

Perinatal Palliative Care



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Learning Objectives

- Enhance your understanding of the scope of Palliative Medicine.
- Understand the elements of a supportive care setting for sharing diagnosis of a lethal congenital anomaly.
- Describe key steps in delivering “bad” news.
- Enhance your knowledge of the functions of the perinatal palliative care team.



Scope of Palliative Care

- Available to persons of any age
- For anyone with a diagnosis that causes suffering
 - Women with pregnancy complications, fetus with a fatal anomaly or a serious-life-threatening diagnosis
- At any time patients or families have a need and are willing to integrate palliative care with therapies to manage a complicated pregnancy
- In any setting where patients receive care - -
 - Home, OB office, Perinatologist visits, L&D, NICU, etc.
- With the patient's primary health team - -
 - Family Physician, OB/GYN, Nurses, Perinatologist, Neonatologist, Genetic Counselors, SW, Doula, Chaplain



Perinatal Palliative Care Teams

- Focus on continuum of care from diagnosis until death of fetus or infant
- Provide support
 - throughout pregnancy
 - delivery
 - immediate post-partum
 - NICU
 - Home care of infant
 - Death of infant
 - Bereavement and grief support
 - Anniversaries of infant's death



Goals of Perinatal Palliative Care

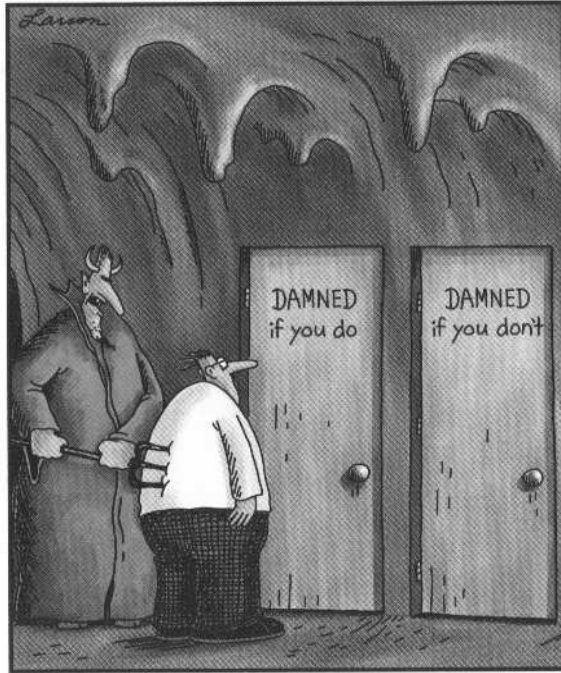
- Support for woman and family after diagnosis of lethal fetal condition
- Multi-disciplinary Team
 - Genetic testing and Antepartum counseling
 - Maternal-fetal medicine evals and visits
 - Counseled regarding fetal dx and prognosis
 - Develop a sensitive birth plan
 - Meet early with neonatologist
 - Preparation of entire family for birth/death and bereavement rituals.



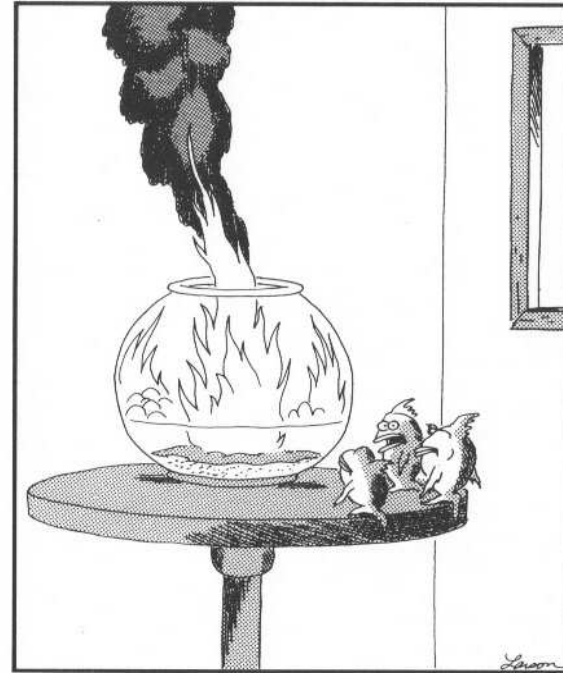
Palliative Care – Before and After Birth

- Support from time of diagnosis through bereavement process.
- Create a personalized birthing plan:
 - How and where delivery occurs
 - Measures that will be taken once baby is born
 - Honor the values and beliefs of parents
 - Discuss supportive care treatments for baby
 - Identify Community Resources
- Childbirth education options
- Bereavement options and Rituals





"C'mon, c'mon—it's either one or the other."



"Well, thank God we all made it out in time. ...
'Course, now we're equally screwed."



Sharing Difficult Information

- Prepare yourself
 - Gather information about the dx
 - Seek support from physician or nurses that have helped patient with similar dx
 - Understand options of community resources
 - Identify who you would like to be present when you share this info with your patient
- Think about your goals for this first meeting
- Use of medical interpreter



Sharing Difficult Information

- Identify your patient's medical fluency
- Be sure that they have a support person with them for this meeting
- Sit down
- Turn off or silence pager
- Have appropriate support for you - - e.g., Perinatal SW or Palliative Care . . .



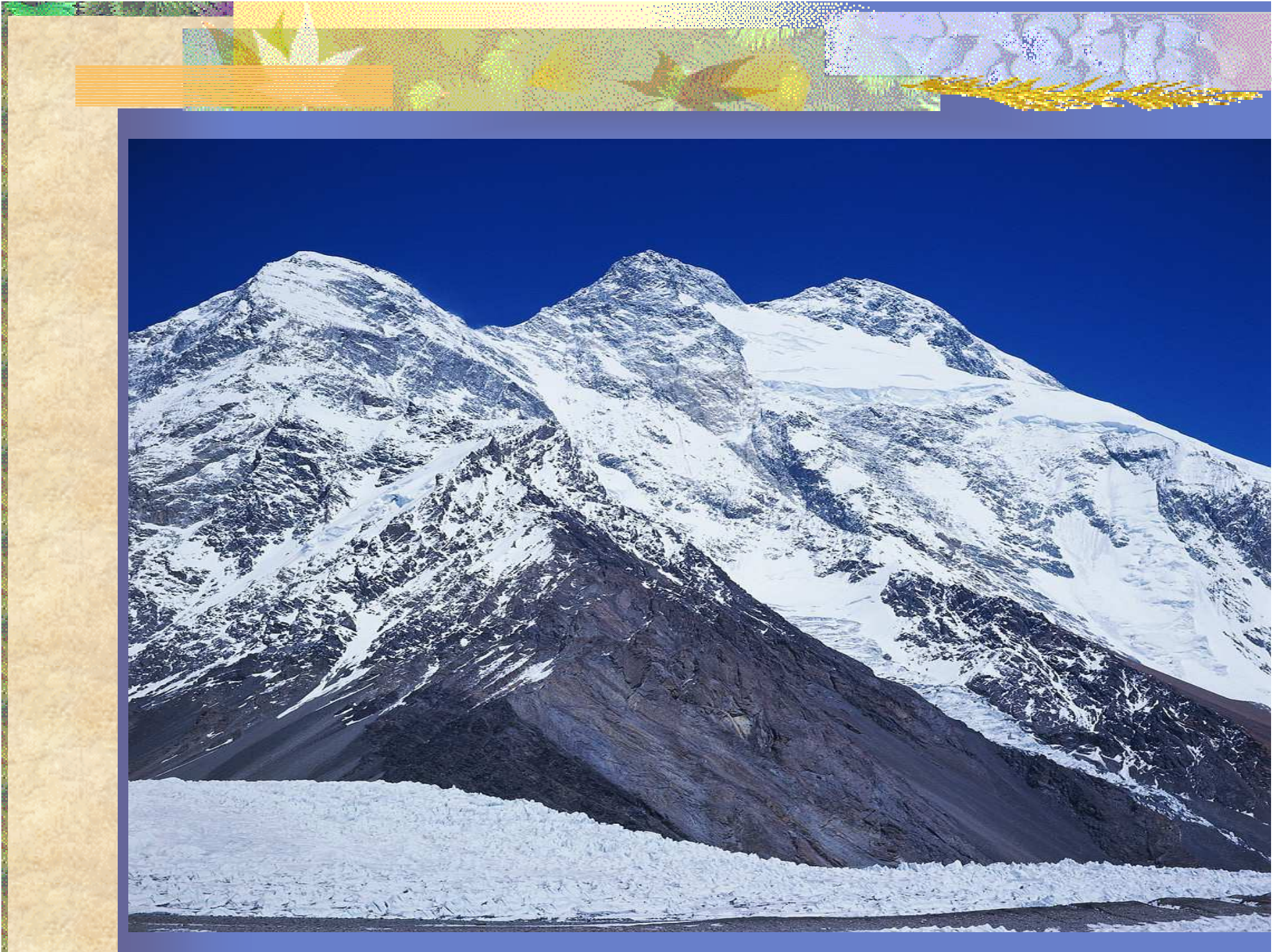
Sharing Difficult Information

- Speak clearly and slowly
- Don't look at chart, look at the woman's eyes
- Give a fair warning: "I'm sorry, but I have some bad news about your prenatal test results . . ."
- PAUSE REMAIN QUIET LISTEN
- Be prepared to repeat information



Sharing Difficult Information

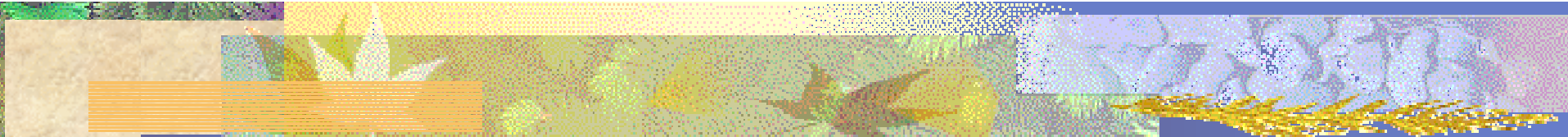
- Be prepared for typical human reactions:
 - Overwhelming emotions
 - Numbness, looks like absence of emotion
 - Acceptance, denial or ambivalence
 - Desire to not share info with other family members
- Validate their experience
 - “This is terrible news, I am so sorry”
 - “This seems so unfair ...”
- Allow enough time for questions
- Set up early follow-up appt





Bereavement Support and Rituals

- Grief – heal and integrate the loss
- Surviving → transformation → dynamic integration of healing and living again
- Validate the loss with visible rituals
 - Miscarriage or infant death - - disenfranchised grief



Bereavement Support and Rituals

- Symptoms and Expressions of Grief
 - Physical/Somatic
 - Psychological
 - Emotional
 - Cognitive
- Complicated Grief
 - Lack of a response
 - Intellectualize the loss
 - Repress feelings of grief



Bereavement Rituals

- Encourage communication
 - Have family and mother share stories of their experience of this pregnancy and birth
 - Have a calming and caring presence
- Memories and Mementos
 - Prepare baby for viewing
 - Photos
 - Memory box – locks of hair, foot and hand prints or casts
 - Name bracelet and certificates
 - Quilts of baby's clothing



Bereavement Rituals

- Rituals
 - Naming
 - Spiritual Blessing
 - Baptism
 - Viewing
 - Memorial Service
 - Religious rites
 - Funeral ceremonies
- Support Groups
- Approaches to Holidays



Summary

- Perinatal Palliative Care Teams provide a continuum of care and support for the mother and family
 - From diagnosis through death of fetus or infant
 - Multidisciplinary Team
 - Integrated into care from initial dx and works with OB, Perinatologist, Neonatologist, Gen Counselor, Nurse Pract., CBE, Nurses, etc



Summary

- Discussed skills needed for sharing difficult information or “bad news”
- Discussed Bereavement Process
- Discussed Bereavement and Healing Rituals

