PERINATAL LOSS & BEREAVEMENT SUPPORT

WELCOME

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Objectives

- **Understand Perinatal Loss:**
  - Participants will be able to define perinatal loss and articulate its impact on families and communities.
- **Recognize the Importance of Bereavement Support:**
  - Participants will gain an appreciation for the critical role of perinatal bereavement support in promoting emotional healing and resilience for families experiencing loss.
- **Identify Barriers to Care:**
  - Attendees will be able to identify common barriers to effective perinatal bereavement support and discuss strategies to overcome these challenges.
- **Implement Supportive Practices**:
  - Participants will learn practical methods for providing compassionate and effective support to families coping with perinatal loss.
- **Care for the Caregiver**:
  - Attendees will understand the importance of self-care for those providing bereavement support and explore strategies to manage their own emotional well-being.

ABORTION

STILLBIRTH

MISCARRIAGE

GRIEF

PERINATAL LOSS

INFERTILITY

INFANT DEATH

SUDDEN INFANT DEATH SYNDROME

LOSS

DEFINITIONS

“Grief isn’t just about losing a loved one. It can manifest in various forms, including the loss of a job, a relationship, or even a dream... grief is a natural response to loss and change, and it’s essential to acknowledge it rather than suppress it.” ~ Brene Brown

LOSS

The fact or process of losing something or someone

GRIEF

The emotional reaction to loss

BEREAVEMENT

The time period during which a person grieves and mourns the loss

MOURNING

The outward expression of grief

LOSS IS NOT TREATED EQUALLY



.

“Women still face enormous stigma and shame when they lose a baby, and they are often not encouraged to talk about their experience and loss. This can lead to isolation and disconnection, even from their partners and close family, and means that women end up trapped in their own personal grief. Such compounded pain is unacceptable.”

-World Health Organization

PERINATAL LOSS

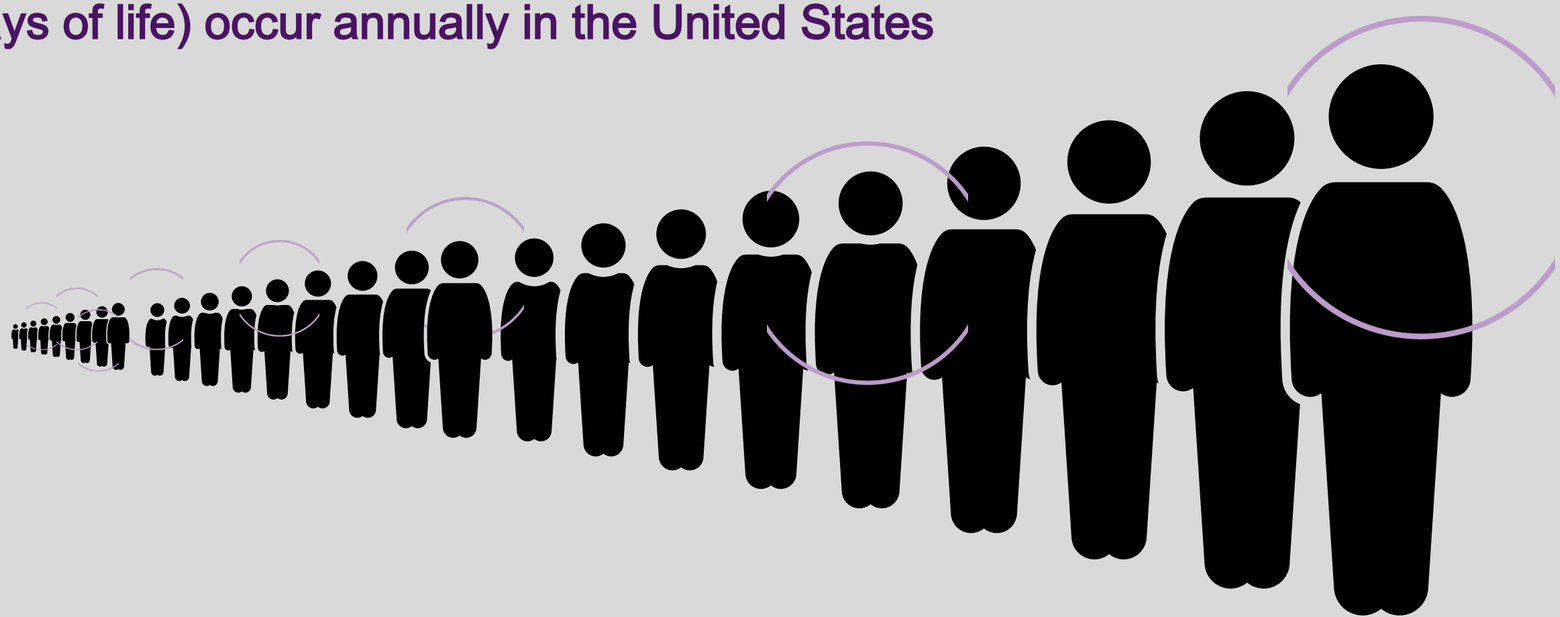






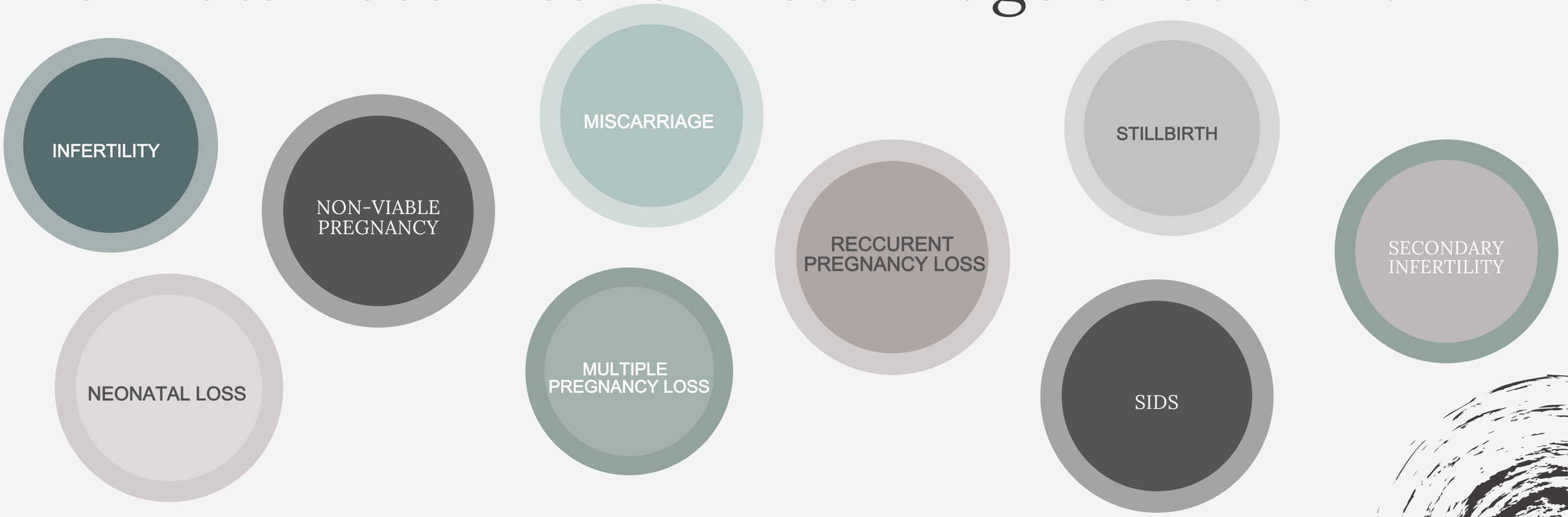
Myth~ Pregnancy loss & infant death are rare

- Perinatal loss occurs in almost 2 million women per year
- 1-4 pregnancies end in a loss
- 25% of all women experience a miscarriage
- 20,000 Stillbirth occur in the US each year
- 36,000 neonatal deaths (birth -28 days of life) occur annually in the United States
- 3,500 infants die each year from SIDS



Myth~

Perinatal loss means miscarriage or stillbirth



~Women can experience more than one type of perinatal loss in their lifetime~

Stigma: Miscarriage is the mothers fault

“It's irrational, but there is such a deep shame attached to not being able to carry a baby to term.... I don't want another baby, I want THIS baby."

“For years after (and even today to some extent) I felt like a complete failure. I couldn’t even protect my unborn baby. I wasn’t able to do what millions of women are able to do.”

"I felt, and feel, literally broken, and betrayed by my body."

“I felt immense grief, anger and shame. I felt betrayed by my body”

MYTH~
Mothers grieve less if the loss occurs early

"I wish people knew how much it's possible to miss a person you have never met, and to mark time by their absence."

“Not only had we lost another baby, I was slowly starting to lose a piece of me and my feelings with each time.”

“My husband and I had hopes and dreams and fears and so much joy tied up into 9.5 weeks of cells."

The intensity of grief does **NOT**
depend on the length of the pregnancy or type of loss.

MYTH~
Women want privacy to deal with their loss ALONE



Disenfranchised Grief

MYTH~
Having another baby will fix it

50-80% of women who experience a loss go on to have another pregnancy

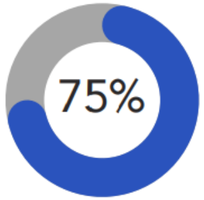
Experiencing a perinatal loss places women at higher risk for mental health complications both immediately following the loss and in any future pregnancies



1 in 5 Mothers are Impacted by Mental Health Conditions



Mental Health Conditions are the Leading Cause of Maternal Deaths



Most Individuals are Untreated, Increasing Risk of Negative Impacts

WHAT CAN WE DO?



What they need:

- Social support
- Normalize the process
- Coping skills

What you can do:

- Acknowledge their loss
- Provide guidance and education
- Offer referrals and resources
- Offer follow-up











You cannot fix it, and you are not expected to

Acknowledge Their Loss

- Active Listening
- Making Time
- Demonstrating Empathy
- Allow Silence



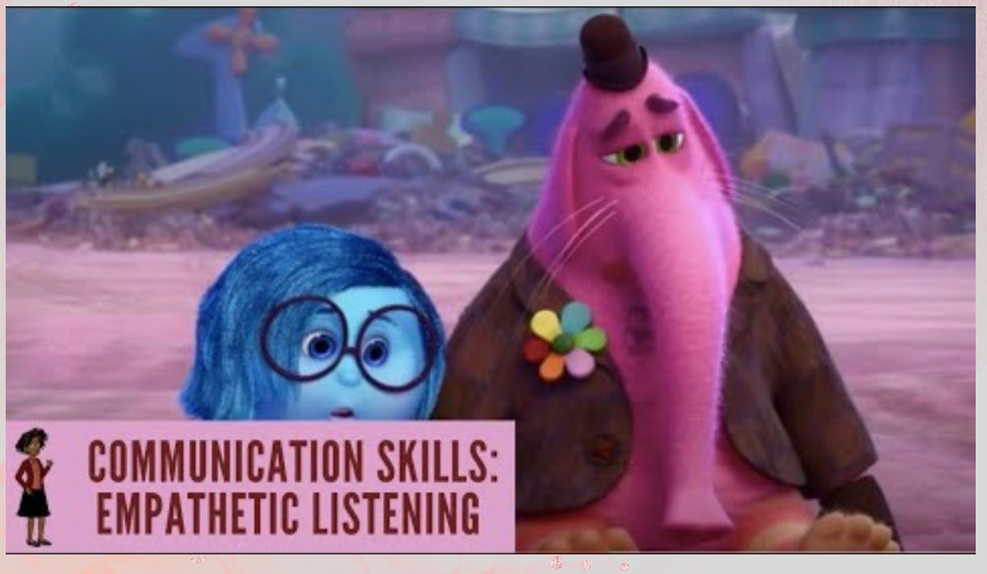
“Bereaved parents never forget the understanding, respect, and genuine warmth they received from caregivers which can be as lasting and important as any other memories of their lost pregnancy or their baby's brief life”

-Kiley’s Mother

What do I say?

Sympathy

- Having thoughts about what someone is feeling
- When in conversation, giving advice
- Passing judgement
- Only noticing the surface level
- Understanding from your own perspective
- Ignoring or suppressing emotions



Empathy

- Feeling what someone else feels
- Just listening to what She/He has to say
- No judgement
- Awareness of nuances and non-verbal cues
- Discovering their perspective
- Acknowledging everyone's feelings



Empathetic Statements

- Use words/language like :
  - Addressing the baby by name if applicable
  - Acknowledge the baby's life and that their life is important
- "I don't know what to say but please know I am here for you."
- "I understand you must be feeling ...."
- "It's understandable that you are feeling this way"
- "I am sorry for your loss. I can't imagine what you must be going through ."
- "You are not alone."
- Any statement or action that demonstrates that you are listening to them and accept them where they are at.

I am sorry for your loss.
I cant imagine what you are going through.

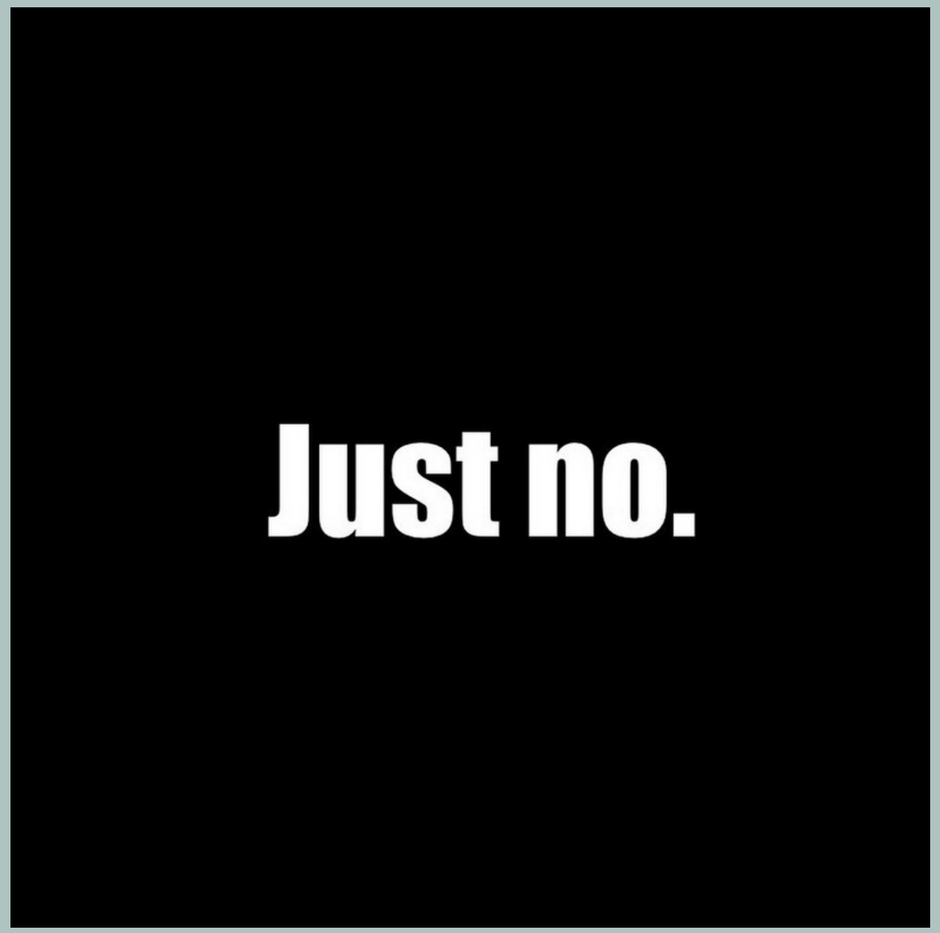
I am beyond sorry to hear about the loss of Connor.
I know there are no words to ease your pain, but I want you to know that I will always be here for you.

It'sunderstandable that you are feeling ...

I don't even know what to say right now, but please know i'm here for you.

Tell me about your Pregnancy. How did you pick your baby's name?





Things to Avoid

- Any statement that begins with “At least .....”
- “Poor thing! This shouldn’t have happened to you.”
- “I know how you feel. I’ve been through something similar ...”
- “Time heals all wounds.”
- “Everything happens for a reason.”
- “You can have another baby.”
- “Be thankful ....”
- “Let go/move on.”
- “Have faith/ You have an angel in heaven.”
- “God doesn’t give you more than you can handle.”
- Any statement that tries to fix, minimize, or make their experience match your own.

NORMALIZE THE PROCESS...

- Normalize the feelings they are experiencing
- Validate their experience
- Follow the parent's lead
- Say the baby's name
- Refer to them as parents
- Offer empathy & your presence
- Help them anticipate triggers
- Know when to intervene



Familes want to know that it is possible to find joy, hope, and meaning again.

What is normal and not normal in grief?
When do we intervene?

#1. Additional support and connection to mental health services or other resources should be a standard for all clients experiencing a loss.

#2. Our job is not to diagnose or classify their grief. Our role is to support the mom and family during their unique time of bereavement.

#3. NEVER dismiss suicidal thoughts or ideations



Signs that additional intervention and referral to a higher level of care may be needed:

- General daily functioning does not return after 4-6 weeks
- Persistently re-experiencing the traumatic event with flashbacks or nightmares
- Insomnia due to increased flight or fight response
- Suicidal ideation
- Emotional numbing, feelings of detachment, or amnesia
- Psychosomatic distress: headaches, nausea, physical pain, ect.

COPING SKILLS



- Coping Skills
  - Permission to heal
  - Anticipate triggers
- Suggest keepsakes or personal memorial services









Offer Follow -Up

- Text, Call, Home Visit
- Business Card
- Birthday Cards







Universal support for all grieving families includes:

- Acknowledge the loss
- Use empathetic language that follows their lead
- Normalize the experience
- Discuss coping strategies
- Offer referral for mental health supportive services
- Offer list of support groups and programs



SPECIFIC TYPES OF LOSS AND NEEDED SUPPORT

Pregnancy Loss

Stillbirth

SIDS

SUPPORT FOR PREGNANCY LOSS

- Discuss coping strategies
- Keepsakes
- Offer follow - up
- Encourage follow - up with a medical provider
- Referral to Nurse for additional education and support



"EVERY SINGLE CALL, TEXT AND EMAIL COUNTED.
JUST
KNOWING SOMEONE WAS THINKING OF US REALLY
HELPED, EVEN IF IT WAS JUST 'I'M SO SORRY'."

"WHEN I WENT BACK TO WORK I STILL REMEMBER PEOPLE
WHO SAID, 'I'M SORRY, IT MUST BE AWFUL ARE YOU OKAY?
THAT IS ALL PEOPLE NEED TO SAY".
- PAUL

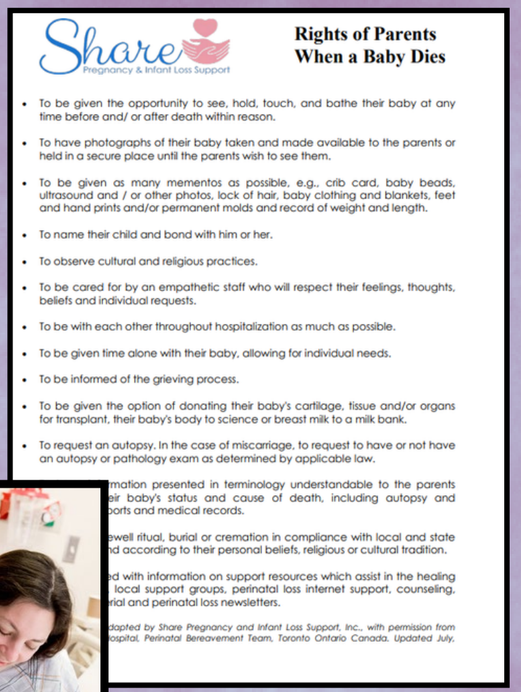
SUPPORT FOR STILLBIRTH & NEONATAL DEATH

- Educate, Support, & Connect
- Rights of the Parents
- Rights of the Baby
  - Aid in creating a birth plan
  - Encourage & support the parent's desires to parent their baby
  - Encourage the collection of keepsakes
- Use the baby's name
- Ask them about their baby
- Refer to the parents as "Parents"

"We will never forget the precious time we had with our daughter"
- Victoria.







Share
Pregnancy & Infant Loss Support

Rights of Parents When a Baby Dies

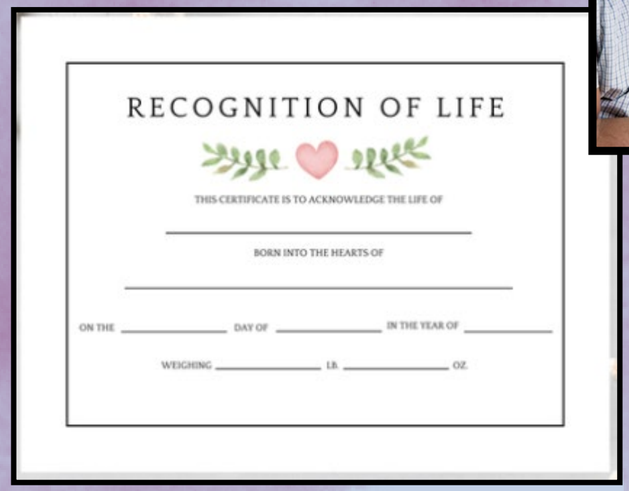
- To be given the opportunity to see, hold, touch, and bathe their baby at any time before and/ or after death within reason.
- To have photographs of their baby taken and made available to the parents or held in a secure place until the parents wish to see them.
- To be given as many mementos as possible, e.g., crib card, baby beads, ultrasound and / or other photos, lock of hair, baby clothing and blankets, feet and hand prints and/or permanent molds and record of weight and length.
- To name their child and bond with him or her.
- To observe cultural and religious practices.
- To be cared for by an empathetic staff who will respect their feelings, thoughts, beliefs and individual requests.
- To be with each other throughout hospitalization as much as possible.
- To be given time alone with their baby, allowing for individual needs.
- To be informed of the grieving process.
- To be given the option of donating their baby's cartilage, tissue and/or organs for transplant, their baby's body to science or breast milk to a milk bank.
- To request an autopsy. In the case of miscarriage, to request to have or not have an autopsy or pathology exam as determined by applicable law.

…rmation presented in terminology understandable to the parents …eir baby's status and cause of death, including autopsy and …orts and medical records.

…ewell ritual, burial or cremation in compliance with local and state …d according to their personal beliefs, religious or cultural tradition.

…d with information on support resources which assist in the healing … local support groups, perinatal loss internet support, counseling, …rial and perinatal loss newsletters.

…dapted by Share Pregnancy and Infant Loss Support, Inc., with permission from …ospital, Perinatal Bereavement Team, Toronto Ontario Canada, Updated July,



RECOGNITION OF LIFE

THIS CERTIFICATE IS TO ACKNOWLEDGE THE LIFE OF

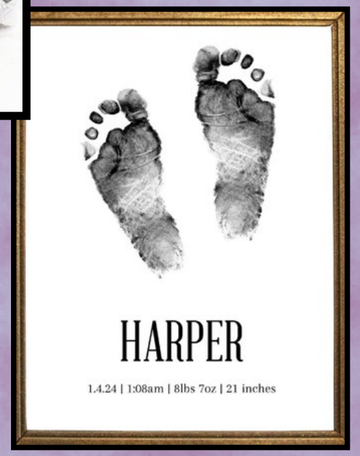
_____

BORN INTO THE HEARTS OF

_____

ON THE _____ DAY OF _____ IN THE YEAR OF _____

WEIGHING _____ LB _____ OZ.



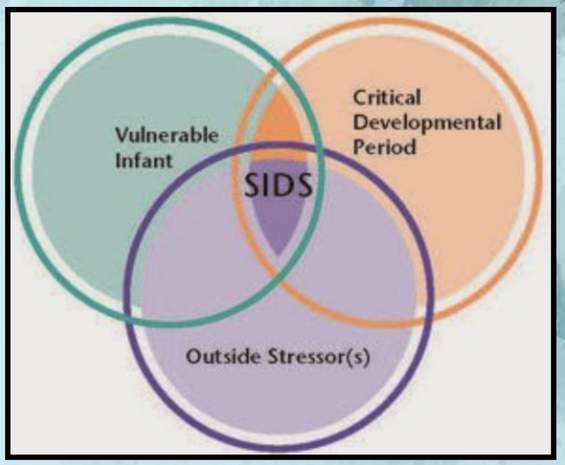
HARPER

1.4.24 | 1:08am | 8lbs 7oz | 21 inches

Support for SIDS



- Support the Family Unit
- Refer families for Public Health Nursing Support
- SIDS: Reassure the family that they did not cause their baby's death
- Trauma - informed care is critical
- Connect to peer support groups



"For parents who have gone through losing a child to SIDS, I want to tell them there is light at the end of the tunnel and there will be happiness again."
Jenna



MyStory
Stories from the California SIDS Program

AERON
March 30, 2017 – February 4, 2018

It can happen to any baby in any family. Sudden Infant Death Syndrome (SIDS), the sudden unexplained death of a baby younger than one year of age, is something no parent should experience. The loss of a baby takes a devastating toll on the parents, families and communities impacted by this type of tragedy.

Jenn & James

Jennifer and James welcomed baby Aeron into their family in March of 2017. He was the happy baby who Jenn and James lovingly dubbed their silent ninja. The name stuck because Aeron had a habit of crawling right over to the dog bowl and knocking it over the minute his parents weren't watching. Aeron was always laughing.

"He was a little angel on Earth,"

says mom Jenn

The day Aeron passed away was memorable for many reasons. It was James' birthday and the family had gone to brunch with a group of old friends. As soon as they arrived home, Jenn nursed Aeron to sleep and placed him in the pack n' play for his nap. Aeron awoke and fussed, but being fussy during nap time was typical for him, so she shut the door and told her husband, James, before leaving for her shift at the hospital. James fell asleep and woke sometime later with a start; Aeron was suspiciously quiet for how much time had passed. James leaped up with a strange feeling to check on Aeron. At first, all he saw was a red blanket. Aeron must have become entangled in the blanket, his body was stiff, James realized immediately. "I screamed, I brought him out to the living room, and I started to do CPR," says James, but it was too late.

Jenn returned home amidst the chaos. She and James jumped into a firetruck, which followed Aeron in the ambulance to the hospital. Says James, "I just remember holding Jenn's hand and I said no matter what happens, we're gonna get through this together."

When a baby dies suddenly and unexpectedly, it may be investigated. As James went home and recreated the scene for investigators, Jenn spent time in the hospital saying goodbye to her son. Jenn recalls that experience: "James just gave me really good advice – told me not to rush the moment and just hold him (Aeron) because it was going to be the last time we held him. I'm so thankful. I don't know how many hours I was there holding and hugging and kissing him, but I do remember that night very well and the intimacy of it and the sorrow and the beauty of the last moments before we had to really say goodbye."

To learn more, visit: cdph.ca.gov/SIDS

CDPH Public Health
mcah

Care for the Caregiver

Vicarious Trauma



Caregivers Require:

- Bereavement Training
- Debriefing: a process to learn and reflect
- recognition of exceptional care provided
- self-evaluation
- Voicing space/safe space
- Employee assistance



Caring for yourself:

- Acknowledge your feelings with mindfulness
- Practice self -care activities
- Take care of yourself and your needs throughout your workday
- Talk with your boss and your team
- Consult with professionals
- Find humor in your day
- Be compassionate with yourself

Resources



Families

- Nationalshare.org
- 48:Angels Born Still
- Miscarriage Association
- MISS Foundation
- Return to Zero: H.O.P.E.
- First Candle
- Noel Alexandria Foundation
- Kern County Public Health Dept.



Caregivers

Training

- AWHONN
- Maternal Mental Health Now
- Nationalshare.org: Power of Presence
- Nationalshare.org- Perinatal Bereavement Skills Training
- Return to Zero: Webinar Series
- California Department of Public Health: SIDS Programs

Support

- CalTrin: Understanding Compassion Fatigue & Secondary Trauma
- Careforcaregivers.CA
- SAMHSA-Understanding and Addressing Vicarious Trauma

Thank You!

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