

**I have no conflicts of
interest to declare...**



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Questions We Will Answer

- What does pregnancy represent to the mother and the family.
- What happens when a life limiting diagnosis is made.
- What is Perinatal Palliative Care
- What is the history of Palliative Care
- What does it take to develop a Perinatal Palliative Care Service
- What Does the Pediatric Palliative Advanced Care Team at Texas Children look like and how do we develop the Birthplan?

What does Pregnancy Represent?

- Hope-for the family, the future, and the baby
- Dreams
- Parents have a “future” orientation
- Fulfillment of motherhood, womanhood, parenting
- Joy
- until the worst happens.....





Grief (Anticipatory) Begins the moment of Diagnosis

Medicine has used terms like....

- Lethal
- Terminal
- Incompatible with Life
- The Preferred term is “Life Limiting”

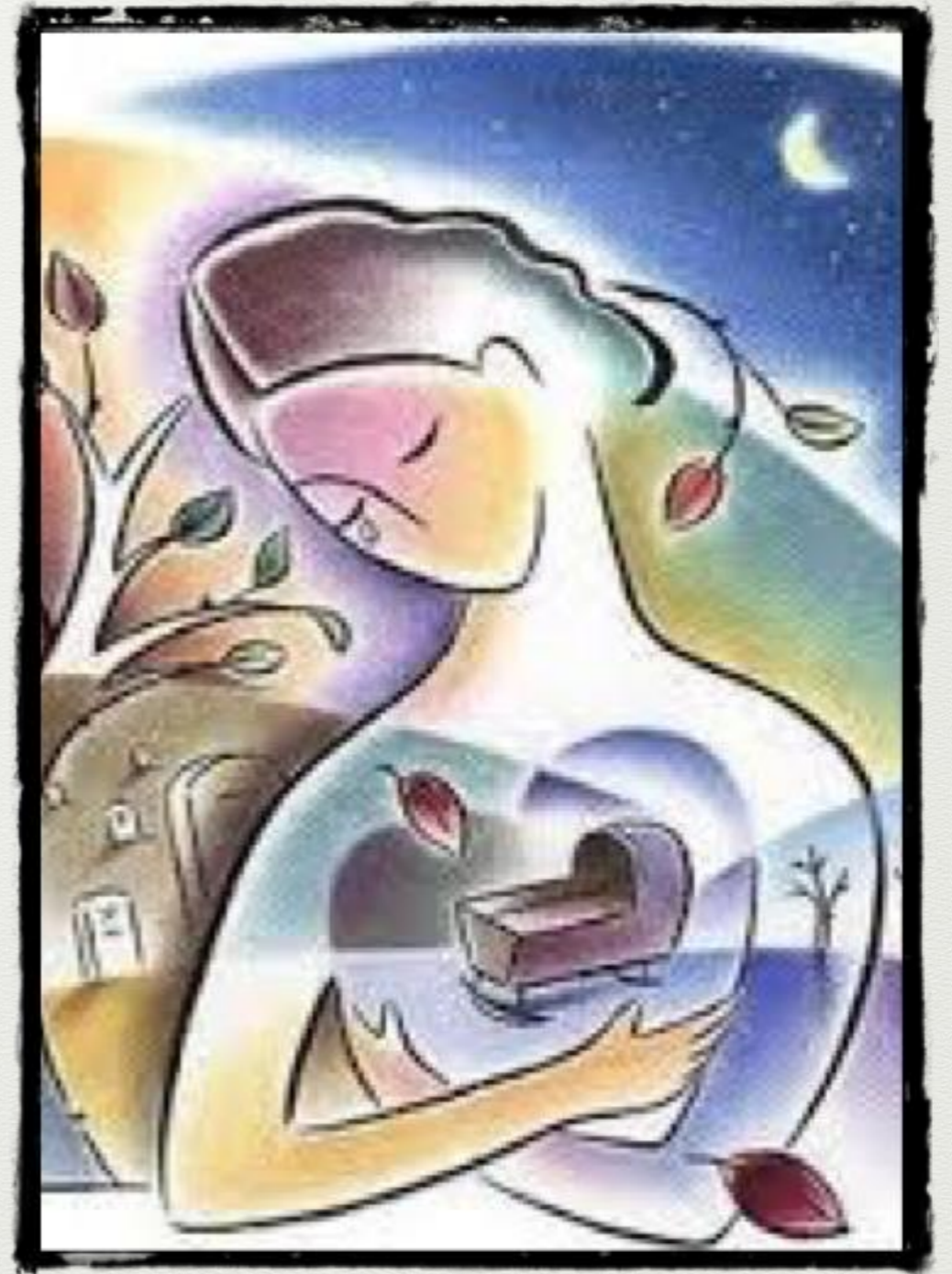
Examples of Life Limiting Conditions

- T13,T18
- Holoprosencephaly
- Anencephaly
- Renal Agencies
- Skeletal Dysplasia
- Acrania
- Pentalogy of Cantrell
- Multiple anomalies combined
- Triploidy
- Encephalocele

3 Choices are given

to parents:

1. Termination
2. Aggressive medical intervention that would be overly burdensome to the baby
3. Perinatal Palliative Care offers a Third Way



History of Perinatal Palliative Care

- 1997-Idea first proposed (Neonatal Network)
- 2001- America Journal of Obstetrics and Gynecology begins to use “perinatal hospice,” because it integrated philosophy and expertise of hospice and palliative care with best practices in perinatal bereavement care for miscarriage, stillbirth, or infant death



World Health Organization

- “Palliative care affirms life and regards dying as normal process” and “intends neither to hasten or postpone death”



Pediatric Palliative Care

- Support begins at the time of a life-limiting prenatal diagnosis-“hospice in the womb” continuing through to traditional hospice if baby lives past mother’s discharge.
- Rather than “doing nothing,” this is an extraordinary form of physical and emotional care that honors the baby as well as the family!
- It includes essential newborn care like warmth, comfort, and nutrition.

Pediatric Palliative Care

- It is Care for the fetus, the mother(partner), and the newborn infant with a life-limiting illness
- It is Interdisciplinary
- It's focus is on relief of suffering, enhanced quality of life for the family and newborn, facilitates informed decision making, assists in the coordination of care, and supports the family throughout the process

Perinatal Palliative Care

- Can create a safe place to discuss continued goals and wishes in a nonjudgmental way
- Parents articulate understanding of the condition and why they are at this meeting
- Open and Honest Communication
- Compassion and Support
- Team Planning
- Inclusion of the entire family
- Develop a birth plan
- Driven by the needs and the decisions of the family

What is important in a Perinatal Palliative Care Service?

Support from Administration-understanding what palliative care encompasses-

Support of a Culture change- to accept palliative care is just as important as “treatment and cure”

Support from and for staff with education

Excellence

Excellent and open communication:
with the family

Excellent and open communication:
between physician disciplines,
i.e. OB to neo/pedi to surgery, etc...

Excellent and open communication:
between members of the healthcare team, i.e.
physician to nursing, nursing to physician, social
work, hospice, child life, chaplain, etc...

Organization

We should be here to provide an organized, systematic approach to the patient requiring our services

Cohesiveness

We need to feel strongly allied to one another to accomplish our mission

Communication

We need to communicate well within the group, and within our facility and beyond. This is one of the most challenging parts of end of life care, it takes ongoing work.

Multidisciplinary, evidence-based, family-centered approach

Team education(initial and continuing)
Emotional support available to team members
Partner with families in care and enable them to make informed decisions

Consistency/Continuity

Funding that ensures services stability
Formal policies and procedures
Families have continuous access to palliative expertise

Regular Assessment

Data collection and analysis to demonstrate effectiveness
Quality and performance improvement

Steps to form a Palliative Care Team Approach

Develop and Implement extensive education
plan for providers.

Birth plans

Process of grief and normal responses of families

Tips for helping families cope

How to support attachment with the infant

Develop a template for a Birth Plan

Identification of resources and care pathways for
infants that do not die in the hospital.

Environment for mothers to give birth/child pass away

Soothing, comforting, personal
Enough space for all family members

Minimal distractions so time spent with
baby can be precious/special

Respecting patient's/parents wishes
as much as possible

Comfort patient's physical needs
Parents emotional/physical comfort as well as infant's

TCH PPACT

MISSION STATEMENT:

To provide the highest standard of comprehensive, compassionate, family-centered palliative care to infants with life limiting diagnosis that preserves dignity and enhances quality of life for both baby and family.

GOAL-

To educate/empower families to make decisions concerning fetal/neonatal care and their delivery/birth experience

PPACT Process:

Referral to Fetal Center from a variety of OB's after diagnostic ultrasound or amnio

Becomes a patient of the Fetal Center where mothers receive follow-up diagnostic care and meet with MD specialist according to the diagnosis as well as transfer of care to MFM

Presentation of case in weekly multidisciplinary team meeting-All agree in life limiting diagnosis and referral to palliative care team is made.

The Birth Plan

- Plan to meet with each family 3-4 times if time permits (1 hour)
- Introduction of team members and roles (MD, RN, CLCS, SW, Chaplain)
- Ask what family understands of diagnosis
- Allow silence...and emotion
- Goal: Creation of Birth Plan
Explain what PPACT team can help them with.



3 PPACT “settings”

1)Antepartum

2)Intrapartum

3)Postpartum

Antepartum

What does the extended family understand?

What does their spiritual support look like?

What ceremonies do they want?

Wish for labor and the birth i.e. who will be there?

Monitor the baby or not? C/Section? Walk around? Pain management? Cut the cord?

All procedures with baby in my arms?

Vitamin K? Erythromycin? Hepatitis B?

Autopsy? Imaging Autopsy?

Chromosomes/Blood work via cord blood?

Funeral arrangements? Hospice?

Breast Feed? Donate Milk?

Intrapartum

Birth Plan Scanned into Epic (EMR) and begins activation

When the Mom is admitted to L&D-Bring a copy of the Birth plan

Neonatologist is only member of the advanced delivery team to attend delivery

NTN (baby nurse) attends with Neonatologist

PostPartum

If Baby Stillborn (no RX needed)

If Baby liveborn (orders entered in EPIC by MD)

MD/NTN care for infant in L&D until mother transferred to postpartum, then Pediatrician takes over until pronounced or discharged.

Pain/Comfort management (**Morphine**), if seizures (**Ativan**), and nutrition

Pink sheet filled out when baby passes away

D/C to home or inpatient hospice if not deceased prior to mother's discharge

Feeding Options

Small amount of food every 3 hours...

if mother chooses & infant can... breast feed

If mother chooses & if infant can suckle breast but too weak to eat, NG passed and formula used

If mother does not choose to breast feed, pass NG and formula fed

If mother wants to donate milk, arrangements can be made

Social Worker



- Evaluates Mother's Mental Health needs
- Follows up with family during pregnancy, birth, & after death
- Helps with funeral/burial plans
- Helps coordinate hospice
- Helps with grief/recovery referrals

Child Life:

Memory making:

molds

photos

memory box

Sibling Support

Spiritual

Care:

Baptism

Naming Ceremony

Supportive Care





Future Work

- Quality Improvement
- F/U with Families 3-6 months following experience to evaluate their experience, to look for areas of improvement.
- Data Collection
- Remembrance Ceremony

“By giving my son the protection of my body to face the announced death, I was giving him life, all of his life, so that it would be recorded in our family, in all of our history, and in the hearts of each of us. It wasn’t a morbid walk but a formidable surge of love.”

–translated from the book “A Child for Eternity”-