2020; Hendson & Davies, 2018; Martini, 2009; Minton et al., 2022; Peters et al., 2015; Smith et al., 2020)

# COMMUNICATION

*“At least you know you can get pregnant”*

*“It would be worse if the baby was born with problems”*

*“Be thankful you didn’t know the baby yet”*

*“I know how you feel”*

*“This is how God fixes His mistakes”*

*“Now you have an angel”*

*“You’re young and can have more”*

*“With these kinds of poor outcomes, ...”*

# TIPS FROM BEREAVED PARENTS

- \* Take care of the basics (sleep, food, etc)
- \* Use things that bring you joy
- \* Be cautious with social media
- \* Speak with a faith or spiritual leader
- \* See a counselor
- \* Check in with your partner
- \* Extend grace to your partner
- \* Do what feels right to you
- \* Journal
- \* Don't avoid the hurt
- \* One breath at a time....



(Fenstermacher & Hupcey, 2019; Minton et al., 2022)

# HONORING BABY

- \* Memorial services
- \* Planting a tree
- \* Candlelighting
- \* Use symbols of the baby
- \* Share photos and mementos
- \* Create new traditions
- \* Tattoo
- \* Jewelry
- \* Visit places of remembrance
- \* Listen to special music



NATIONAL  
**PREGNANCY AND INFANT LOSS**  
REMEMBRANCE DAY  
OCTOBER 15

# RESOURCES

## ACCESS TO RESOURCES

- \* Support groups
- \* Peer support
- \* Support lines
- \* Written materials
- \* Funeral services
- \* Counseling
- \* Financial support
- \* Community activities



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|                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                       |                                                                                                                                                                                                                             |                                                                                                                                                                                                     |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>BEREAVED PARENTS</b><br><b>1ST &amp; 3RD MONDAY OF EACH MONTH</b><br>7PM ET   6PM CT<br>5PM MT   4PM PT<br><br><b>2ND &amp; 4TH THURS OF EACH MONTH</b><br>8PM ET   7PM CT<br>6PM MT   5PM PT<br> | <b>PREGNANCY AFTER LOSS</b><br><b>EVERY MONDAY</b><br>8:30 PM ET<br>7:30 PM CT<br>6:30 PM MT<br>5:30 PM PT<br>     | <b>GRANDPARENTS GROUP</b><br><b>1ST WEDNESDAY OF EACH MONTH</b><br>8 PM ET<br>7 PM CT<br>6 PM MT<br>5 PM PT<br>                          |                                                                                                                                                                                                     |
| <i>Free Support Groups</i><br><a href="http://starlegacyfoundation.org/support-groups">starlegacyfoundation.org/support-groups</a><br> <b>STAR LEGACY</b><br>FOUNDATION                                                                                                                 |                                                                                                                                                                                                       |                                                                                                                                                                                                                             | <b>DAD'S GRIEF DISCUSSION</b><br><b>2ND MONDAY OF EACH MONTH</b><br>7 PM ET<br>6 PM CT<br>5 PM MT<br>4 PM PT<br> |
| <b>PARENTING AFTER LOSS</b><br><b>1ST AND 3RD WEDNESDAY OF EACH MONTH</b><br>1 PM ET<br>12 PM CT<br>11 AM MT<br>10 AM PT<br>                                                                                                                                                          | <b>GRUPO DE PADRES EN DUELO</b><br><b>PRIMER VIERNES DEL MES</b><br>8 PM ET<br>7 PM CT<br>6 PM MT<br>5 PM PT<br> | <b>COPING WITH SUID/ SIDS &amp; INFANT DEATH</b><br><b>2ND WEDNESDAY OF EACH MONTH</b><br>7 PM ET<br>6 PM CT<br>5 PM MT<br>4 PM PT<br> |                                                                                                                                                                                                     |

# RESOURCES FOR FAMILIES



## **National Crisis Text Line**

Text HOME to 741741

## **National Suicide Prevention Hotline**

Call 988

[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

## **National Maternal Mental Health Hotline**

1-833-9-HELP4MOMS

## **Postpartum Support International Helpline**

(English & Spanish)

Text 503-894-9453

Call 800-944-4773

[www.starlegacyfoundation.org](http://www.starlegacyfoundation.org)



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