Against all odds:
Making a Difference with Palliative care:

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PEDIATRIC CRITICAL CARE & PEDIATRIC PALLIATIVE CARE TEAM

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To Cure Sometimes

To Relieve Often

To Comfort Always

Anonymous folk saying, 15th century

Pediatric Palliative Care

- Active total care of mind body and spirit
- Involves supporting the entire family
- Begins at diagnosis, continues whether child receives disease directed treatment or not
- Requires broad multidisciplinary approach
- Can be provided WHEREVER the child is located

Pediatric Palliative Care

- Prevents or relieves symptoms produced by a life threatening medical condition or its treatment
- Offers help for children with such conditions and families to live as normally as possible
- Provides families with timely and accurate information and support in decision making
- Provides support for caregivers

Pediatric Palliative Care

Goal of adding life to the child's years and not simply adding years to the child's life'

American Academy of Pediatrics

Why is Palliative Care Important?

- 53,000 children die annually
- 500,000 children are coping with life-threatening conditions
- 1-1.5 million children are coping with complex chronic conditions

Why is Palliative Care Important?

Infant mortality > 50% childhood deaths : congenital malformations, chromosomal abnormality, prematurity/low birth weight, SIDS, accidents

Most common cause of death in 1-19 y/o: unintentional injuries, homicide, malignancy

Cancer is the primary cause of disease related death

1:5 children with cancer die

Not just death and dying

- > 1 million children living with chronic, life-limiting or life-threatening conditions in USA
- Death rate decreasing slightly
  - more technology
  - population increasing steadily
  - more children with chronic conditions
  - ↑ drain on families, communities, society, hospitals

Evolution of Pediatric Palliative Care

- 1967 – Dame Cicely Saunders founded the first modern hospice
- 1974 – Florence Wald opens hospice in Connecticut
- 1975 – First hospice incorporated into medical center in CT
- 1982 – Children's hospice center opens in UK
- 1990 – WHO recognizes Palliative Care

Palliative Medicine

- WHO estimates that over 20 million people are in need of palliative care worldwide annually
- American Board of Medical Specialties, 2006
- Core responsibility of all clinicians

Primary Palliative Care

Basic management of pain and symptoms

Basic management of depression/anxiety

Discussions about

- Prognosis
- Goals of treatment
- Suffering
- Code status

Quill TE, Abernethy AP. NEJM 368; 13; 2013 p 1173-1175

Specialty Palliative Care

Management of refractory pain

Management of more complex depression, anxiety, grief, existential distress

Assistance with conflict resolution

- within families

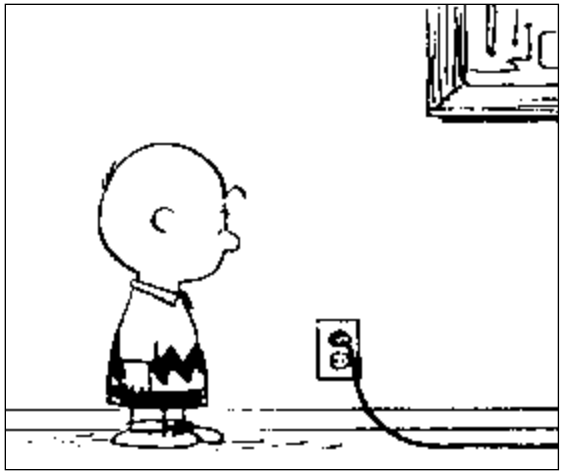
- between staff and families

- among treatment teams

Assistance in addressing cases of near futility

Quill TE, Abernethy AP. NEJM 368; 13; 2013 p 1173-1175

Myths of the Palliative Care Team



Palliative Care Myths

#1 Child must be terminally ill or at end of life

#2 Palliative Care = Hospice = Giving Up Hope

#3 Child must have a DNR to have hospice or palliative care

#4 Only for children with cancer

#5 Must abandon all disease directed therapy

Palliative Care Myths

#6 Must abandon the primary care team

#7 Child must move to different location

#8 Children will die sooner/lose hope if palliative care is introduced

#9 All families want end of life care to be at home

#10 Administering opioids results in respiratory depression and hastens death

Identifying Patients in need of Palliative Care

Group 1

Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be beneficial alongside attempts at life-prolonging treatment and/or if treatment fails.

- Advanced or progressive cancer or cancer with a poor prognosis
- Complex and severe congenital or acquired heart disease
- Trauma or sudden severe illness
- Extreme prematurity

National Hospice and Palliative Care Organization – Standards of Practice

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Identifying Patients in need of Palliative Care

Group 2

Conditions where early death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life, allowing participation in normal activities, and maintaining quality of life *(e.g. life-limiting conditions)*.

- Cystic fibrosis
- Severe immunodeficiencies
- Human immunodeficiency virus infection
- Chronic or severe respiratory failure
- Renal failure (non-transplant candidates)
- Muscular dystrophy, myopathies, neuropathies
- Severe short gut, TPN-dependent

National Hospice and Palliative Care Organization – Standards of Practice

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Identifying Patients in need of Palliative Care

Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative after diagnosis and may extend over many years.

- Progressive severe metabolic disorders, *(e.g. metachromatic leukodystrophy, Tay-Sachs disease, severe mitochondrial disorders)*
- Certain chromosomal disorders, *(e.g. Trisomy 13 and 18)*
- Severe osteogenesis imperfecta subtypes
- Batten disease

National Hospice and Palliative Care Organization – Standards of Practice

Identifying Patients in need of Palliative Care

Group 4

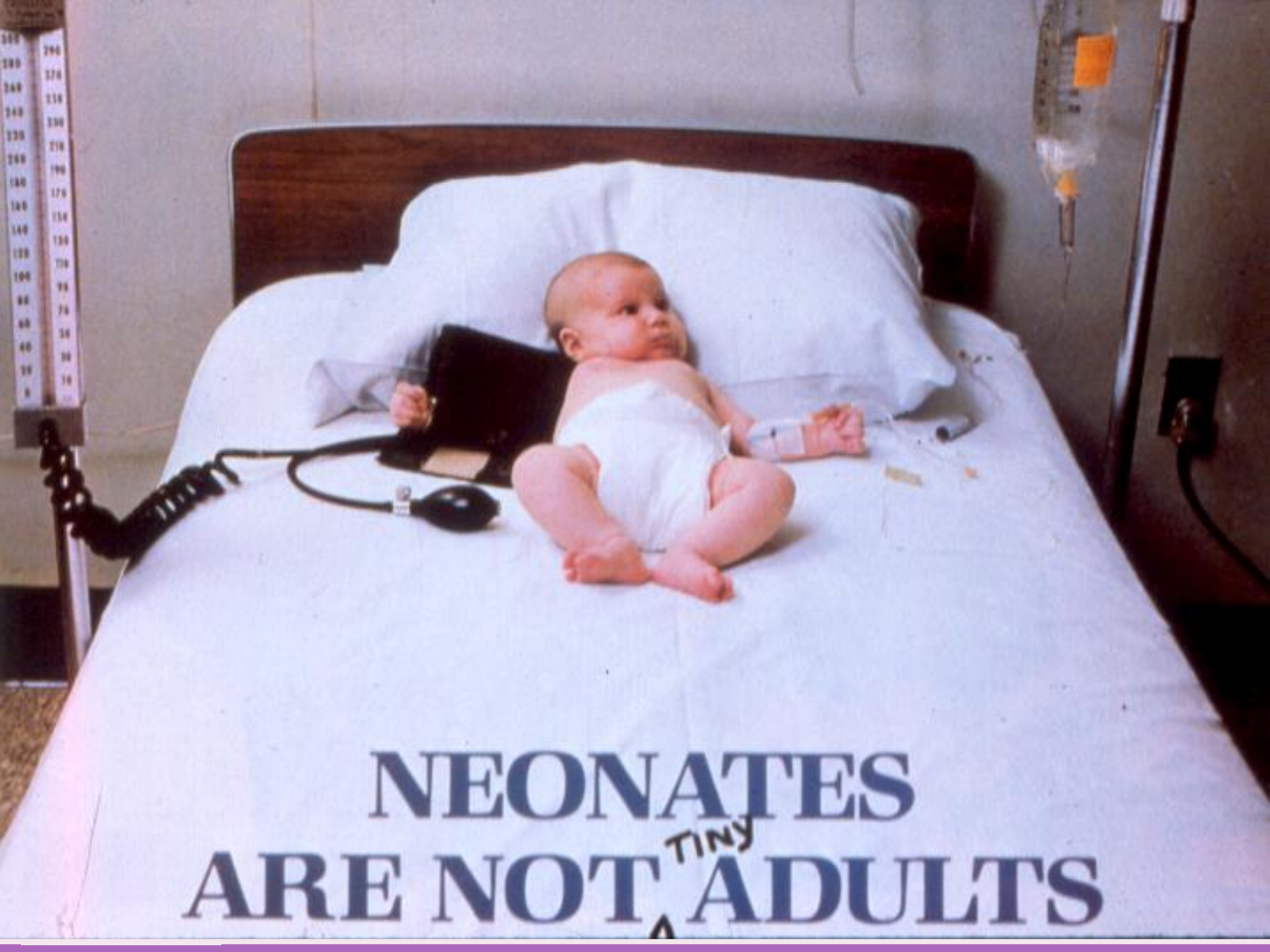
Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death.

- Severe cerebral palsy
- Prematurity with residual multi-organ dysfunction or severe chronic pulmonary disability
- Multiple disabilities following brain or spinal cord infectious, anoxic or hypoxic insult or injury
- Severe brain malformations, *(e.g. holoprosencephaly, anencephaly)*

National Hospice and Palliative Care Organization – Standards of Practice

Palliative Care- Eligibility

- Life-threatening or life-limiting conditions
- Severe symptoms of chronic disease
- Palliative care supplements usual medical therapies
- Palliative care services are provided without limitation or withholding medical therapies and without a stipulated DNR


NEONATES
ARE NOT TINY ADULTS

How is Pediatric Palliative Care different from adults?

- Widely varied epidemiology contributes to great uncertainty in diagnosis and prognosis
- Interpersonal dynamics
- Developmental stages – communication and symptoms management
- Legal and ethical issues regarding consent

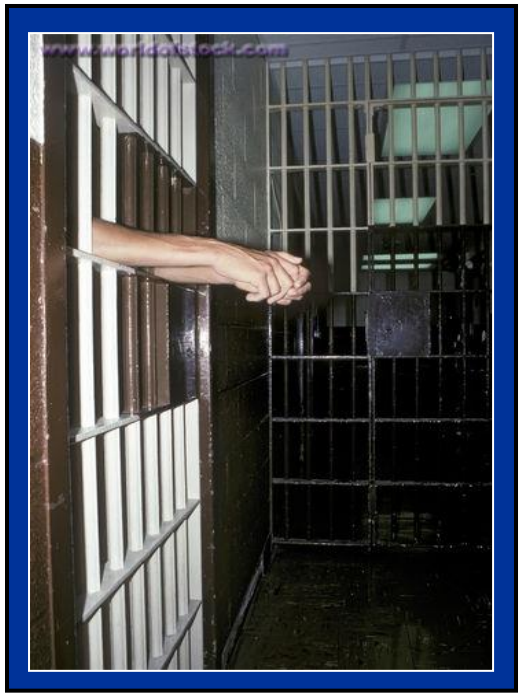
How is Pediatric Palliative Care different from adults?

- Paucity of evidence on effectiveness of treatment modalities
- Decreased ability/ willingness to discontinue life sustaining therapies by parents and healthcare providers
- Complicated and long duration of bereavement for survivors of pediatric death

Hurdles: Caring for chronically ill patients

- Under Tx of physical/emotional symptoms
- Psychological/physical debilitation of caregivers
- Conflicts over decision making
- Diminution of financial resources
- Care without continuity
- Lack of critical resources: home health care

Think about it: “Baby Jail”



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Inaccurate survival predictions

- Long-standing doctor-patient relationship
- Physician's desire to preserve patients hope
- Lack of reliable prognostic models

Barriers to Palliative Care

- Societal attitudes
  - - reduced expectations for quality of life
  - - technological advances
  - - increases in hospitalization
- Heath care system
  - - reimbursement constraints for providers
  - - limited availability of palliative care
  - - caregivers providing complex care

Barriers to Palliative Care

- Poor communication with families/patients
- Suboptimal communication between providers
- Under referral to palliative care specialists
  - - unrealistic prognostication
  - - patient/ family desire for life-sustaining treatments
  - - discomfort with the subject
- Limited ability to appropriately treat common symptoms

Palliative Care Team Challenges

- Need for solid, effective relationships with colleagues
- High emotional burden
- Significant uncertainty and ambiguity
- More complex patient and family needs
- More informed patients and families

Staff Barriers to Palliative Care

- "Marked for death"
- "Too soon" for palliative care
- Reluctance in shift from cure-focused medical training

Strategies for success

- Collaborative rounds
- Frequent telephone communication
- Participation in family conferences
- Written documentation
- Interdisciplinary morbidity and mortality conferences or grand rounds

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6 step approach: Delivering Bad News

- Getting started
- What does the patient/family know?
- How much does the patient want to know?
- Sharing information
- Responding to feelings
- Planning follow-up

Tips for Discussion

- Chair
- Sit up, sit close
- Eye level
- Give the patient/family your full attention
- Ensure support for the family (family member/friend)
- Sensitivity to different cultures
- Convey hope

Tips for Discussion

- Introduce everyone present
- Find out what the patient/family understands
- Discuss the prognosis in frank terms

Tips for Discussion

- Avoid temptation to give too much detail
- Withholding life-sustaining treatment is NOT withholding caring
- Use active listening
- Allow family adequate time to speak

Tips for Discussion

- Acknowledge strong emotions
- Use reflection to encourage patients/families to talk about these emotions
- Respond empathetically to tears or other grief behavior
- Tolerate silence

Tips for Discussion

- Achieve a common understanding of disease and treatment issues
- Make a recommendation about treatment
- Ask for questions
- Ensure a basic follow-up plan

Symptom Prevalence

- Pain
- Fatigue
- Lack of energy
- Weakness
- Appetite loss
- Body image challenges

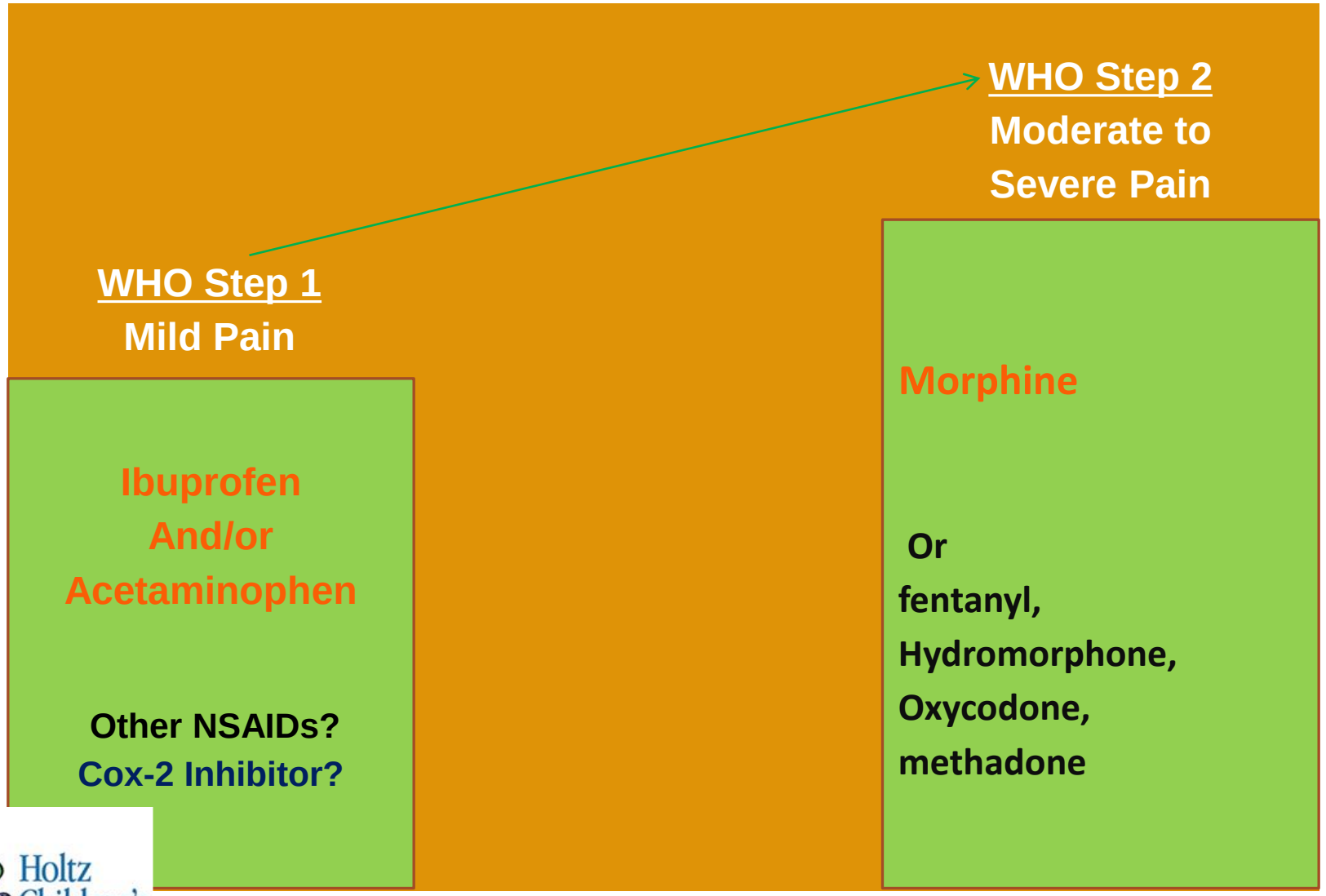
Principles of Pain Assessment
QUEST

- Question – Ask about pain
- Use appropriate pain scale
- Evaluate behavior/physiologic response
- Secure family involvement
- Take holistic cause of pain into account
- Take Action!!

World Health Organization Principles of Pain Management

- By the Clock
- By the Appropriate Route
- By the Child
  - - individualized to the child's pain
  - - response to treatment
  - - frequent reassessment
- By the Analgesic Ladder

WHO: Analgesic Ladder 2012



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Life Sustaining Therapies

- Mechanical ventilation
- Vasopressors
- Dialysis
- Antibiotics
- Blood products
- Intravenous fluids
- Nutrition

Principles of Withdrawing Support

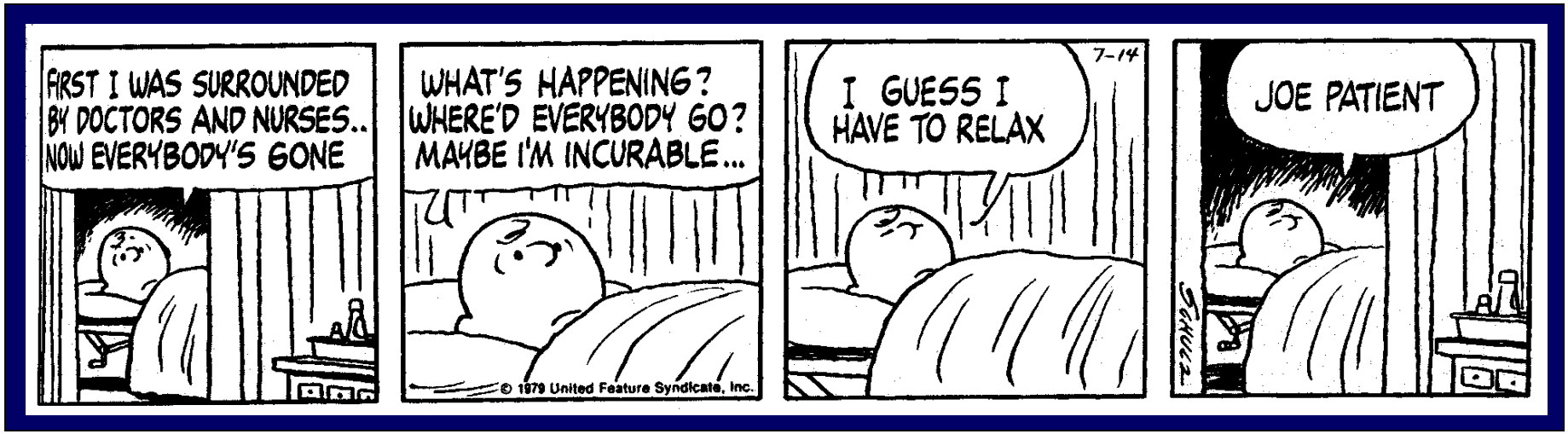
- Remove treatments no longer desired and not providing comfort to the patient
- Withholding life-sustaining treatments is morally and legally equivalent to withdrawing them
- Actions whose sole goal is to hasten death are morally and legally problematic

Principles of Withdrawing Support

- Any treatment can be withheld or withdrawn
- Withdrawal of life-sustaining treatment is a medical procedure
- When circumstances justify withholding one indicated life-sustaining treatment, strong consideration should be given to withdrawing all current life-sustaining treatments

Parental Stress

- Guilt
- Sense of giving up
- Great fear of events for which they have no experience



Family Reactions

- Anguish
- Helplessness
- Aggravation

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Impact Patterns of Stress

- Anxiety
- Social disruption
- Physical malaise, weakness, sickness
- Marital/relationship dissolution
- Family disruption
- Economic instability/employment loss

Stages of Hope

- AVOID: “There is nothing more we can do”
- Cure
- Treatment
- Prolongation of life
- Peaceful death

Holtz Children's Hospital PediPals Program

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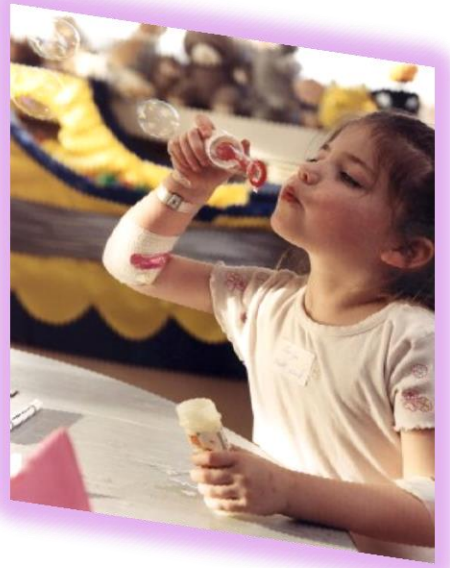
Education and Preparation – Child Life Specialists

- Diagnosis and procedural support
  - PICC Line Prep Book & OR Prep Book
  - Coping strategies
- Non-pharmacological pain management
  - Distraction (blowing Bubbles)
  - Guided imagery
  - Comfort items



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Sibling Needs and Support

- Maintenance of a familiar lifestyle
- Family cohesion
- Distraction from immediate crisis
- Hospital visitation
- Developmentally appropriate information

Parent/Caregiver Support

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Hospitality Interventions

- Sleeping accommodations
- Transportation and parking
- Laundry facilities
- Telephones
- Gym access

Recreation and Distraction Activities

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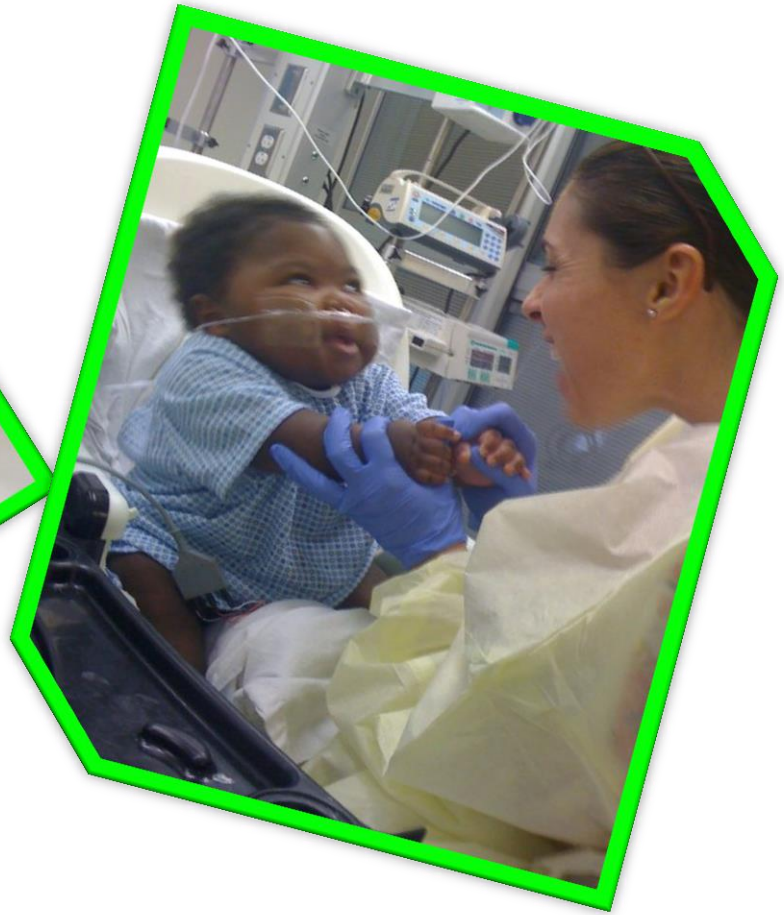
Therapeutic Activites



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Miami Seaquarium ♥ Holtz Children's

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Team Sundance

Distraction Technique

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Ocean Times

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Before & After

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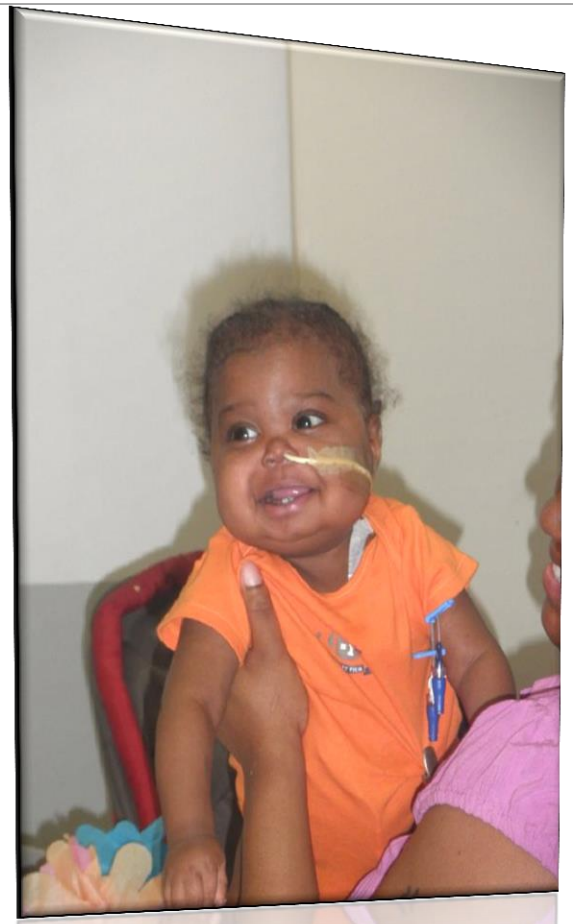
Creating Memories…



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Holtz Children’ s Hospital Consult Room

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“Road Trips”

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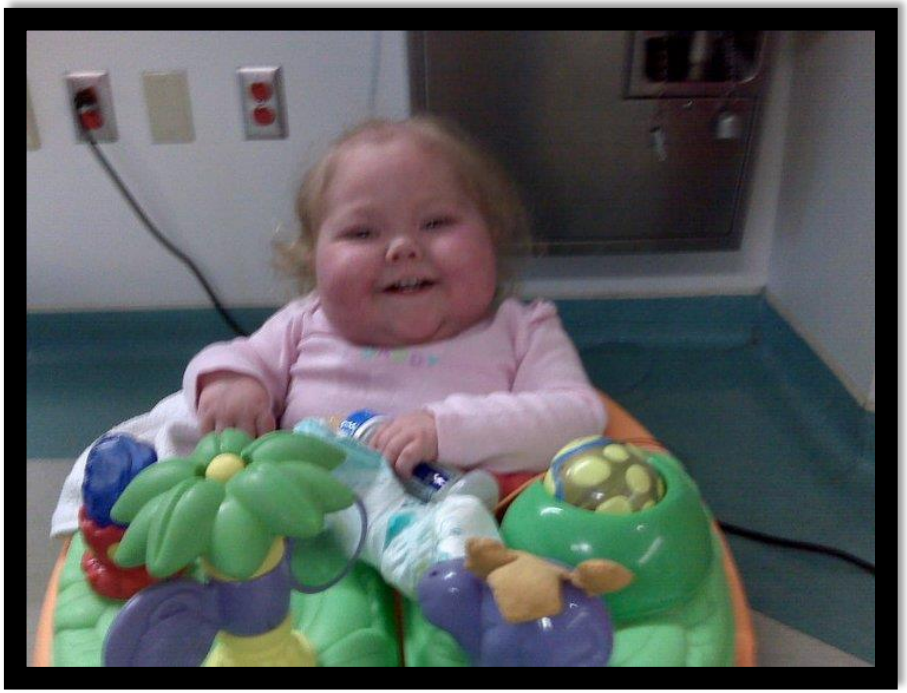
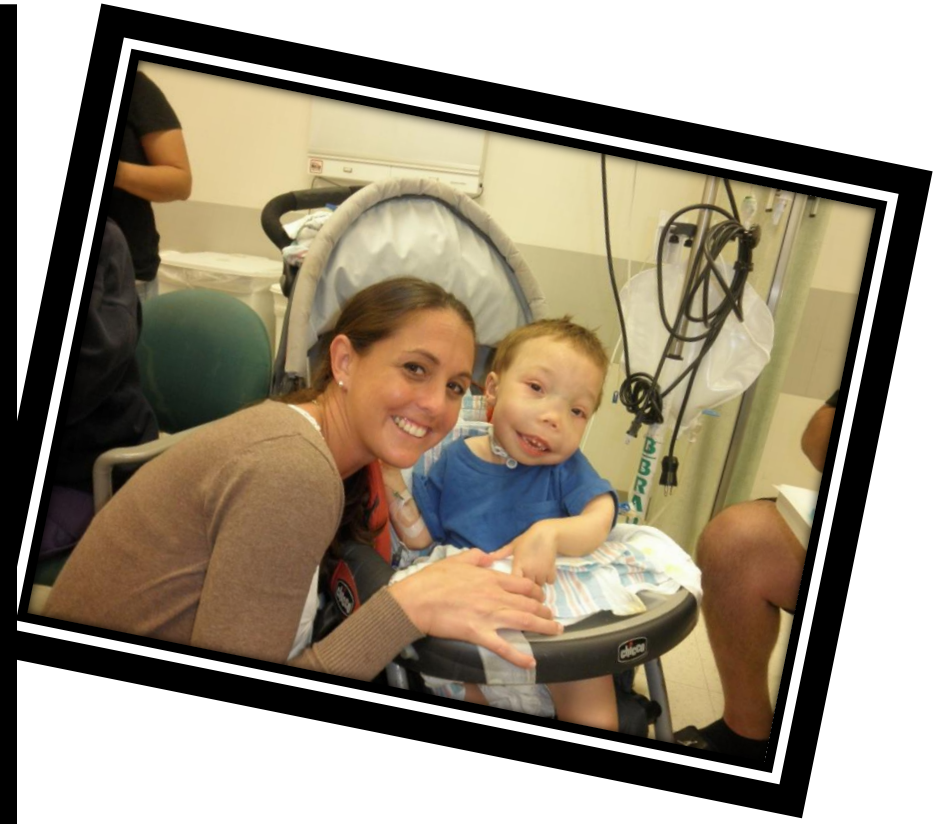
Making Smiles



More Smiles



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Pet Therapy

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Pool Therapy

Art Therapy

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Art Therapy

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Miami Heat ❤ Holtz

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HOOTERS ♥ Holtz

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Family Dinners

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Ice Cream Socials

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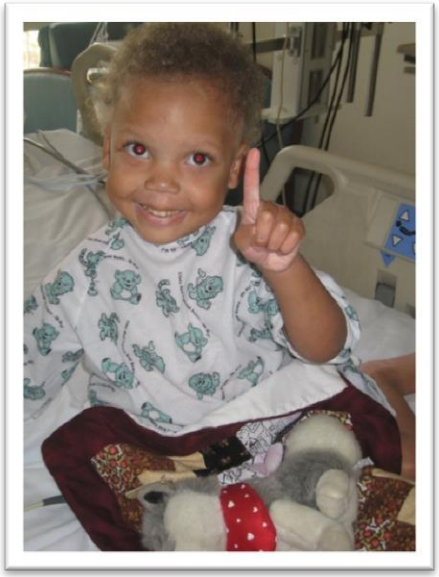
Mr. Teddy Kilpatrick
- Quilt Master -



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JACKSON PEDIATRIC CENTER
PPEC-Prescribed Pediatric Extended Care

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Bereavement Materials

Butterfly Release

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“Combat” Strategies for Burnout

Embrace Quality of Life !

" You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die"

Dame Cicely Saunders