

# Listening, Language and the Power of Truth-Telling: Pediatric Considerations



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# Objectives

- Review the evolution of 'truth-telling' in children
  - Describe the legal and ethical aspects of truth-telling in pediatrics
  - Define the challenges and opportunities of sharing information about diagnosis, treatment and prognosis with a child or teenager affected by a life-threatening condition
  - Define the challenges and opportunities of sharing information about diagnosis, treatment and prognosis with a child or teenager whose parent/guardian/caregiver has a life-threatening condition
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# Evolution of Truth-telling

- 1950s and 60's
  - ‘protective’ approach to disclosure, where children were shielded from bad news
- Late 1960's and early 70s
  - More ‘open’ approach recommended by a growing number of clinicians and researchers
- Late 1980's
  - Shift to ‘always tell’
- Present day
  - Case by case
  - Emancipated minor
  - Mature minor law



Sisk et al, Prognostic Disclosures to Children: A Historical Perspective

# Legal Considerations

- Greater recognition of children's rights in the last 100 years
- The locus of pediatric decision making remains with the parents
- Technically, parents provide “permission” rather than consent
- Refusal of appropriate treatment for a child constitutes neglect



Young girl working in  
American Mills; Winooski, VT

# Ethical Considerations



*The Sick Child*, Edward Munch

- Explore parental reasons for non-disclosure
- If resistance persists
- How to respond to the direct question of a child in cases of firm preference for parental non-disclosure

# Case # 1

- Devon is a 6-year-old boy with osteogenic sarcoma of the left femur who will need chemotherapy, radiation, surgery
- His parents want to delay discussion of the upcoming surgery because they fear he will refuse chemotherapy and radiation if he finds out he may have his leg full or partly amputated



# Perspectives



**Marina**  
Mother

Works per diem as a home health aide; had professional experiences where disclosure went poorly and the patient “gave up all hope”.



**Floyd**  
Father

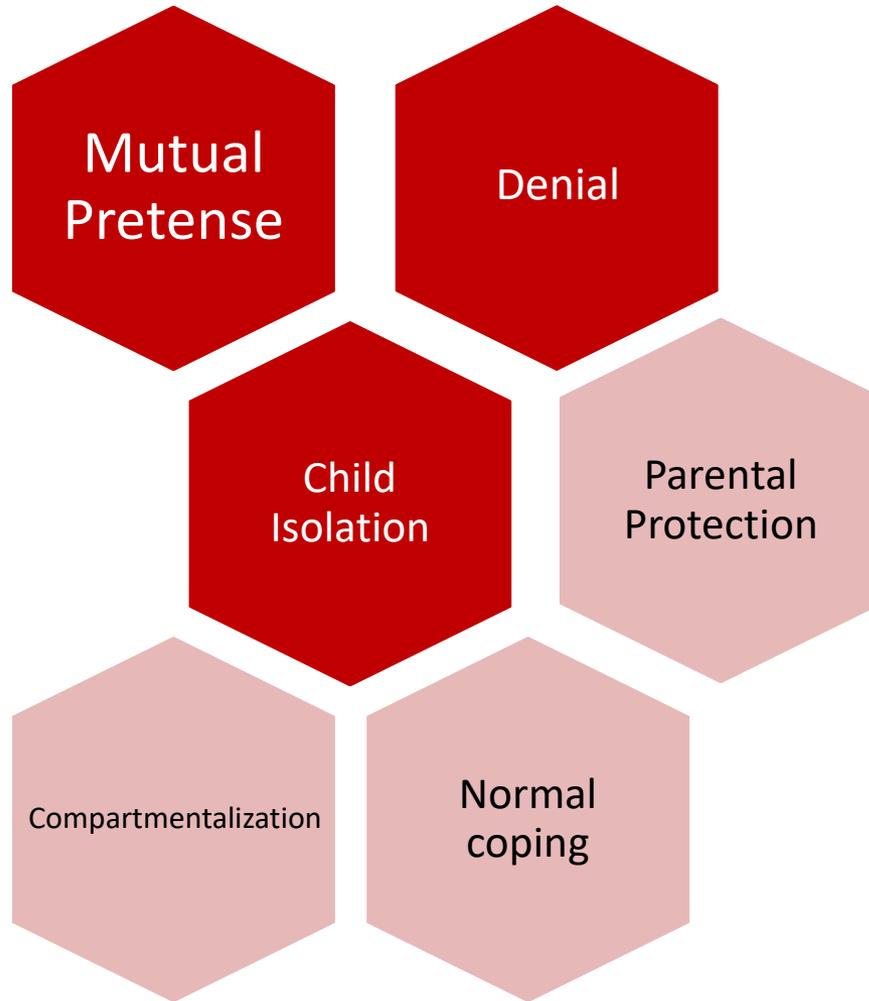
Floyd became angry when a surgeon told his father before open heart surgery that he might “die on the table”.



**Devon**  
6 years old

Open and gregarious; bonds with staff easily.

# Parental requests to withhold information



# Are there data to support honest communication with a sick child about prognosis?

New England Journal of Medicine

ORIGINAL ARTICLE

## Talking about Death with Children Who Have Severe Malignant Disease

Parental interview after death children, asking about discussions of illness and death

- Of 429 parents, all of whom had child die of cancer in Sweden, 147 (34%) talked about death with their child and 282 (66%) had not
    - None of the parents who talked about death regretted it
    - Of the parents who did not talk about death, 69 (27%) regretted and 189 (73%) did not regret
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Just because a child or teenager doesn't have  
Decision Making Capacity doesn't mean they  
play no role in Decision Making

- Consent

- Assent



What if Devon were 13 years old and didn't want to know?

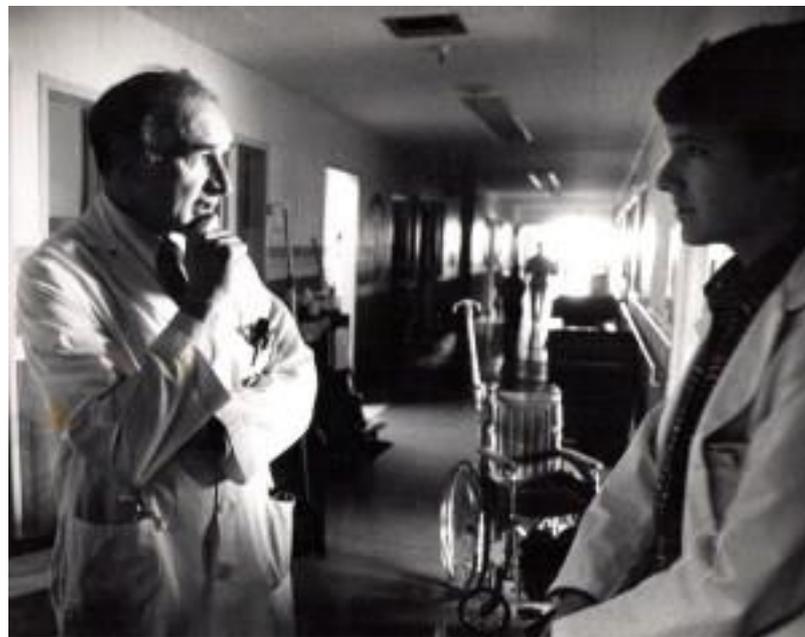


MY ANXIETIES HAVE ANXIETIES.



# Principles and Practice for talking to the child or teenager

- Preferences about how information is communicated
  - Truth, honesty, empathy, respect
  - Language, time, continuity, source, location
- Preferences about what information is communicated
  - Illness and treatment
  - Prognosis
  - Decision Making
- Preferences about who should be involved in communication
  - Age
  - Presence of child



Drs Arthur Ablin and Christopher May, UCSF June 1988

## Case # 2

- Hailey is a 15 yo female. Her mother is on the waiting list for a heart transplant following severe heart failure from idiopathic cardiomyopathy. She is in the Cardiac Intensive Care Unit on a Left Ventricular Assistive Device. She is awaiting a heart transplant.
- You are the health care clinician (social worker, nurse, chaplain, physician, psychologist, patient advocate) whom Hailey's father has asked to speak to her about her mom.



# Imagine you are Hailey...

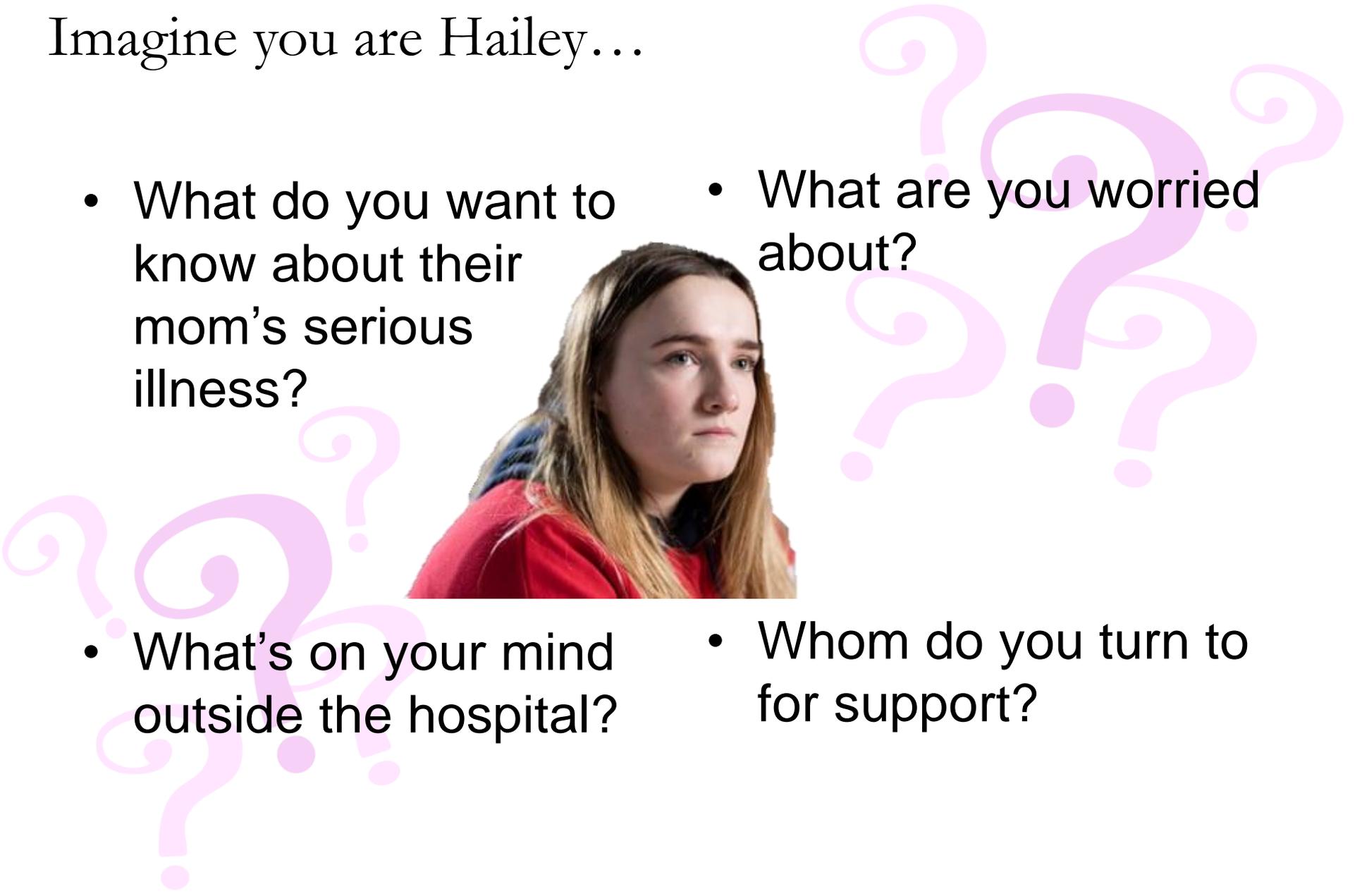
- What do you want to know about their mom's serious illness?



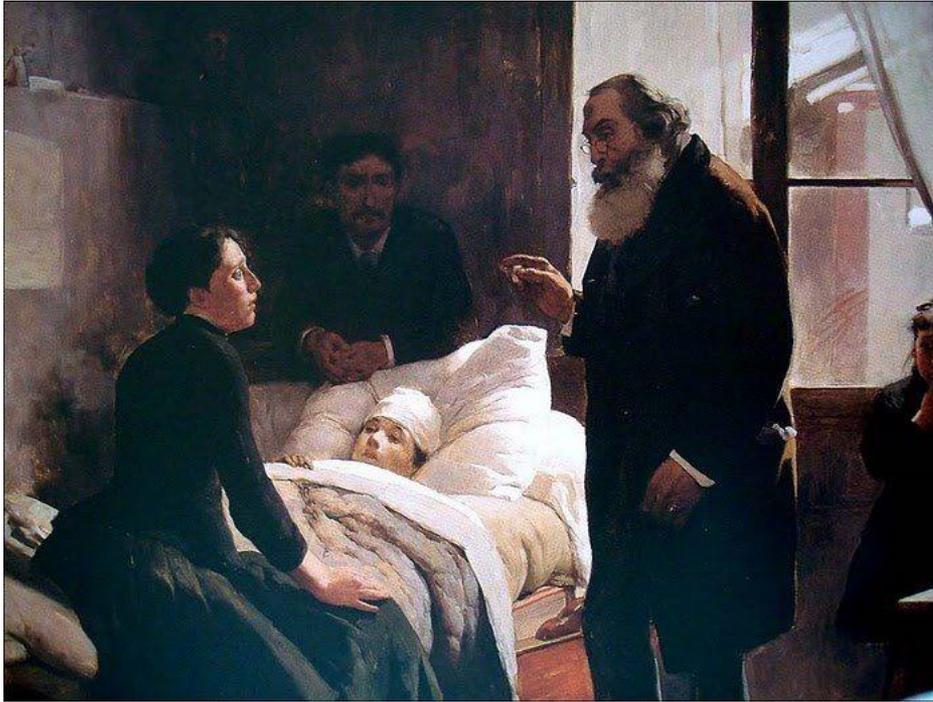
- What are you worried about?

- What's on your mind outside the hospital?

- Whom do you turn to for support?



# Recommendations for professionals and caregivers when a teenager's parent is seriously ill



El Niño Enfermo, Arturo Michelena

- Information as soon as possible
- Anticipation of disruption in ability to function well
- Specific ways they can be helpful
- Recognize additional stressors
- Counseling for teen who is struggling with communication or other behavior

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# Questions, Comments, Concerns?

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*The Doctor, Sir Luke Fildes; 1891*