



Taking Time to Listen: Pediatrics

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Amy

- 8 year old with Rett Syndrome
- Admitted for increased work of breathing
- Decline over last 9 months with difficulty controlling seizures
- Peg-tube dependent x 2 months
- Hospitalized x 8 in last year of life

Amy

- **Rett Syndrome**
 - Neurodevelopmental disorder
 - Affects mostly girls
 - Variable course
 - Grow normally at first
 - Lose purposeful hand movements, speech, gait
 - Seizures
 - Breathing problems

Amy

- At time of initial consult Mom's goals:
 - Aware of decline and loss of QOL
 - Elected DNAR status
 - Wanted treatment for acute, reversible issues
 - Had home nursing 12 hrs/day
 - Sent home with POLST form

Amy

- Home after 10 days
- Returned to ED (after 8 days) for increased secretions & fever
- Tx'd for aspiration pneumonia
- Mom would like to keep her at home as much as possible
- Would like to do IV abx at home

Amy

- Transferred to LLUMC 2 wks later for increased oxygen requirement
- Offered trach – Mom is ambivalent
- Trach done to help with secretions
- Back home with POLST form

Pediatrics

- 53,000 US children age 0-19 die each year
- 50% are children < 1 year old
- 75-85% of children die in the hospital, often in ICU
- 400,000 children living with serious illness

Pediatrics

- Congenital defects
- Chromosomal abnormalities
- Acquired devastating injuries
- Malignancies

Different than Adults

- Children aren't supposed to be sick, let alone die!
- Impact of death
- Developmental level of child
 - Parents make decisions rather than patient

Barriers to Quality EOL Care

- Realities of life-limiting conditions
- Lack of professional training
- Misunderstanding of Palliative Care
- Failure to acknowledge limits of medicine
- Asking families to stop treatments
- Reimbursement issues

...Barriers

- Gap between MD & parents view of prognosis or QOL
- Primary goal: CURE (not comfort)
- MD's not comfortable with bad news
- Delayed (or non-existent) referral to hospice
- Hospice not comfortable with peds
- Denial that children die

AAP

- The AAP supports an integrated model of palliative care “in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.”

Amy

- DNAR does not mean “do not treat”
- Recommendations for code status should be given
- Do not ask “Do you want everything?”
- “Concurrent care” – hospice care with ongoing disease-modifying treatments

Amy

- Admitted to PICU 1 mo later for intractable seizures
- Tx'd with anti-seizure meds, IV abx, midazolam & morphine drips
- Died on HD #6 surrounded by family

Meaning

- “We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed...When we are no longer able to change a situation,...we are challenged to change ourselves.”

Victor Frankl 1959