CYSHN Condition Follow-up Community of Practice

July 22, 2026

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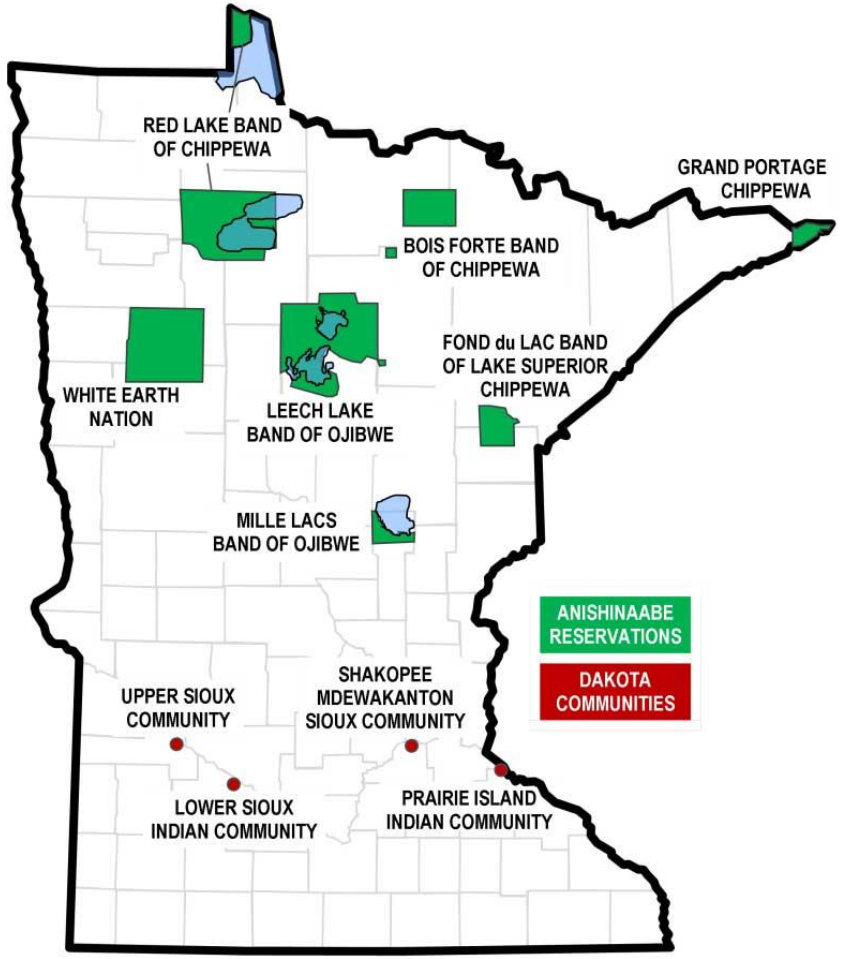
Agenda

10:30 - 10:45 a.m.	Welcome and announcements
10:45 – 11:45 a.m.	Supporting families before, during, and after perinatal loss
11:45 - noon.	Wrap-up and evaluation

Tribal-State relations acknowledgement statement

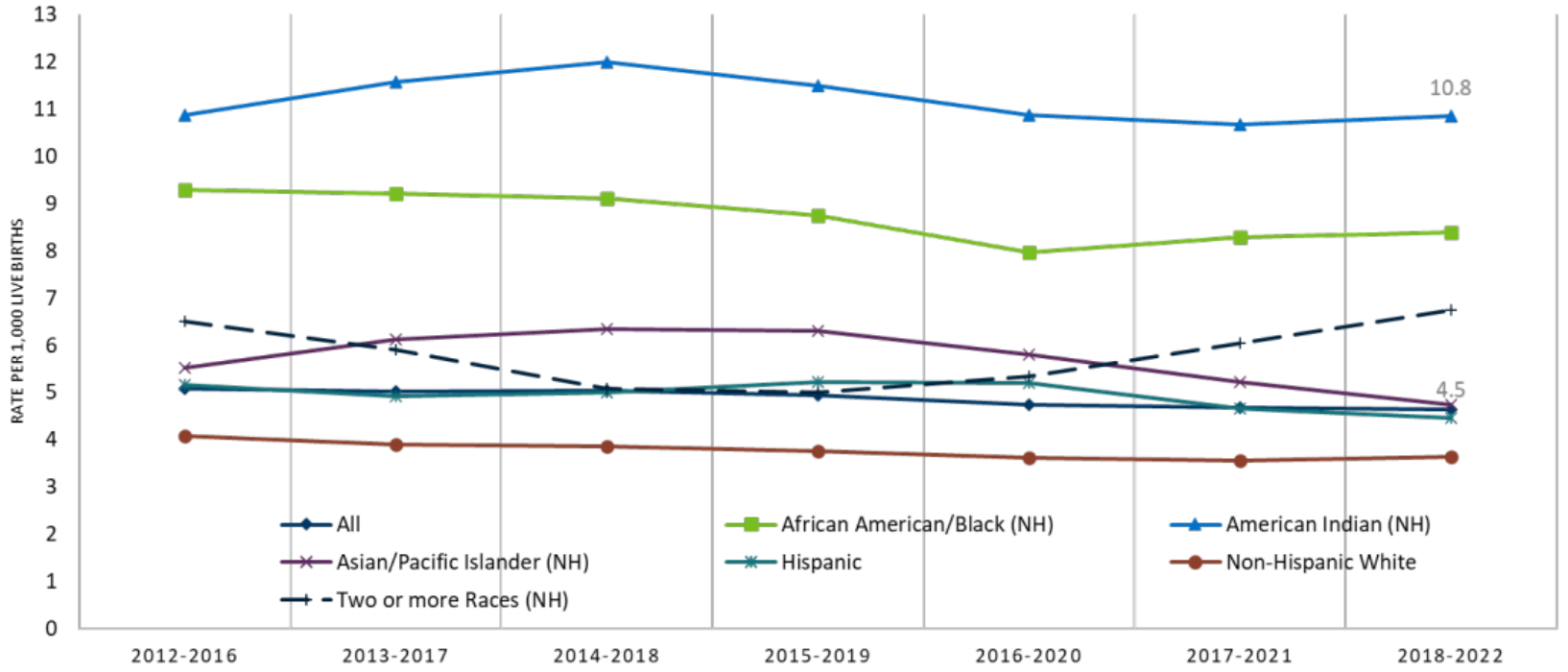
The State of Minnesota is home to 11 federally recognized Indian Tribes with elected Tribal government officials. The State of Minnesota acknowledges and supports the unique political status of Tribal Nations across Minnesota and their absolute right to existence, self-governance, and self-determination. This unique relationship with federally recognized Indian Tribes is cemented by the Constitution of the United States, treaties, statutes, case law, and agreements. The State of Minnesota and Tribal governments across Minnesota significantly benefit from working together, learning from one another, and partnering where possible.

Minnesota Department of Health recognizes, values, and celebrates the vibrant and unique relationships between the 11 Tribal Nations and the State of Minnesota. Partnerships formed through government-to-government relationships with these Tribes will effectively address health disparities and lead to better health outcomes for all of Minnesota.



Health inequity

Figure 30: Infant Mortality Rates by Race/Ethnicity of Birthing Person, Minnesota 2012-2022



Source: Linked Birth-Infant Death Minnesota Resident Period Cohort File; Data Reported as Five-Year Averages

Infant mortality

Figure 31: Leading Causes of Infant Mortality by Race/Ethnicity, Minnesota 2018-2022

RANK AMONG LEADING CAUSES	Total	Black/African American	American Indian	Asian/Pacific Islander	Hispanic	Non-Hispanic White	Two or More Races
1st	PREMATURITY	PREMATURITY	SIDS/SUID	PREMATURITY	PREMATURITY	CONGENITAL ANOMALIES	PREMATURITY
2nd	CONGENITAL ANOMALIES	CONGENITAL ANOMALIES	INJURY	CONGENITAL ANOMALIES	CONGENITAL ANOMALIES	PREMATURITY	SIDS/SUID
3rd	OTHER PERINATAL CONDITIONS	OTHER PERINATAL CONDITIONS	CONGENITAL ANOMALIES	OTHER PERINATAL CONDITIONS	OTHER PERINATAL CONDITIONS	OTHER PERINATAL CONDITIONS	OTHER PERINATAL CONDITIONS
4th	SIDS/SUID	SIDS/SUID		ALL OTHER	SIDS/SUID	SIDS/SUID	CONGENITAL ANOMALIES

Source: Linked Birth-Infant Death Minnesota Resident Period Cohort File
Causes of death are listed in order of frequency. To be included there must be more than 5 deaths in the time period.

CYSHN respect for identities statement

Short version

We strive to use language that honors individual preferences, recognizing health conditions and disabilities are a natural and valuable part of human diversity. While our program reflects statutory terms like "special," we remain open to changing our language practices based on community feedback to foster belonging, respect, and inclusivity.

Long version

www.health.state.mn.us/people/childrenyouth/cyshn/about.html#respect

2026 Workshops

- April 14th Metro
- April 27th Southeast
- June 9th Northwest
- June 10th West Central
- **October 7th Southwest**
  - Southwest Health & Human Services Office - Lyon County
    607 West Main Street, Marshall, MN 56258
- **October 20th Northeast**
  - St. Louis County Public Health and Human Services - Duluth Government Services Center
    320 West 2nd Street, Duluth, MN 55802

Information and resources webpage

Think of a time when you worked with a family who experienced perinatal loss…

What training and/or resources do you need to grow your skills to support families?

Supporting families before, during, and after perinatal loss

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INTERNATIONAL PARTNERSHIP FOR PERINATAL EXCELLENCE

Supporting Families Before, During, and After Perinatal Loss

Lindsey J. Wimmer, DNP, CPNP, RN, PHN, IPPE-C
lindsey@starlegacyfoundation.org

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There are no relevant financial relationships with ineligible companies for those involved with the ability to control the content of this activity.

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Learning Objectives:

- Describe common impacts of grief on families.
- Identify resources, programs, and services available to families who experience perinatal bereavement.
- Implement evidence-based and culturally appropriate care for those who experience perinatal bereavement.
- Describe needs of families who experience pregnancy after loss.
- Apply strategies to reduce the risk of poor pregnancy outcomes.

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1 IN 4 WOMEN
WILL EXPERIENCE A PREGNANCY OR INFANT LOSS
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Infertility
Miscarriage
Stillbirth
Neonatal Loss
Infant Loss

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Reducing Risk in Pregnancy

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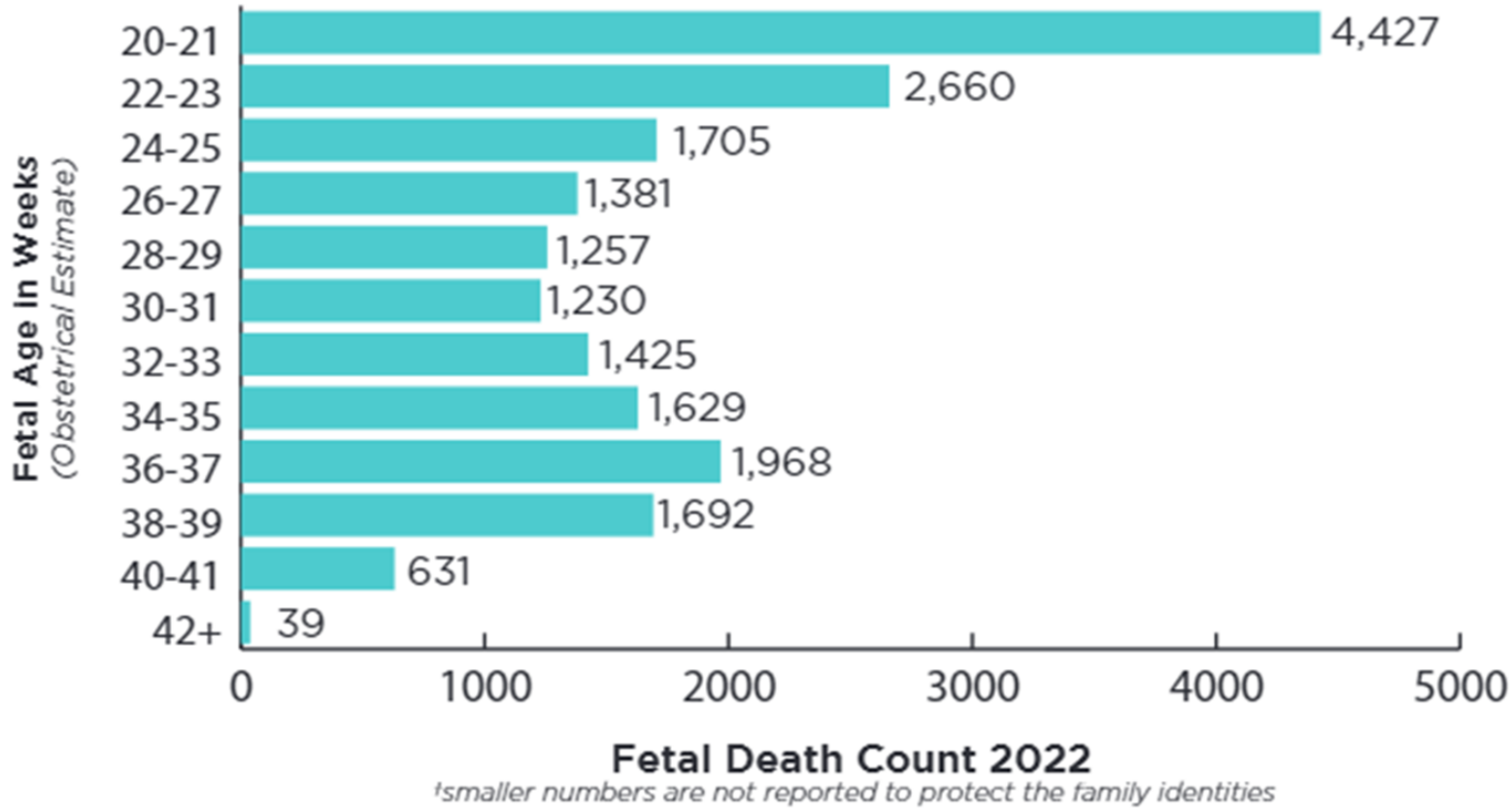
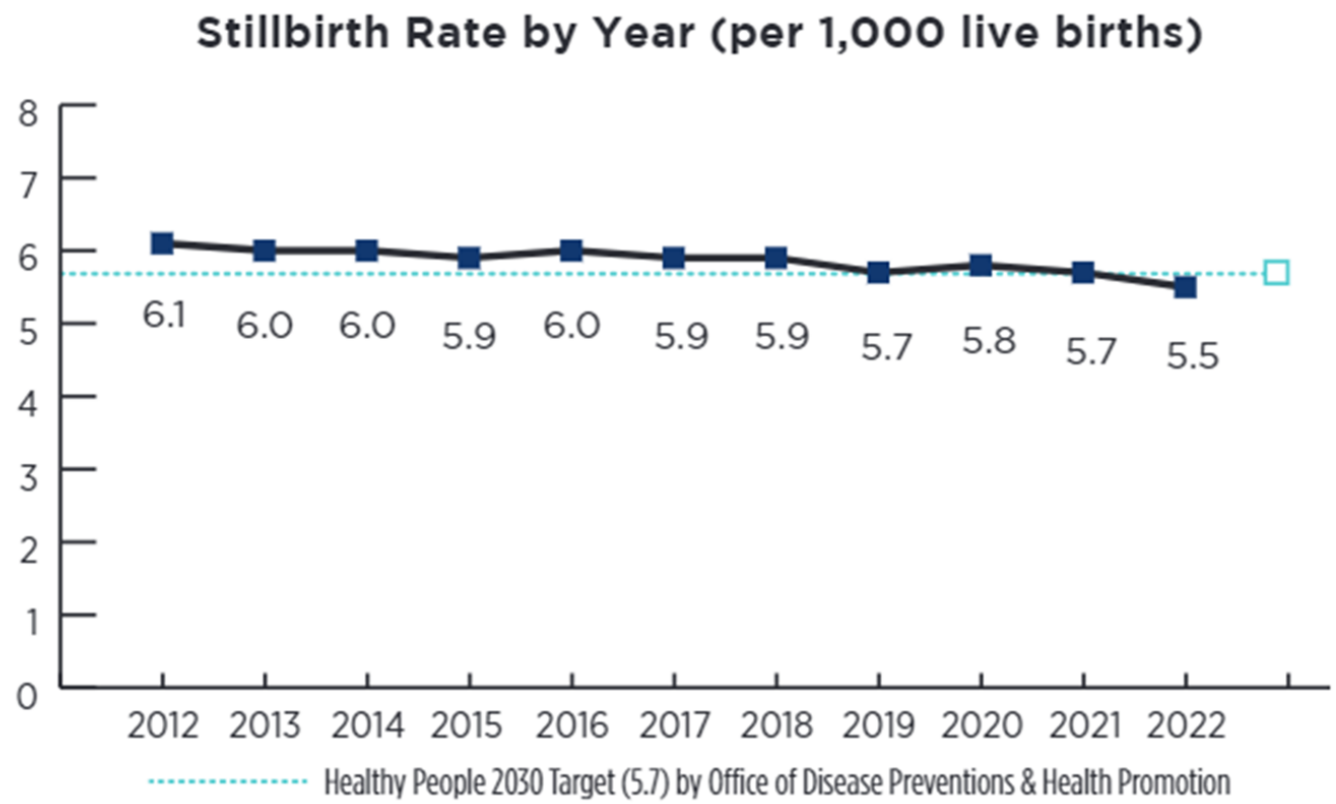
GESTATIONAL AGE



STILLBIRTH RATE FOR 2012-2022

Definition of Stillbirth: 20 weeks of gestation or more



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WHAT IF STILLBIRTH IS PREVENTABLE?

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25% of all stillbirths
in the United States
are preventable

47% of all stillbirths at
37+ weeks
in the United States
are preventable

(Page et al, 2018)

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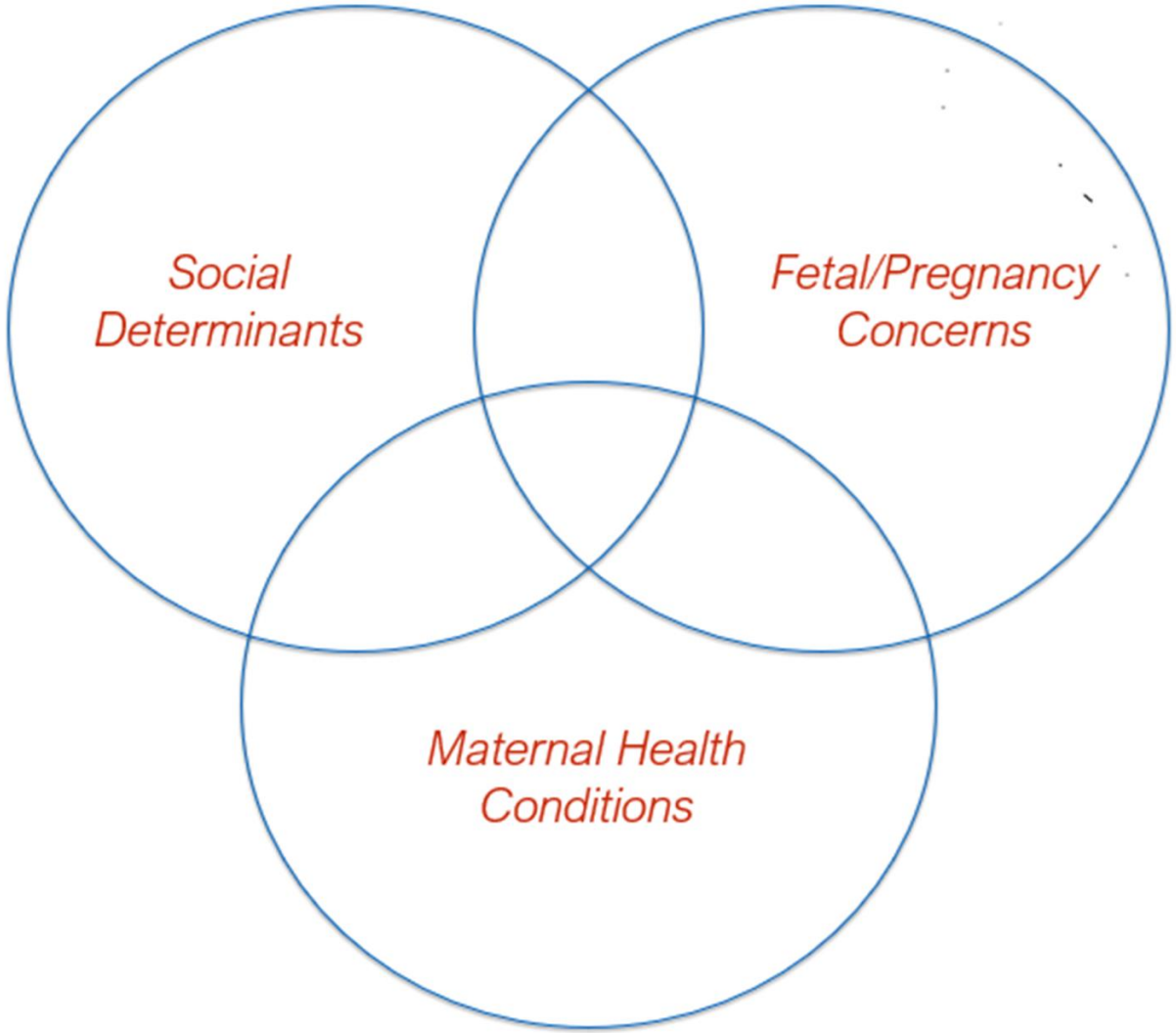
Gestational Diabetes
Preeclampsia
Lupus/Autoimmune Diseases
Maternal substance use
Maternal obesity
Maternal age
Primiparity
History of previous poor outcome
Maternal sleep position and quality

IVF pregnancy
Multiple gestation
Altered fetal movement
Fetal growth restriction
Umbilical cord abnormalities
Placental conditions

Low income
Poor access to care
Exposure to Racism
Lower maternal education level
Little/no preconception/prenatal care
Stress/Trauma

(Escañuela Sánchez et al., 2019; Flenady et al, 2011; Gardosi et al, 2013)


Social Determinants
Fetal/Pregnancy Concerns
Maternal Health Conditions

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Saving Babies' Lives Version Three

A care bundle for reducing perinatal mortality

1 – Smoking Cessation

2 – Fetal Growth Restriction

3 – Fetal Movements

4 – Fetal Monitoring during Labor

5 – Preterm Birth

Safer Baby Bundle

WORKING TOGETHER TO REDUCE STILLBIRTH

1 – Smoking Cessation

2 – Fetal Growth Restriction

3 – Fetal Movements

4 – Maternal Sleep Position

5 – Timing of Delivery

FETAL MOVEMENT

- 72% of stillbirth mothers reported DFM in the preceding weeks
- 22-26% of women who report DFM had a poor pregnancy outcome

- 57% of women reporting DFM felt their concerns were dismissed or ignored by their HCP

(Dutton, et al., 2012; O'Sullivan, et al., 2009; Saastad, et al., 2010; Warland, et al., 2015)

FETAL MOVEMENT

- Get to know THIS baby's norm
- Monitor frequency, pattern, and strength
- Assess for ***altered,*** not just decreased movement
- Number doesn't matter
- Report changes in movement immediately
- Babies do NOT slow down
- Do not wait for 2 hours or try a cold drink

(Dutton, et al., 2012; O'Sullivan, et al., 2009; Saastad, et al., 2010; Warland, et al., 2015)

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Fetal Movement Concerns: Myths

Babies do NOT slow down

Sugar, caffeine, temperature are NOT shown to change fetal movement or NST

(Gardener et al, 2017; Pollock, et al., 2020)

Fetal Movement: Key Messages

- Begin when movements are felt regularly
- Include pattern, frequency, strength
- Base assessment on THIS baby's typical movements
- Report ANY changes *immediately*
- It is NOT normal for babies to slow down

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MATERNAL SLEEP POSITION

- Go to sleep on your side
- Third trimester
- Improves blood flow to baby
- Reduces risk of stillbirth

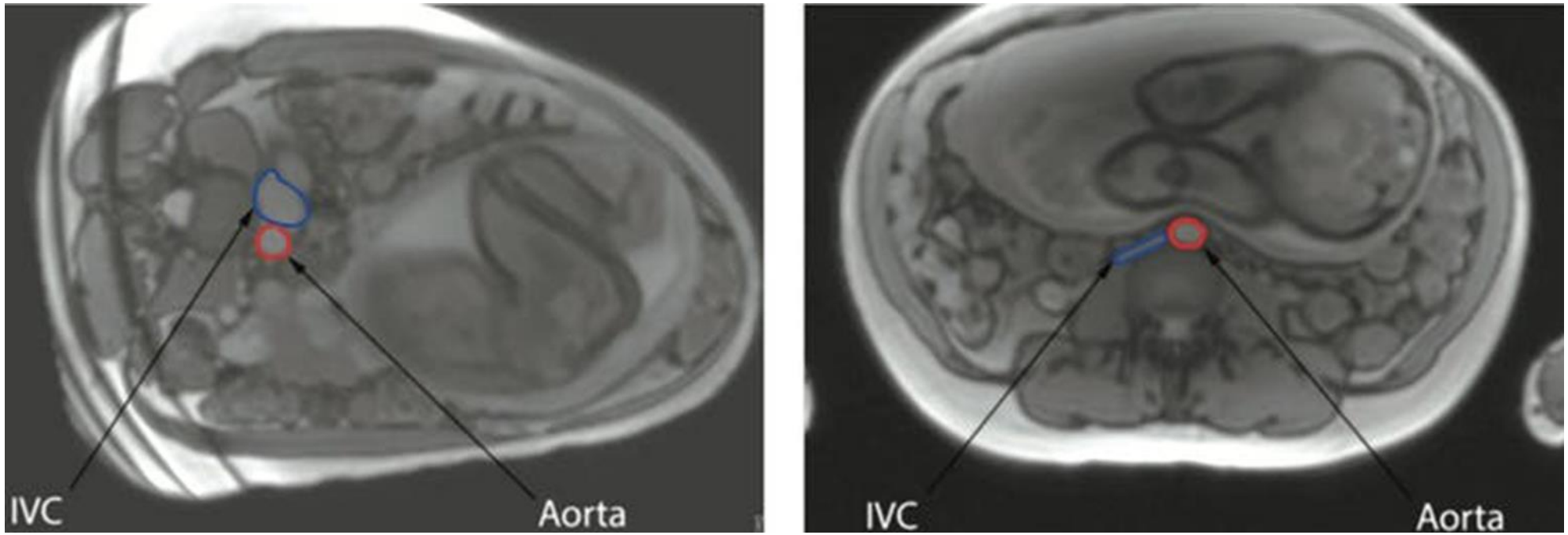
MATERNAL SLEEP POSITION

* Increasing weight of the gravid uterus decreases blood return

* A decrease in maternal cardiac output and subsequent reduction in uterine perfusion has been documented when the woman is supine

* Change in fetal behavior and HR variability when mother is supine

(O'Brien & Warland, 2014; Robertson et al, 2019; Rossi et al, 2011; Stone et al, 2017; Warland et al, 2017)



Left: An MRI showing blood flow of a pregnant woman lying on her side.
Right: An MRI showing blood flow of a pregnant woman lying on her back.
Image courtesy CC BY-SA

(Goecker, 2017)

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Maternal Sleep Position: Key Messages

- Go to sleep on your side in the third trimester
- Improves blood flow to baby
- Reduces risk of stillbirth

FETAL GROWTH RESTRICTION

- Fetal Growth Restriction (FGR) is NOT the same thing as Small for Gestational Age (SGA)

- FGR biggest risk factor for stillbirth

- Associated with:
  - Premature birth
  - Intrapartum hypoxia
  - Prolonged neonatal hospitalization
  - Feeding & respiratory difficulties
  - Abnormal brain development
  - Long-term cardiovascular disease
  - Developmental delay
  - Early mortality

(Debbink et al, 2021; Loussert et al, 2020; NHS England, 2019)

FETAL GROWTH RESTRICTION

- When undiagnosed, FGR is associated with an *8x increased risk of stillbirth* compared to non-FGR pregnancies
- Improving identification of FGR babies plus surveillance and timely delivery is associated with a decrease in stillbirth due to FGR
- Most common cause is placental insufficiency
- Early onset FGR impacts nutrition/growth
- Late onset FGR impacts respiratory demands

(ACOG, 2021; Heazell et al, 2019; Loussert et al, 2020; McCowan et al, 2018;Selvaratnam et al, 2019;Thiliganathan, 2018)

FGR SCREENING CRITERIA

HIGH RISK FACTORS

Maternal Conditions:
- History of IUGR, preeclampsia, or stillbirth in a previous pregnancy
- HTN or hypertensive disorders of pregnancy
- Auto-immune disorders (Systemic lupus erythematosus, anti-phospholipid syndrome)
- Thrombophilias
- Renal Conditions
- Diabetes Melletis
- Age >40 years
- Gestational hypercholanemia
- Malnutrition
- Use of anti-neoplastic, anti-thrombotic, or anti-epileptic medications
- Infection (CMV, rubella, toxoplasmosis, varicella, syphilis, parvovirus B19)
- Significant first-trimester bleeding

Fetal Conditions:
Fetal genetic or chromosomal abnormalities
EFW <10th percentile
AC <10th percentile

Pregnancy Conditions:
Multiple gestation pregnancy
Placental Abruption
Velamentous Cord Insertion
Marginal Cord Insertion
Two Vessel Cord

MODERATE RISK FACTORS

Biomarkers:
- Low PAPP-A in 1st trimester
- Low PlGF in 1st trimester
- High AFP in 2nd trimester
- AFP: PAPP-A ratio in 1st trimester > 10

Maternal Conditions:
- Substance use
- Nulliparity
- Poor access to care
- Age >35 years
- Black/Native American

Fetal/Pregnancy Conditions:
IVF Conception
EFW 10th - 25th percentile

Consider:
- Screening for unrecognized auto-immune disorders

Fetal Growth Restriction: Key Messages

- Know your risk factors
- Attend prenatal appointments for SFH screening and/or ultrasound measurements
- Education about fetal movement and maternal sleep position
- Discuss plan for surveillance and delivery with care team

MATERNAL INTUITION

Retrospective study:

- 65% stillbirth mothers reported a ‘gut instinct’

Case control study:

- 83.8% of cases reported gut instinct
- 19.1% of controls reported gut instinct

($p<0.0001$)

(Warland, et al ., 2015)

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MATERNAL INTUITION

- Develop a trusting partnership between families and HCP
- Communicate honestly and openly
- Offer culturally sensitive care
- Practice active listening
- Provide assistance with challenges
- Respect their perspectives
- Shared Decision Making
- Advocate for them
- Support them in advocating for themselves

HOW YOU CAN HELP

1. Talk about stillbirth
2. Ask about smoking cessation.
3. Teach how to monitor baby's movements
4. Look for growth-restricted babies
5. Encourage side sleep in the 3rd trimester
6. Help families advocate for themselves
7. Provide Respectful Care
    - good communication
    - cultural sensitivity and support
    - honest, trusting relationships

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www.starlegacyfoundation.org/store

www.perinatalexcellence.org

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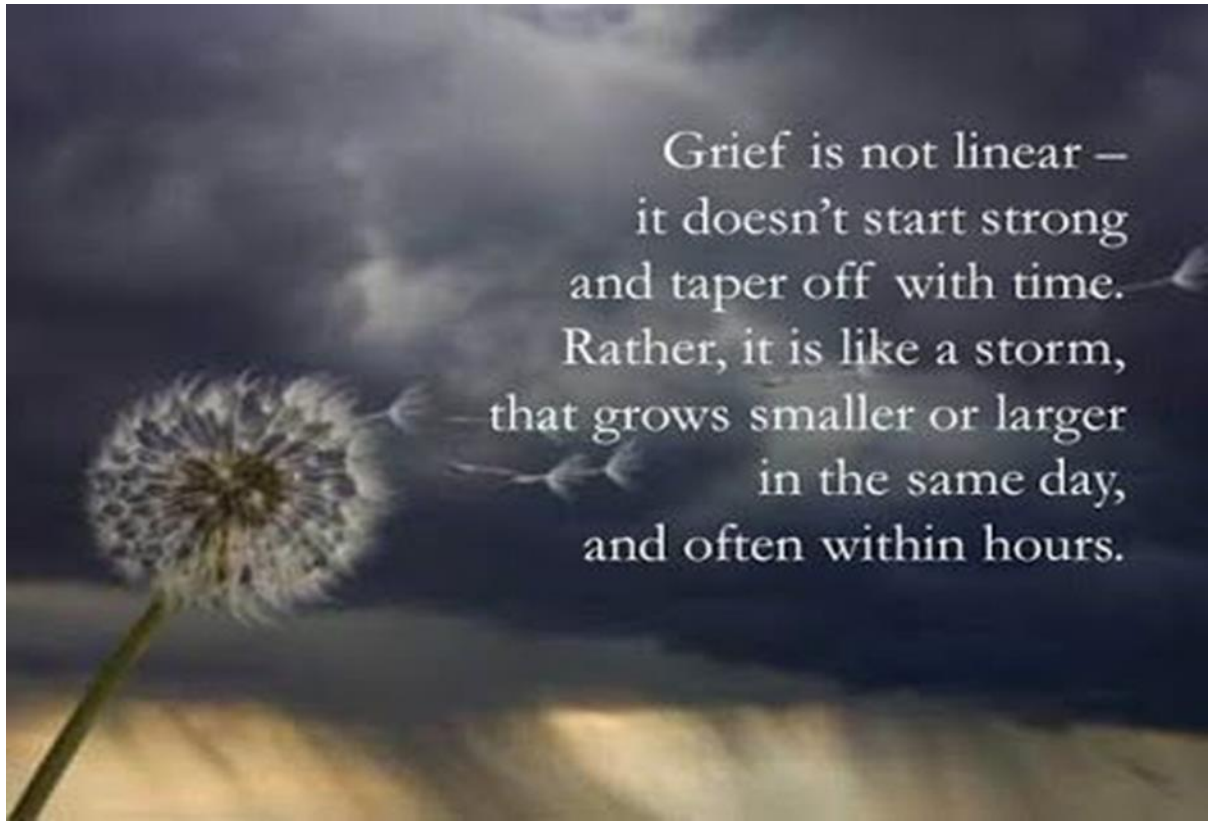
Working with Grieving Families

NO ROADMAP FOR GRIEF

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



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

WIDE VARIETY OF EMOTIONS

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

(Aggarwal & Moatti, 2022; Aiyelaagbe et al., 2017; Cacciatore 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 & 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)

PHYSICAL SYMPTOMS

* Nausea
* Headache
* SOB/chest pain
* Abdominal pain
* Arm aches
* Physical illness
* Hallucinations/dreams/nightmares
* Appetite changes
* Sleep changes
* Fatigue
* Malaise
* Memory lapses
* Throat tightness

(Aggarwal & Moatti, 2022; Aiyelaagbe et al., 2017; Cacciatore 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 & 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)

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"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."

(Pollock et al., 2020)

FATHERS/PARTNERS

* Same symptoms and responses
* Most people focus on the mothers
* Social pressure to be strong
    - positive impact
    - negative impact
* Often return to work before the mother
* Want to be included in decision-making

(Burden et al., 2016; Hendson & Davies, 2018; Jones et al., 2019; King et al., 2021; Koopmans et al., 2013; Leon, 2009; Obst et al., 2020; Shakespeare et al., 2020)

SIBLINGS

* Response and needs depend on developmental stage
* Similar grief responses
* Myth: Young children don’t understand death or grieve
* Desire to protect young children

(Bugge et al., 2014; Cacciatore et al., 2008; Cole et al., 2017; Davidson, 2018; Hendson & Daviews, 2018; Leon, 2009; O’Leary & Gaziano, 2011)

GRANDPARENTS

* Dual loss
* Priority is supporting and protecting their child
* May be a primary source of support and advice
* May not be physically present
* May be generational differences

(Kersting & Wagner, 2012; Leon, 2009; Lockton et al., 2021; O'Leary et al., 2011; Pachalla et al., 2021; Paraiso Pueyo et al., 2021)

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

(Bakhbakhi 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)

MENTAL HEALTH

* 3-fold increased risk of depression, anxiety, and PTSD for both parents

* Associated with sleeping disorders, social phobia, panic disorder

* 25% of bereaved parents have significant psychological difficulties in the first two years after the loss

* 28% of mothers reported serious suicidality

* 2.5x increased risk of ER visit/hospitalization for substance use in the year after a stillbirth vs live birth

(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)

CULTURAL CONSIDERATIONS

* Traditions surrounding birth and death
* Variations within cultures and families
* Connection between motherhood and other social roles/value
* Stigma

- Ask about cultural preferences
- Be flexible
- Use translators
- Include community leaders and spiritual care team
- Be open-minded and supportive

(Eyerly-Webb et al., 2014; Whitaker et al., 2010)

VARIATIONS

* Immigrant vs US-born
* Generational differences
* Multi-cultural families
* Previous experiences with loss

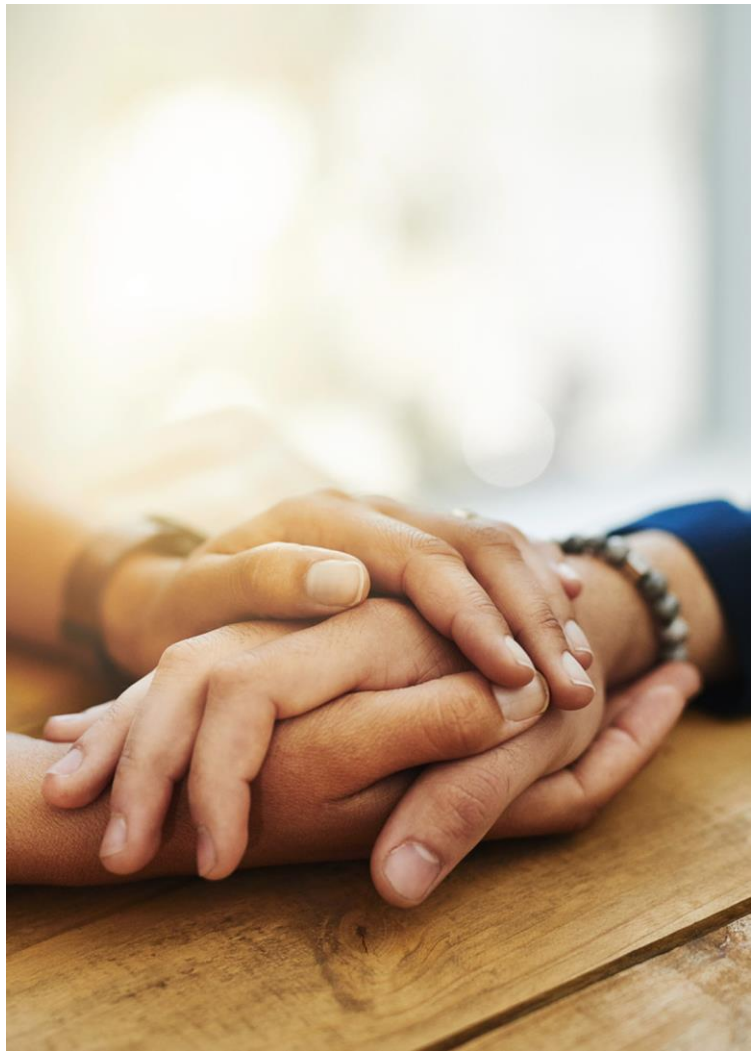
OTHER DISPARITIES

* Cultures where femininity is synonymous with motherhood, gender identity is at risk
* Women with a history of opioid use felt ignored, minimalized, uninformed
* Same-gendered couples may not feel comfortable in support groups
* Rural families often separated from each other, support system, therapists

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”
* “Some parents find it helpful to…”

* Use the baby’s name
* Validate their emotions



WHAT NOT TO SAY

* Euphemisms
* Platitudes/Clichés
* Comments that minimize their feelings
* Religious comments
* Refer to baby as a miscarriage or stillborn
* Avoid questions that imply guilt
* Tell them what to do or how to feel
* Imply the baby is replaceable

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TIPS FROM BEREAVED PARENTS

* Take care of the basics (sleep, food, etc)
* Use things that bring you joy
* Avoid 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)

COMMUNITY ACTIVITIES

* 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

((Black, 2020; Clarke & Connolly, 2022; Cole et al., 2017; de Andrade Alvarenga et al., 2021; Fenstermacher & Hupcey, 2019; Fernández-Basanta et al., 2020; Flenady et al., 2014; Fuller & Kuberska, 2022; Hendson & Davies, 2018; Hennegan et al., 2015; Information for You When Your Baby Dies before Birth, 2012; King et al., 2021; Koopmans et al., 2013; Leon, 2009; Martini, 2009; Nurse-Clarke et al., 2019; O'Connell et al., 2016; ; Paraíso Pueyo et al., 2021; Smith et al., 2020; Thornton et al., 2020)

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STAR LEGACY
FOUNDATION

Family Support Referral

STAR LEGACY FOUNDATION

Connecting Pregnancy and Infant Loss Families with Free Resources

support@starlegacyfoundation.org
(952) 715-7731 ext 1

To Refer a Family,

please scan the QR code or visit
starlegacyfoundation.org/family-support/

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VIRTUAL
SUPPORT GROUPS


SUPPORT LINE


PEER COMPANION


STAR LEGACY FOUNDATION
STILLBIRTH
Finding your way when your baby dies
STAR LEGACY FOUNDATION
COPING WITH INFANT DEATH
STAR LEGACY FOUNDATION
A FATHER'S GRIEF
Finding your way out of the shadows
STAR LEGACY FOUNDATION
NAVIGATING A MISCARRIAGE
BROCHURES

National Crisis Text Line

Text HOME to 741741

Call 1-800-273-8255

National Suicide Prevention Hotline

Call 988

www.suicidepreventionlifeline.org

National Maternal Mental Health Hotline

1-833-TLC MAMA (1-833-852-6262)

Postpartum Support International Helpline

(English & Spanish)

Text 503-894-9453

Call 800-944-4773

TYPES OF RESOURCES

* Bereavement Photography
    - Now I Lay Me Down To Sleep
    - Local photographers/agencies

* Photo Editing
    - Baby Angel Pics

* Funeral Homes

* Disposition Items
    - Heaven's Gain
    - Trappist Caskets
    - In the Light Urns

TYPES OF RESOURCES

* Financial Support
    - Daniel Lee's Gift
    - Collette Louise Foundation
    - Weeping Willa
    - Fletcher Foundation
    - Luca John Foundation
    - Aubri Brown Club
    - Child Loss Foundation

* Doulas
    - International Partnership for Perinatal Excellence

TYPES OF RESOURCES

* Keepsakes
    - My Forever Child
    - Phoenix Bears
    - Remembering My Child
    - Project Sweet Pea
    - The Vintage Pearl

* Therapists
    - Postpartum Support International (PMH-C)
    - Bright Side Health

TYPES OF RESOURCES

* Books
* Websites
* Blogs/Podcasts
* Playlists
* Support Groups
* Medical Care
* Faith/Spiritual Support
* Birth Certificate/Tax Credit
* Star Memorials
* Community Groups


Thank you
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Highlights, accomplishments, and kudos!

In the chat, please add a key takeaway from today or a celebration you would like to share.

Evaluation

Thank You!

The next community of practice will be announced in our newsletter.

health.cyshn@state.mn.us