Perinatal Bereavement and Perinatal Palliative Care

Navigating Support for Families Before, During, and After Fetal Demise, Neonatal Death, and Life-Limiting Illness

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Learning Objectives

1. Define common terms in perinatal palliative care, perinatal hospice, and perinatal bereavement care.
2. Support compassionate communication with families.
3. Define considerations for advanced care planning.
4. Implement mental health screening and processes for support.
5. Identify options for staff support.
6. Define next steps and potential barriers.

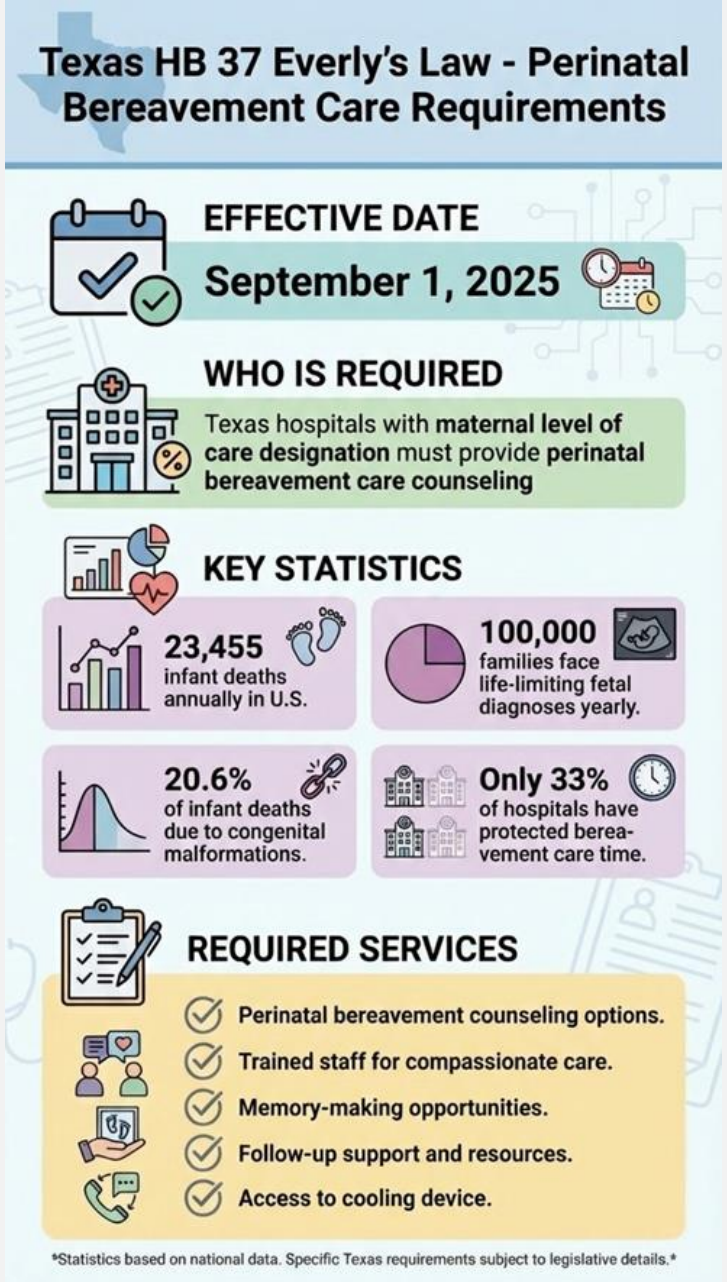
Introduction

H.B. 37, “Everly’s Law”

HB 37 Overview

Overview and Rationale

- Goal to expand and improve bereavement care for all families experiencing loss
- Established in honor of Everly Grace Talman
- Effective 9/1/2025



Perinatal Palliative Care, Perinatal Hospice, and Perinatal Bereavement Care

Definitions

Miscarriage – loss of a pregnancy prior to 20 weeks gestation

Intrauterine fetal demise (IUFD) – death of a fetus occurring at or after the 20th week of gestation

Stillbirth – unintended death of a baby after 20 weeks and before or during birth

- < 20 weeks gestation or < 350 grams
  - Option to bury, cremate, take home, or common burial
- > 20 weeks gestation or > 350 grams
  - Issued a fetal death certificate
  - Option to bury or cremate

Neonatal death – death of a live-born baby within the first 28 days of life

Bereavement vs. Palliative Care

Perinatal Palliative Care

- A specialized approach that focuses on providing comfort and support for families facing life-limiting conditions in their newborn, ensuring quality of life and emotional support during pregnancy and after delivery.

Perinatal Hospice Care

- Services provided to families when the death of their child is imminent or is expected soon. There is a focus on comfort (including pain and symptom management) in the end-of-life period.

Perinatal Bereavement Care

- Designed to support families facing the loss of a baby during pregnancy or shortly after birth. This care acknowledges that the loss of a child at any stage is deserving of time, tenderness, and dignity.

Perinatal Palliative Care

- Scope and Timing:
  - Begins during the prenatal period at the time of diagnosis;
  - Continues throughout the pregnancy into labor and delivery; and
  - May extend beyond birth if the infant is born alive.
- Focus and key components:
  - Quality of life during pregnancy and after birth;
  - Family support and preparation;
  - Coordinated prenatal and postpartum care; and
  - May include curative treatments alongside comfort care.

Perinatal Hospice

- Scope and timing:
  - Typically begins when death is imminent or expected soon;
  - Focus on end-of-life period;
  - Typically covers a shorter time frame; and
  - Focus of care is on maintaining comfort, not curative treatment.
- Focus:
  - Comfort and dignity at end-of-life;
  - Pain and symptom management; and
  - Family presence and memory making.

Perinatal Bereavement Care

- Scope and timing:
  - Begins at the time of diagnosis of a life-limiting condition, IUFD, or neonatal death (when unanticipated); and
  - Continues into the postpartum period.
- Focus:
  - Emotional and psychosocial support;
  - Memory-making; and
  - Ensuring appropriate follow-up.

Communication with Families

Establishing Rapport

How do we build rapport with families in the prenatal or antepartum setting?

- Call parents and other family members by their preferred names.
- There is a wide range of “normal” reactions.
- Allow them to set the pace.

Talking with Families

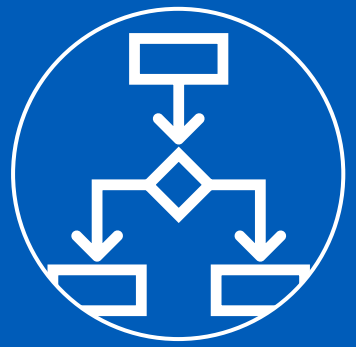
- It is normal to feel overwhelmed or unsure when supporting bereaved families.
- Remember that you are not alone in caring for this patient and family. Rely on your team members and unit resources.
- You are not expected to have all the answers.
- Take your cues from the family throughout your interactions.
- The most important thing to do is listen to the families and tailor your support accordingly.
- Sometimes the best thing to do is just listen and be with the family.

Supporting Informed Decision-Making

Present Options in a Neutral Manner

Discuss Key Topics

Establish Access



Use Decision Aids

Document Consent

Active Listening and Presence

Use open-ended questions

- Invite parents to share their story with questions like, “Can you tell me about your pregnancy?” or “How are you feeling right now?” rather than yes/no inquiries.

Normalize emotions

- Validate their reactions as natural responses to trauma. “Many parents feel angry or numb in this situation; whatever you’re feeling is okay.”

Provide privacy and safety

- Create a safe environment for vulnerability. Close doors, minimize interruptions, and ensure conversations happen in private spaces away from public areas.

Reflect and summarize

- Show you are listening by repeating back key feelings or points. “It sounds like you’re feeling incredibly overwhelmed by these decisions.”

Monitor nonverbal cues

- Pay attention to body language, eye contact, and silence. Sit at eye level, lean forward slightly, and allow for pauses without rushing to fill the silence.

Close the loop

- End interactions by checking understanding and offering support. “What questions do you have right now?” or “Is there anything else you need before I step out?”

Grief Looks Different for Everyone

- How long have they been aware of the diagnosis?
- Was this outcome anticipated?
- Prior loss experience.
- Support system.
- Other life stressors?
- Cultural or religious beliefs around death/dying/grief.

Compassionate Communication

What to say

- “I am sorry for your loss. Your baby, (name), is deeply loved.”
  - Validates the loss and acknowledges the baby as a person.
- “You can spend as much time as you wish with your baby.”
  - Empowers parents and removes pressure/rush.
- “I’m here to support you. What questions do you have right now?”
  - Offers presence and invites open communication.
- “Would you like to tell me about your pregnancy/baby?”

What NOT to say

- “Everything happens for a reason.”/”It was meant to be.”
  - Minimize pain and offers unwanted philosophical justification.
- “At least you can try again.”/”You’re young, you can have another.”
  - Dismisses the unique value of the baby who died.
- “It’s for the best.”/”He/she is in a better place.”
  - Imposes spiritual beliefs that may not be shared or comforting.
- “I know exactly how you feel.” (Unless shared experience)

Communication Techniques

- Essential practices for supporting grieving families include:
  - Sit at eye-level;
  - Validate emotions;
  - Allow silence;
  - Use the baby's name;
  - Use simple language;
  - Utilize the teach-back method; and
  - Acknowledge what comes next.

Best Practices for Providing Information

Strategies to verify comprehension during emotional distress include:

- Concise verbal information;
- Comprehensive written packets;
- 24/7 support access; and
- Scheduled follow-up.

Consistent Communication & Follow-Up

Provide clear, balanced info

- Make sure information is prompt, accurate, and balanced throughout the stay. Avoid overwhelming parents with too much at once, but don’t withhold critical details.

Oral and written delivery

- Grief impacts cognitive processing. Always provide key information both verbally and in writing to prevent forgetfulness and help inform other family members.

Single point-of-contact

- Assign a specific nurse or bereavement coordinator as the primary contact person to reduce fragmentation and build trust.

Explain discharge and disposition

- Discuss discharge steps and baby disposition options before discharge. Parents need clarity to reduce anxiety and confusion.

Confirm understanding and access

- Use teach-back methods to confirm comprehension. Always use professional interpreter services for non-English speaking families.

Schedule follow-up outreach

- Do not wait for parents to call. Schedule proactive follow-up calls or appointments to check on their well-being and answer emerging questions.

Bereavement Care Throughout the Hospital

Care in the Emergency Department

- The emergency department (ED) is a common initial site of presentation for mothers experiencing loss.
- Facility policies generally dictate where patients will receive care after triage.
  - May be based on gestational age and/or condition.

Considerations for care in the ED

- Education and training for staff and providers
  - Consider designating a unit champion in the emergency department
- Resource packets
  - Premade packets for ease of staff use and consistency of materials provided
- Memory-making
  - Maintain appropriate supplies in the ED with quick reference guides and instructions
- Ensuring follow-up at discharge

Care in Non-Women's Services Units

- Mothers may require critical care or care in non-obstetric units during labor and delivery and/or the postpartum period.
- Collaborative care is paramount. Staff in non-women's services units need support when caring for this population.

Considerations for care

Education and training for staff and providers

- Consider designating a unit champion in the ICU and other non-women's services units that may routinely care for obstetric patients

Use of a cooling device

- Appropriate for use throughout the facility

Resource packets

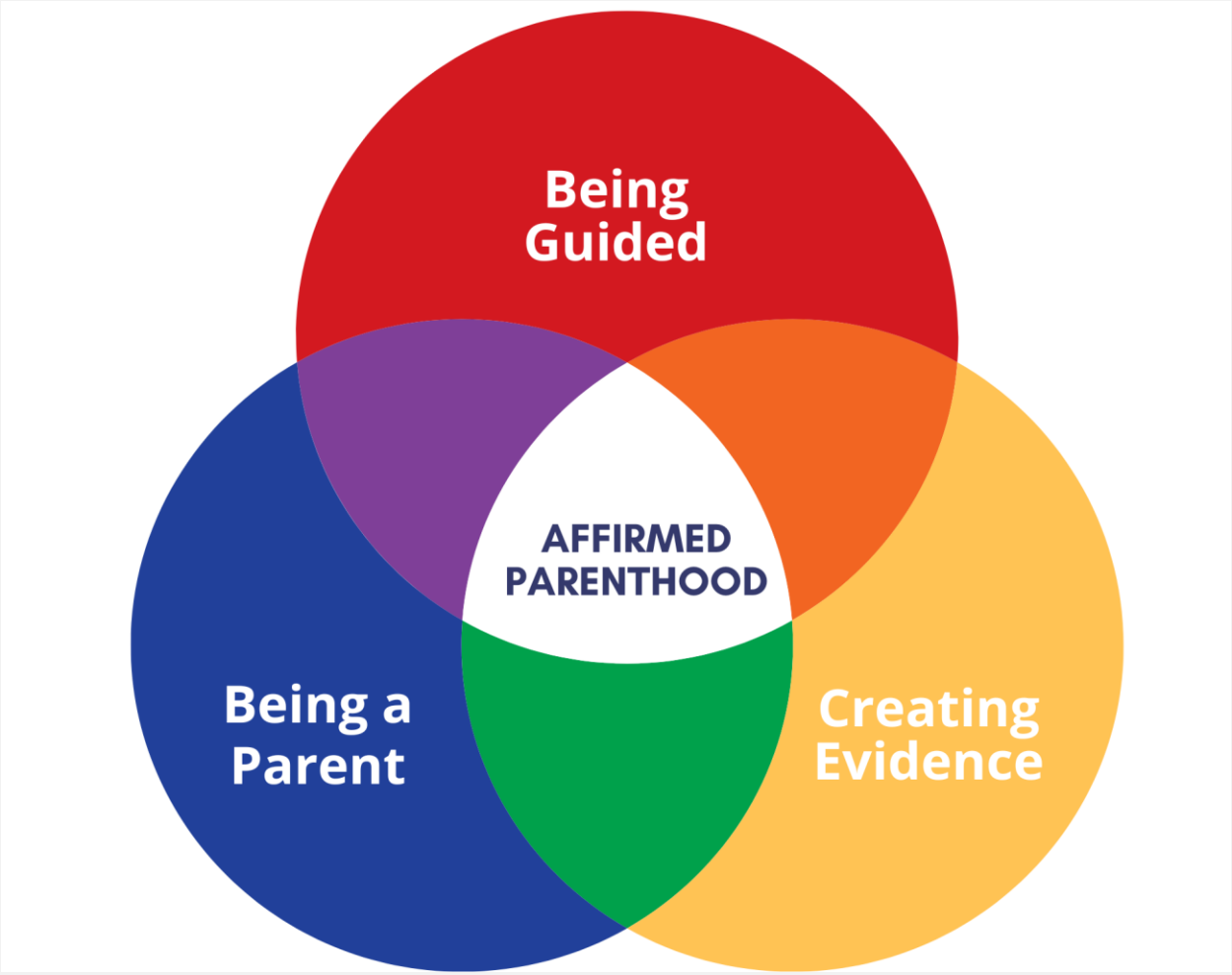
- Collaborative care with women's services units to check consistent resource provision

Coordination of care throughout the hospitalization, including follow-up at discharge

Care Planning

Advance Care Planning

- The care or birth plan is a vital component.
- Should involve a multidisciplinary care team.
- May be thought of as a “wish list.”
- There are no wrong choices.
- Reinforce with the family that the plan may change as new information is received.
- Planning helps parents feel prepared, gives them a sense of control, and validates their role as the parent.
- Few decisions need to be made immediately.
- Include the certainty of diagnosis, certainty of prognosis, meaning of prognosis to parents, and affirming parenthood.



Key Questions for Care Planning (1 of 2)

Planning may include:

- Where will the patient give birth (level of facility should take into consideration maternal and fetal/neonatal risk factors and needs);
- Mode of delivery;
- Who will be present for the delivery;
- Whether patient desires a trial of treatment;
- Options for memory making and support; and
- Hospital visitation after birth.

Key Questions for Care Planning (2 of 2)

Make sure to talk about:

- Whether family members want to hold and spend time with the baby;
- Autopsy, genetic testing (including timing), and pathology;
- Funeral home (if required or desired by family);
- Whether family would like to try to take their baby home; and
- If the family is open to follow-up communication after discharge?

Why Memory-Making Matters

Time is precious

- The time spent with the baby is often the only time parents will ever have.

Preferences evolve

- Shock can impair decision making.
- Consider offering options more than once, as parents' readiness may evolve over time.

Grief integration

- Tangible memories and shared moments help parents integrate the loss into their lives, validating their parenthood and the baby's existence.

Reducing regret

- Many parents who initially decline memory-making later express regret.
- Gentle re-offering confirms they have every opportunity to say yes.

Humanity and Personhood in Bereavement Care

Use name and pronouns

- Always refer to the baby by name if given and use correct pronouns. If unnamed, use “your baby” rather than clinical terms like “fetus” or “remains.”

Offer rituals and certificates

- Provide opportunities for naming ceremonies, blessings, or baptisms. Offer a certificate of life or acknowledgement of birth to validate their existence.

Dignified handling and transport

- Handle the baby with the same care and respect as a living infant during all transport. Use specialized carriers or baskets rather than clinical containers.

Consistent EHR documentation

- Document the baby’s name, weight, and length accurately. Use bereavement alerts in the electronic health record to inform all staff.

Standardize memory-making offerings

- Make sure every family is offered the same high standard of mementos and keepsakes, regardless of gestational age or circumstances.

Bedside Checklist

- ❑ **Immediate Care and Comfort**
  - ❑ Provide private, quiet room for family
  - ❑ Offer unlimited family visitation and presence
  - ❑ Confirm infant warmth and comfort
  - ❑ Facilitate skin-to-skin contact
  - ❑ Minimize painful and invasive procedures
  - ❑ Assess and manage infant pain
  - ❑ Offer feeding options (breast, bottle, comfort)
- ❑ **Memory-making opportunities**
  - ❑ Professional bereavement photography
  - ❑ Hand and footprints (ink or clay molds)
  - ❑ Lock of hair (if appropriate)
  - ❑ Crib card with baby's name and stats
  - ❑ Baby's hospital bracelet and hat
  - ❑ Blanket or clothing baby wore
  - ❑ Baptism or naming ceremony (if desired)
  - ❑ Create memory box with keepsakes
- ❑ **Communication and Support**
  - ❑ Use baby's name (if named)
  - ❑ Provide honest, compassionate updates
  - ❑ Explain what family can expect
  - ❑ Offer spiritual and chaplain services
  - ❑ Assess family support needs
  - ❑ Provide interpreter services if needed
  - ❑ Include siblings appropriately
- ❑ **Before discharge or after death**
  - ❑ Discuss funeral home arrangements
  - ❑ Provide information on autopsy options
  - ❑ Offer bereavement resource materials
  - ❑ Schedule follow-up appointments
  - ❑ Provide 24/7 crisis contact information
  - ❑ Connect to support groups and counseling
  - ❑ Address lactation donation or suppression needs
  - ❑ Check certificate of birth and death copies
- ❑ **Documentation**
  - ❑ Review birth or care plan in chart
  - ❑ Document family wishes and decisions
  - ❑ Complete required legal documents
  - ❑ Coordinate with social work and case management
- ❑ **Staff self-care**
  - ❑ Debrief with team after difficult cases
  - ❑ Access employee support resources

Practical Strategies for Facilitating Memories

Ask and Explore Wishes

Gently ask permission to discuss options. Explore parents' wishes early and often, as preferences may evolve.

Create Quiet Space

Ensure privacy and minimize interruptions. Create an unrushed atmosphere where parents can just "be" with their baby.

Encourage Bonding

Normalize parenting acts: skin-to-skin contact, bathing, dressing, naming, reading books, or singing lullabies.

Include Family

Invite siblings and grandparents if desired. Prepare them for what they will see and support their interactions.

Use Technology

Utilize bereavement devices to cool the baby, extending the time families can spend together safely.

Key Practice Point: Offer options more than once. Shock may cause initial refusal, but many parents later express gratitude for gentle re-offers or staff taking photos and creating mementos on their behalf to be stored.

Maintaining Items for Future Retrieval

Offer Secure Storage

If parents decline to take items home immediately, offer to store them securely at the hospital for a defined period (e.g., 1-5 years per policy).

Label and Track

Maintain strict chain-of-custody. Label all items clearly with patient information, date, and contents. Use barcode tracking if available.

Assign Contact Person

Designate a specific role (e.g., Bereavement Coordinator or Unit Manager) as the point-of-contact for future inquiries.

Provide Instructions

Give parents written information on how to retrieve items later, including hours, location, and required identification.

Why This Matters: Many parents who initially decline mementos due to shock or trauma, later regret not having them. Safe storage provides a compassionate safety net for future healing.

Neonatal Tissue and Organ Donation

Donated organs may include:

- Heart;
- Lungs;
- Liver;
- Kidneys;
- Pancreas; and
- Intestine.

In many neonatal donations, kidneys are the exclusive organs that can be transplanted due to the small size of the organs.

- Heart valves may also be donated as life-saving tissue.
- When transplant is not an option, organs and tissue may be donated for research use.
- Organ and tissue donation will not impact family's time with their baby or the timing of funeral and memorial plans.

LifeGift Launches Neonatal Donation Program: Saving Lives from the Earliest Moments

July 18, 2023

Lactation Support

Comprehensive Care Planning for Lactation Management and Support

Discuss Options Early Present choices between suppression, expression for comfort, or donation. Support the patient's preference based on their emotional and physical needs.	**Safety Counseling** Educate on signs of mastitis (fever, redness, extreme pain) versus normal engorgement. Provide clear instructions on when to seek medical help.
Non-Pharmacologic Measures Recommend supportive bras, cold compresses, NSAIDs for pain, and avoiding breast stimulation to aid natural suppression.	**Written Care Plan** Provide a written lactation plan including management steps, 24//7 contact numbers for questions, and what to expect physically over the next 2 weeks. • Texas Lactation Support Hotline 1-855-550-6667
Pharmacologic Suppression Consider dopamine agonists (e.g., cabergoline) per hospital protocol if appropriate and desired. Discuss risks and benefits clearly.	**Specialist Referral** Refer to a lactation specialist experienced in bereavement or milk donation programs if the patient expresses interest in donating milk.

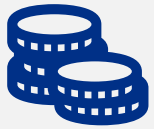
Burial and Cremation

Key Information for Supporting Families

- Families do not have to choose a funeral home immediately. Hospitals can safely hold the baby while families take time to make decisions.

- Funeral and burial costs can be significant and may create unexpected stress for families.

- Cremation is often a lower-cost option and may allow families more flexibility in memorial decisions.



- Some nonprofit organizations and hospital funds may help support burial or cremation expenses.

- When early neonatal loss is anticipated, gently remind families they may bring a special outfit, blanket, or keepsake if that would feel meaningful.

Clinical Considerations for Postpartum and Discharge

When supporting families in postpartum and at discharge:

- Allow the baby to stay in the room as much as the parent's request;
- Share that use of the cooling device is not mandatory;
- Prepare specialized discharge instructions when needed;
- Perform Edinburgh Postnatal Depression Scale or other depression screening prior to discharge; connect to mental health services for positive screen;
- Provide listing of community resources and support groups;
- Give parents something to hold; and
- Follow-up communication after discharge.

Mental Health Considerations

The profound impact on families

Emotional and Psychosocial Support

- Bereavement care extends beyond the medical event.
- Our aim is to provide immediate and long-term emotional, psychosocial, and practical support for parents, partners, and family members.
- We should also:
  - Establish emotional safety and psychological support;
  - Connect families to peer networks and community resources; and
  - Identify risks for depression, anxiety, and PTSD.

Support is the bridge that carries families from the darkness of loss into a future of healing.

Why Mental Health Support Matters

The death of a baby is not just a medical event, but a profound loss of a future, a hope, and a family member. The grief is often disenfranchised, leaving parents isolated in their suffering.

60-70%

Depressive Symptoms

Of women experience clinically significant grief-related depressive symptoms 1 year after stillbirth.

4x Higher

Depression Risk

Mothers with stillbirth are 4 times more likely to experience depression compared to live birth mothers.

~50%

Long-term Persistence

Symptoms may endure for 4 years or more in approximately half of affected women.

~25%

Post-traumatic Stress

Anxiety is also common in subsequent pregnancies.

Mental Health & Partner Support

Comprehensive Screening for All Parents

- Screen both the birthing parent and non-birthing parent for depression, anxiety, and PTSD, recognizing that grief manifests differently for each individual.

Tailored Resources for Partners

- Provide specific resources addressing the unique grief of partners, who often feel overlooked or pressured to “stay strong” for the mother.

Grief Education and Support Groups

- Offer education on the grieving process and connect families to local or virtual support groups to normalize their experience and reduce isolation.

Long-Term Support Planning

- Establish clear, long-term support plans with defined referral pathways, ensuring families have continued care beyond the immediate hospital stay.

Peer and Community Support

Star Legacy Foundation	Postpartum Support International (PSI)	AWHONN Resources
Dedicated to stillbirth research and education. Offers free online support groups for parents, grandparents, and pregnancy after loss.	Provides direct peer support, local provider directory, and specialized coordinators for pregnancy and infant loss.	Evidence-based resources for nurses and families, including “Gone Too Soon” books and care guidelines.
• Starlegacyfoundation.org • 952-715-7731 (Support Line) • Free virtual support groups	• Postpartum.net • 1-800-944-4773 (HelpLine) • Text “Help” to 800-944-4773 • Text in Spanish 971-203-7773	• Awhonn.org/bereavement • Parent booklets and planning guides • Nurse education modules

Peer and Community Support

Texas DSHS	Hand to Hold	Now I Lay Me Down to Sleep
State-funded initiatives providing support to hospitals and families and connecting them with local resources.	Based in Austin, providing NICU and bereavement support. Matches seasoned parent mentors with grieving families.	Provides professional remembrance photography to parents suffering the loss of a baby with a free gift of heirloom portraits.
• PerinatalBereavement@dshs.texas.gov • Dshs.texas.gov/maternal-child-health	• HandtoHold.org • Bereavement podcast series • Peer mentor matching	• NowILayMeDownToSleep.org • “Find a photographer” tool • Retouching services available

Mental Health Screening and Support

Validated Screening Tools Utilize standardized instruments like the Edinburgh Postnatal Depression Scale (EPDS) and PHQ-9 to objectively assess mental health status before discharge.	**Warm Handoffs** Facilitate direct introductions to mental health providers rather than just providing a list of names, ensuring a smoother transition to care.
Trauma-Informed Assessment Screen for PTSD symptoms and acute stress reactions, recognizing that perinatal loss is a traumatic event requiring specialized sensitivity.	**Inclusive Partner Support** Include partners in all screening and support planning discussions, acknowledging their grief and unique mental health needs.
Structured Contact Schedule Establish a firm follow-up timeline: initial check-in at 72 hours post-discharge, followed by contact at 2 weeks and standard postpartum visits.	**Crisis Resources and Documentation** Provide immediate access to 988 and local crisis lines. Thoroughly document the care plan and all referrals in the medical record.

Continuity of Care and Follow-Up

72-Hour Contact

Initiate a compassionate check-in call within 72 hours of discharge. Assess immediate coping, lactation status, and answer pressing questions.

1-2 Week Visit

Schedule an early clinic visit (1-2 weeks post-loss) for physical check, mental health screening, and debriefing in a supportive environment.

Direct Access

Provide a direct phone number or contact person for questions to bypass general call centers. Ensure families know exactly who to call.

Share Results

Clearly communicate timelines for autopsy or genetic results (often 6-12 weeks). Schedule a dedicated appointment to review findings sensitively.

Track Referrals

Monitor and close referral loops for mental health, lactation support, and grief groups. Ensure families successfully connected with resources.

Continuity is Critical: Bereaved families often feel “abandoned” after discharge. Structured follow-up protocols reduce isolation and identify complications early.

Barriers, Pitfalls, and Strategies

Potential Pitfalls

Even with the best intentions, systemic and practice-based barriers can hinder optimal care. We must acknowledge and address common gaps to ensure support for every family.

Common gaps may include:

- Inconsistent communication and follow-up procedures;
- Missing guidance and limited partner support; and
- Access issues and system-level constraints.

Identifying the gaps is the first step toward bridging them with compassionate care.

Cultural Considerations

Cultural background, spiritual beliefs, language, and social determinants of health profoundly shape how families process perinatal loss.

Culturally responsive care honors each family's unique needs.

Best practices for respecting beliefs and practices for all families include:

- Asking directly about beliefs and rituals;
- Offering meaningful alternatives;
- Ensuring interpreter services (as needed); and
- Clear documentation of their preferences.

Cultural differences in grief expression may include considerations around:

- Mourning practices and memory-making;
- Viewing and touching baby;
- Decision-making; and
- Spiritual and religious rituals.

Cultural humility over cultural competence. We cannot know everything about every culture, but we can always approach families with openness, respect, and a willingness to learn from them.

Practical Strategies for Care

- Ask, don't assume: 'What is important to you and your family right now?' 'Are there cultural or spiritual practices we should support?'
- Provide professional interpreter services, not family members for sensitive content.
- Offer culturally appropriate food options and accommodate dietary restrictions.
- Respect family structure and identify who should be included in decision-making.
- Be flexible with visitation policies to accommodate extended family and community support.
- Ensure memory-making materials represent diverse families (forms with varied family structures, inclusive language).
- Recognize bias: Examine your own assumptions about grief, family dynamics, and cultural practices.
- Address barriers: Transportation, childcare, work leave, financial constraints may impact family's ability to access care.
- Connect families to culturally-specific support groups and community resources.

Ensuring Access

Critical Practice Areas

Language access

- Guarantee professional interpreter services are utilized (not family members) and provide translated bereavement materials.

Cultural humility

- Train staff in cultural humility and trauma-informed care to navigate diverse grieving practices and avoid assumptions about rituals or expressions of loss.

Telehealth access

- Offer telehealth counseling and support group options to bridge gaps for rural families who may lack local specialized bereavement resources.

Community Partnership

- Collaborate with community-based organizations (CBOs) that serve specific cultural or linguistic groups to provide culturally relevant support; and
- Build referral networks.

Unit-Level Actions

- Audit educational materials;
- Identify local liaisons or champions;
- Review policies; and
- Include metrics in quality improvement.

System-Level Barriers and Solutions

The Challenge Low-volume and rural hospitals	Strategic Solutions Leveraging H.B. 37 and state initiatives	
× Limited specialized staff training	✓ Leveraging DSHS Perinatal Bereavement Care Initiative	✓ Apply for state grants for devices and training
× Lack of bereavement devices	✓ Utilize tele-education and regional networks	✓ Adopt standardized statewide protocols
× Financial constraints for resources	✓ Conduct regular simulation drills for readiness	✓ Track quality metrics and share best practices
× Inconsistent protocols due to infrequent events		

Self Care for Hospital Staff

Your well-being matters!

Caring for the Caregiver

- It is okay to show emotion.
- Consider prior experiences with loss and how caring for bereaved families may affect you.
- Consider your cultural and religious beliefs around death/dying/grief.
- Utilize hospital resources such as EAP, Code Lavender, etc.

Recognizing and Managing Compassion Fatigue

- Not all the patients we care for will survive.
- Being prepared to support patients in this situation helps families as well as staff.
- Moral distress and burnout are correlated with lack of support and resources for perinatal loss.
- Even for those of us who are committed to this population by choice, compassion fatigue is a significant issue which impacts mental health and job satisfaction.

Signs of Compassion Fatigue

Signs of compassion fatigue may include:

- Emotional exhaustion and detachment;
- Decreased empathy or numbness;
- Physical symptoms;
- Difficulty concentrating or making decisions;
- Avoidance of certain patients or situations; and
- Increased irritability or cynicism.

Strategies to Address Compassion Fatigue

- **Immediate self-care strategies:**
  - Take brief breaks during the shift to decompress;
  - Use deep breathing or grounding techniques;
  - Stay hydrated and nourished;
  - Debrief with colleagues after difficult cases; and
  - Allow yourself to feel your emotions.

- **Long-term wellness strategies:**
  - Establish clear work-life boundaries;
  - Engage in regular physical activity;
  - Prioritize adequate sleep;
  - Pursue hobbies and activities;
  - Connect with supportive friends and family;
  - Seek professional counseling or therapy;
  - Practice mindfulness or meditation; and
  - Join peer support groups.

Formal Workplace Support

Elements of a formal workplace support plan may include:

- Formal debriefing;
- Employee Assistance Programs (EAP);
- Mentorship or peer support;
- Specialized training;
- Protected time for processing after difficult events; and
- Assignment rotation.

Building a Team

Start where you are with what you have!

Goals for Bereavement Support

How can we as providers improve the way we deliver our message to families carrying a fetus with life limiting anomalies, navigating infant death, or experiencing stillbirth or miscarriage?

- Goals include:
  - Memory making;
  - Legacy building;
  - Affirming parenthood; and
  - Gift of time.

Key Considerations – Team Building

Key pieces as you put together your team and program:

- Needs assessment;
- Education and awareness;
- Engage key stakeholders;
- Standardize triggers for consultation, dissemination of birth plan, follow-up with families, and implementation of birth plan;
- Education around communication tools for difficult conversations; and
- Develop tools and resources.

The Role of the Health Care Team

Provide respectful, trauma-informed care

- Deliver compassionate support that is culturally sensitive and acknowledges the profound loss, validating the parents' experience.

Ensure clear and balanced information

- Communicate prompt, accurate details both orally and in writing, ensuring families understand their options without feeling rushed.

Facilitate choices and autonomy

- Support informed consent and shared decision-making, empowering parents to make choices that align with their values and wishes.

Coordinate interdisciplinary support

- Connect families with social work, chaplaincy, and mental health resources to ensure comprehensive follow-up care.

Meet Everly's Law obligations

- Consistently offer bereavement counseling options and available devices, documenting all care provided.

Action Steps for Implementation

Unit-level strategies to align with H.B. 37		
Form Bereavement Team	**Standardize Protocols**	**Train All Staff**
Identify a multidisciplinary champion team (nurses, lactation, social work, chaplaincy) to lead initiatives and inventory current unit practices against best standards.	Adopt uniform checklists, bereavement packets, and EHR templates to ensure consistent documentation and care delivery for every family.	Implement mandatory annual education for all L&D, NICU, and postpartum staff, including simulation drills for sensitive communication.
Establish Follow-Up	**Maintain Resources**	**Align and Certify**
Create clear workflows for post-discharge contact within 72 hours and long-term referral pathways to ensure continuity of care.	Curate and regularly update directory of local and virtual support groups, mental health providers, and grief resources for families.	Ensure full compliance with H.B. 37 requirements and prepare documentation to apply for the DSHS Hospital Recognition Program.

Structured Protocols, Training, and Equipment

Standardizing care to ensure consistency, safety, and compassion		
Unit Protocols and Checklists	**Standardized Orders and Packets**	**Annual Training and Simulations**
Standardized workflows ensure no critical step is missed during high-stress bereavement events. • Admission-to-discharge checklist • Role-specific task assignments • Shift handoff protocols	Pre-built tools reduce cognitive load for staff and ensure comprehensive care delivery. • Bereavement order sets in EHR • Consistent discharge packets • Resource directory updates	Regular practice builds confidence and competence in managing complex bereavement scenarios. • Communication skill drills • Memory-making workshops • Post-event debriefing sessions
Bereavement Device Policy	**Quality Metrics and Audits**	**Monitoring**
Clear guidelines for the safe, respectful use of cooling devices per Everly's Law. • Usage and consent protocols • Cleaning and maintenance logs • Family education materials	Data-driven improvement strategies to monitor compliance and outcomes. • Chart audits for documentation • Parent feedback mechanisms • Adherence to H.B. 37 standards	Ensuring all families receive equal access to high-quality bereavement support. • Disparity reviews by demographic • Interpreter utilization tracking • Cultural competency checks

Environment and Comfort Measures

Physical separation and privacy

- Whenever feasible, care for bereaved families in rooms away from the nursery and limit exposure to crying babies and joyous celebrations.

Bereavement signaling

- Place discreet symbols (e.g. leaf, butterfly, white rose) on the patient's door to alert staff and prevent insensitive interruptions.

Noise and atmosphere management

- Actively manage noise levels in the hallway and control visitor flow to be conducive to rest and grieving.

Flexible policies and access

- Suspend restrictive visiting hours for key support persons and ensure access to chaplaincy services.

Comfort amenities

- Ensure the room is stocked with extra tissues, water/snacks, comfortable seating, and memory-making supplies.

Key Takeaways

Honor the baby and parents

- Validate parenthood through memory-making, keepsakes, and treating every baby as a unique individual.

Communicate with empathy

- Use sensitive language, active listening, and shared decision-making to support informed choices.

Provide clear information

- Ensure families receive balanced verbal and written information, including follow-up plans and resources.

Build protocols and support staff

- Implement structured unit protocols and prioritize staff well-being to sustain compassionate care.

Peer and Community Support (1 of 2)

DSHS Perinatal Bereavement Care Initiative	Star Legacy Foundation	AWHONN Resources
Leading Everly's Law implementation. Hosting training events in 2026 for hospital recognition program.	Dedicated to stillbirth prevention and care. Offers free online support groups, peer companions, and provider education.	Best practice clinical guidelines for nurses. “Gone Too Soon” parent booklets and staff bereavement training modules.
• dshs.texas.gov/Perinatal Bereavement • 2026 Training Events • 2027 Online Training • Hospital and Family Toolkits	• Starlegacyfoundation.org • 952-715-7731 (Support Line) • Free virtual support groups • Specific groups for dads, grandparents, and more	• Awhonn.org/bereavement • Clinical Practice Guidelines • Discharge planning templates

Peer and Community Support (2 of 2)

Postpartum Support International (PSI)	Count the Kicks	Crisis and Hospital Support
Specialized support for pregnancy and infant loss. Provider directory for mental health referrals and peer mentor program.	Evidence-based stillbirth prevention campaign. Provides free educational materials and an app for tracking fetal movement.	Immediate mental health crisis support and internal hospital resources for spiritual and social care.
• Postpartum.net • 1-800-944-4773 (HelpLine) • Text “Help” to 800-944-4773 • Text in Spanish 971-203-7773	• Countthekicks.org • Free App for Patients • Free brochures	• 988 Suicide and Crisis Lifeline (Call/Text) • Hospital Chaplaincy Services • Medical Social Work Department

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Questions?

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