Pediatric Palliative Care and Having Difficult Conversations
Palliative Care

• A philosophy
• A care model
• Comprehensive care for children with life-threatening conditions
• Active, multi-disciplinary, inpatient and outpatient
• Address physical, emotional, social and spiritual elements
• Concurrent care- can continue curative or disease directed treatments
• Goal is to maximize quality of life and relief of suffering through recovery or death and bereavement
Model of Concurrent Palliative Care

- Therapy to Modify Disease (curative or life prolonging)
- End of Life Care (Hospice)
- Bereavement Care
- Palliative Care
- Presentation
- Therapy to Relieve Suffering And/or Improve Quality of Life
- Death

Illness Continuum:
- Acute
- Chronic
- Advanced Life-threatening
Criteria for referral to PC

Primary Criteria
• The surprise question
• Frequent hospital admissions
• ICU stay >7 days
• Difficult to control physical or psychological sx
• Decline in function, feeding ability, weight
• Disagreements among staff, patient, family re major medical decisions

Secondary Criteria
• Admission to long term care facility
• Out of hospital cardiac arrest
• Limited social support
• Awaiting or deemed ineligible for solid organ transplant
• Discussion of G tube, tracheostomy, or dialysis
• No documented advanced directive
Opportunities to initiate PC

- Initial diagnosis
- First bad news
- Acute decompensation, admission to ICU
- Developmental steps- age of assent 12th or 13th birthday, 18th birthday
Tasks of Early PC

- Identify problems or challenges, focus on QOL
- Explore hopes and goals
- Facilitate communication between subspecialists and family
- Identify community resources
- Address needs of patient and family
- Anticipate decisions
Concurrent Care for Children

• Part of the Affordable Care Act signed 3/2010
• Section 2302 Concurrent Care for Children
• Allow continuation of developmental and disease-directed or curative therapy while obtaining hospice and related services
• State based Models- eliminate the need for <6mo prognosis, add Care Coordination, Expressive therapies, Family counseling
Family meetings/Breaking bad news

• To gather information
• To provide information
• To provide support
• To develop realistic goals and treatment plan
The meeting as 3 course meal

• Appetizer- Meeting Preparation
• Main Course- the meeting
• Dessert- Provider Debrief
SPIKES

- Setting
- Perception
- Invitation
- Knowledge
- Emotions
- Summarize
Setting

- Team - who should be there, who will lead, interpreter if needed?
- Review the medical facts
- Tissues, water, privacy
- Ditch the pager if you can
- Set a time limit
Perception

- Ask first, talk later
- What does the patient or family know?
- What are their concerns?
- Ask open ended questions
Invitation

- Find out how they would like information delivered
  - every detail vs broad brush-strokes
  - will patient be included? What family members?
Knowledge

- Provide clinical information
- Small bites of information at a time
- Have them repeat it
- Fire a warning shot before bad news
- Don’t say “I’m sorry”
- Use real words- not medical jargon, not euphemisms
Emotions

• You cannot prevent distress from bad news
• Silence is important
• Pre-empt guilt if possible
• Words are mighty- do not say “there is nothing we can do”
• Frame code discussions as one type of treatment vs another (resuscitation vs aggressive comfort measures)
• Burden vs Collaboration
• MD emotions are O.K.
Summarize

- Repeat, Review, Revise
- Redirect hope in realistic directions
• www.getpalliativecare.org
• www.nhpco.org/pediatrics
• www.capc.org
• www.cms.gov/medicaidgeninfo/stateplanlist.asp