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"Finding Calcutta" A Primer on Pediatric Hospice

The level of education I have received about end-of-life care thus far in my career:

1. Includes comprehensive didactic and bedside learning.
2. Includes "some" didactic and bedside learning
3. Includes no formal education and only minimal observational learning
4. I have never been taught how to care for a child dying from a terminal illness.

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My level of comfort in caring for a dying child is:

1. Completely comfortable
2. Somewhat comfortable
3. Not comfortable
4. Makes me nauseous to think about it.

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- **Senior Medical Students' Perceptions of the Adequacy of Education on End-of-Life Issues** Heather C. Fraser, Jean S. Kutner, and Mark P. Pfeifer. Journal of Palliative Medicine. September 2001, 4(3): 337-343.
- **Pediatric Residents' Clinical and Educational Experiences With End-of-Life** Megan E. McCabe, Elizabeth A. Hunt and Janet R. Serwin *Pediatrics 2008;121;e731; originally published online March 17, 2008;*
- Hospice Referral Practices for Children With Cancer: A Survey of **Pediatric Oncologists** *Kimberly Fowler, Katherine Poehling, Dean Billheimer, Rodney Hamilton, Huiyun Wu, John Mulder, J Clin Oncol 24:1099-1104.*

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To consider…….

- Are we providing the best care to dying children?
- Who are the appropriate providers of Pediatrics Hospice?
- Pediatric Hospice as a true subspecialty

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- Mental Pause

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- Mental Pause

The elderly couple

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"Dying is a very dull, dreary affair. And my advice to you is to have nothing whatever to do with it."

W. Somerset Maugham

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Dying is more than a set of problems to be solved. The nature of dying is not medical, it is experiential. Dying is fundamentally a personal experience, not a set of medical problems to be solved.* Ira Byock M.D., Author of "Dying Well"

*It certainly includes "medical", which is crucial for all to learn, but also to put in to the context of the individual's/families experience

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Case #1

- 9 yo with Mitochondrial disorder- 1º GI, cognitive spared. Chronic worsening abdominal pain, tolerating G/J tubes poorly. Long term TPN, also tolerating poorly.
- Pain poorly controlled, feeds and TPN worsens pain.
- Pt and mom wishes to dc nutrition.

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Case 1 (continued)

- Gradual increased dosing over time to:

Ativan 7.5 mg prn
Dilaudid 150 mg q1h w/ 30 mg bolus q10 min
Lyrica 50 mg daily
Methadone 105 mg q4h
Phenobarbital 150 mg q8h

STILL having pain at 8/10, awake at times and conversant

What do you do now?

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Case #2

- 5 yo with Lennox-Gastaut syndrome
- Intractable seizures- "hundreds" per day despite maximal medical therapy, vagal nerve stimulator, Apnea with some seizures, lasting as long as 20 seconds
- Vomits most feeds
- Multiple episodes of "neuroirritiability" throughout day
- Parents wish to withhold nutrition and hydration.

What do you do now?

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Case #3

- 9 yo with multiply relapsed osteosarcoma
- Multiple previous chemo regimens, including phase 2 trials. Parents have been very aggressive in seeking "curative" therapy
- Hospitalized for sx control.
- You are making rounds on her with the nurse while parents are out of the room and she asks you: Am I going to die?

What do you do now?

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History

- *Hospice- a place*
  - term dates back to Middle Ages –
    - of hospitality for the sick, wounded, or dying, as well as those for travelers and pilgrims.

"It's just a flesh wound"

Hospice – philosophy

- modern concept of care
- Dame Cicely Saunders
  (22 June 1918 – 14 July 2005)

Dame Saunders

1967-Developed world's first stand alone hospice- *St Christopher's Hospice* in London

Pioneered the concept of "total pain" –
and ***total pain control***
Physical
Spiritual
Psychological
Existential

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Modern hospice philosophy spread internationally in 1960's

1969- *On Death and Dying* -Elizabeth Kubler-Ross

Hospice, Inc., developed in New Haven, CT in 1971

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Hospice growth

- By 1995, hospices were a $2.8 billion industry, with $1.9 billion from Medicare alone funding patients in 1,857 hospice programs with Medicare certification.[i]
- By 1998, there were 3,200 hospices either in operation or under development throughout the United States
- According to 2007's *Last Rights: Rescuing the End of Life from the Medical System*, hospice sites are expanding at a national rate of about 3.5% per year.[i]
- In 2007, 1.4 million people in the United States utilized hospice, with more than one-third of dying Americans utilizing the service, approximately 39%
- In 2008, Medicare alone, which pays for 80% of hospice treatment, paid $10 billion to the 4,000 Medicare-certified providers in the United States

In February, 2009, balance of non-profit and for-profit hospices was shifting.

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Pediatric Hospice

- The children's hospice movement is still in a relatively early stage in the United States.
  - In 1983, of the 1,400 hospices in the United States, only ***four*** were able to accept children. Key developments since then include:
- 1996: the Children's Hospice International began collaboration with the US DHHS to produce a better solution for families and the Medicaid program at large.
- George Mark Children's Hospice, opened March 2004 in California
- Today, most of the ~ 4,000 hospices in the U.S. will now consider accepting children. Also, approximately 450 programs have children-specific hospice, palliative, or home care services.

However…..

Of concern is some evidence to show that the number of hospices willing to accept children might be slowing/decreasing

24. Lindley LC, Mark BA, Daniel Lee SY, Domino M, Song MK, Jacobson Vann J. Factors associated with the provision of hospice care for children. J Pain Symptom Manage. 2013;45(4):701–711

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What does hospice do?

- Provides the dying with **quality, compassionate care.**
- Involve a **team-oriented approach** to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.
  - ***Total symptom control***
- Provide support to the patient's **family and caregivers.**
- At the center of hospice and palliative care is the belief that each of us has the **right to die symptom-free and with dignity,** and that our families will receive the necessary support to allow us to do so.

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How well do we do this in Pediatrics?

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Symptoms at End of Life

- Interviewed parents of children who had died of cancer at least one year prior to study.
  - N = 103 (62% of families contacted).
  - Mean time since patient death = 3.1±1.6 years
- Parents were asked whether their children:
  - suffered from an array of symptoms,
  - rate the degree of suffering,
  - whether symptoms were treated,
  - and whether they were treated effectively
- 79% died of progressive disease; 21% died of complications of therapy
- 50 children died in the hospital. 44 in the study hospital (Limitation- paper does not indicate use of hospice for patients!)

Symptoms and Suffering at the End of Life in Children with Cancer Joanne Wolfe, M.D., M.P.H., Holcombe E. Grier, M.D., et.al., NEJM 2000; 342:326-333 Feb, 2000

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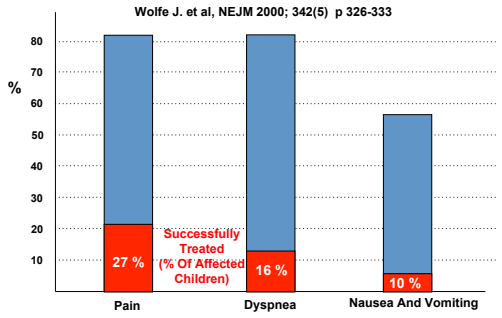
Symptoms At The End of Life in Children With Cancer



Symptoms At The End of Life in Children With Cancer

- Others:
  - Fatigue- 97%
  - Poor appetite- 80%
  - Constipation- 50%
  - Diarrhea- 40%

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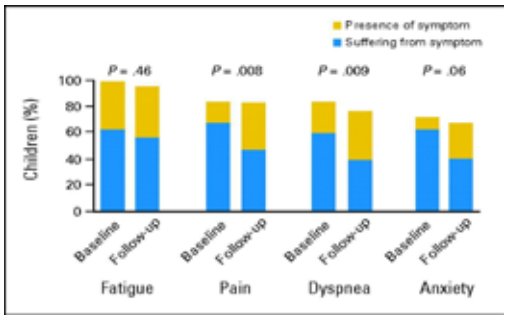
Follow up study at Dana Farber



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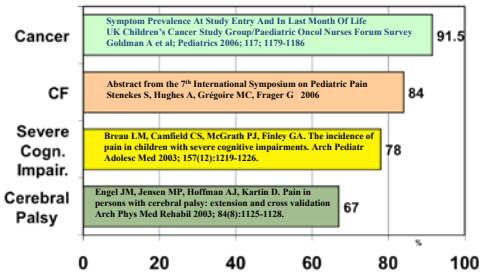
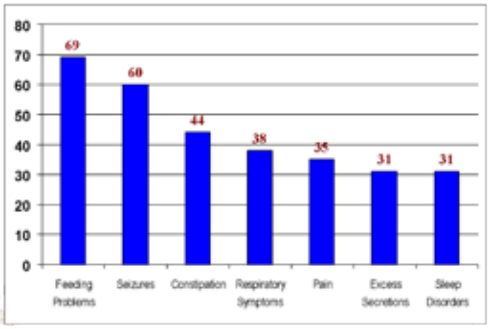
Wolfe, J et.al., JCO April 1, 2008 vol. 26 no. 10 1717-1723

Pain In Advanced Childhood Illness



Symptoms in Children with Neurodegenerative Illness



- Clearly, we need to pay more attention to providing *physical* symptom control at end of life.
- Also, relief from anxiety, sadness, loss of dignity, body image distress, loneliness, concerns about "after".
- Hospices are the front line, along with the patient's physicians for the management of these issues

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•Mental Pause

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Mental Pause

hands of hope

Mental Pause

Outside of a dog, a book is a man's best friend, inside of a dog it's too dark to read.

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Mental Pause

Outside of a dog, a book is a man's best friend, inside of a dog it's too dark to read

I was married by a judge. I should have asked for a jury.

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Mental Pause

Outside of a dog, a book is a man's best friend, inside of a dog it's too dark to read

I was married by a judge. I should have asked for a jury.

One morning I shot an elephant in my pajamas. How he got into my pajamas I'll never know.

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Mental Pause

Outside of a dog, a book is a man's best friend, inside of a dog it's too dark to read

I was married by a judge. I should have asked for a jury.

One morning I shot an elephant in my pajamas. How he got into my pajamas I'll never know.

Well, I've had a wonderful evening

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Mental Pause

Outside of a dog, a book is a man's best friend, inside of a dog it's too dark to read

I was married by a judge. I should have asked for a jury.

One morning I shot an elephant in my pajamas. How he got into my pajamas I'll never know.

Well, I've had a wonderful evening, but this wasn't it.

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Who needs hospice?

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Who?

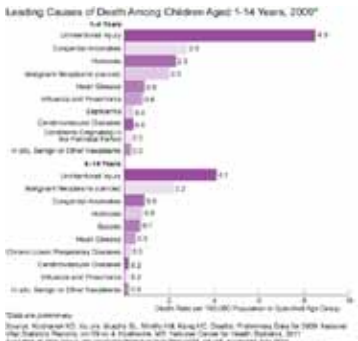
Approx. 55,000 children die per year in U.S.
80% die in hospitals; ~ half are infant deaths.

Of the remainder (age 1-19), 1/3 will die of chronic conditions. 2/3 will die of trauma
(- accidents, homicide, suicide.)

On any given day, ~5000 children are living in the U.S. within the last 6 months of their lives.

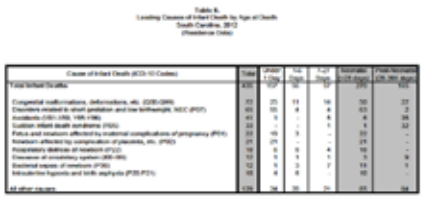
Feudtner C, et al, *Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. Pediatrics. 2001;107(6).*

10 Leading Causes of Death by Age Group, United States – 2007



Total infant deaths 423.
39% < 24 hours old

SC Detailed Mortality Statistics–Division of Biostatistics
Office of Public Health Statistics and Information Services
South Carolina Department of Health and Environmental Control



129 "other causes"
What is the timeframe for understanding the problem in the children who died in less than a day? Opportunity for perinatal hospice?
How do you determine who can benefit from hospice/palliative care from the neonatal group? ASK THE QUESTION?
Who will provide hospice services to these patients?

SC Detailed Mortality Statistics–Division of Biostatistics
Office of Public Health Statistics and Information Services
South Carolina Department of Health and Environmental Control

"Other" causes

- Infection
- Heme-Onc
- Endocrine/Metabolic
- Neuro/Brain
- Resp
- GI
- "Unknown"

SC Childhood deaths 2012

	<1 yr	1-4	5-9	10-14	15-19	20-24*	Total
ALL	435	59	35	46	178	335	1088 (753)
Cancer	1	6	3	5	5	13	33 (20)
Heart	12	5	4	4	6	10	42 (32)
Endo/ Metab/ Nutr.	3	2	1	2	2	6	16 (10)
Totals							91 (62)

SC Detailed Mortality Statistics- Division of Biostatistics
Office of Public Health Statistics and Information Services
South Carolina Department of Health and Environmental Control

* May likely include young adults dying from Pediatric diseases.

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Hospice Patients Admitted by Age South Carolina CY2011 Data

Age	Number	Percent
< 1 year	9	9.5
1-4	8	8.4
5-14	15	15.8
15-24	17	17.9
25-34	46	48.4
total	95 (49)	100%

Data from: The Carolinas Center for Hospice and End of Life Care

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Medicaid Data 2012

- 49 Pediatric patients received Medicaid Hospice benefit
  - Malignancy = 11
  - Neurologic = 10
  - Cardiac = 8

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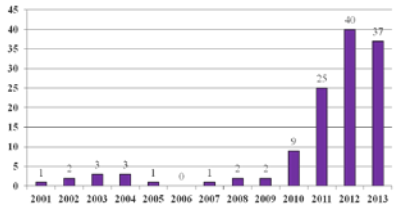
Admissions



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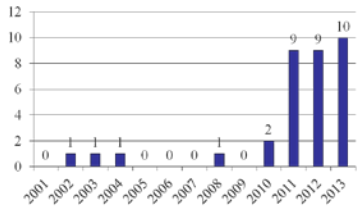
Admissions < 1 Year



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Hospice Benefit

- nursing
- social services
- physician services
- Counseling/chaplain services to patient, family, caregivers
- short-term inpatient care
- medical appliances and supplies
- home health aide and homemaker services,
- PT/OT/Speech
- Bereavement services

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Four levels of care

- 1) **Routine** home care where most hospice care is provided
- 2) **Continuous** home care which is furnished during a period of crisis and primarily consists of nursing care
- 3) **Inpatient respite care** which is short-term care and intended to relieve family members or others caring for the individual
- 4) **General inpatient care** which is short term and intended for pain control or acute or chronic symptom management which cannot be provided in other settings.

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Certification

- Two physicians must certify
  - Attending MD and Hospice MD
- Document that patient has a life expectancy of **< 6 months**.
- Initial 6 month benefit – then unlimited 90 day benefits. Must be recertified before each benefit period.
  - **APRN** can recertify.
- Live discharges, revocations.

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Concurrent Care

- ACA includes a provision *Concurrent Care for Children Requirement* (Section 2302).
- Medicaid or CHIP patients can receive hospice services while still receiving "curative" or other disease-modifying treatments.

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Concurrent Care

- Increases hospice utilization
- Earlier admissions to hospice
- Decreased ED visits, hospitalizations, ICU admissions, overall costs

- Spettell CM, et al., J Palliative Med. Sep 2009;12(9):827-832

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•Mental Pause

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Who should care for dying children?

- "All hospitals and large health care organizations that frequently provide care to children with life-threatening conditions and routinely provide end of-life care should have dedicated interdisciplinary specialty PPC-PHC teams."
- "Teams should have sufficient collective expertise to address the physical, psychosocial, emotional, practical, and spiritual needs of the child and family."
- "To ensure quality and safety, teams must have an adequate number of dedicated staff, ideally trained in PPC PHC…… should bridge the physical locations of patients, from their homes or schools to the hospital and, potentially, to other partnering facilities.
- The medical homes and pediatricians who provide primary and specialty care to children with life-threatening conditions remain invaluable, must advocate for and involve interdisciplinary PPC-PHC in the care of these patients and their families, and, for their patients, may become active members of the interdisciplinary palliative care

Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations
SECTION ON HOSPICE AND PALLIATIVE MEDICINE AND COMMITTEE ON HOSPITAL CARE
PEDIATRICS Volume 132, Number 5, November 2013

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Who should care for dying children?

- Should the primary caregivers have experience with children?
- Which physician should be responsible?
- Are there services that are needed/can be provided that are unique to Pediatrics?

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Who should care for dying children?

- Should the primary caregivers have experience with children?
  - Absolutely!
- Which physician should be responsible?
- Are there services that are needed/can be provided that are unique to Pediatrics?

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Who should care for dying children?

- Should the primary caregivers have experience with children?
  - Absolutely!
- Which physician should be responsible?
  - The one most knowledgeable about the patient
  - Assisted by the Hospice Medical Director
- Are there services that are needed/can be provided that are unique to Pediatrics?

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Who should care for dying children?

- Should the primary caregivers have experience with children?
  - Absolutely!
- Which physician should be responsible?
  - The one most knowledgeable about the patient
  - Assisted by the Hospice Medical Director
- Are there services that are needed/can be provided that are unique to Pediatrics?
  - Definitely!

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- Child Life
- Social Work
- Chaplain
- Pharmacy
- Nutrition

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Pediatric Resource Model

- Pediatric Nurses care for patients and supervise "local" team.
- Directly communicate with PCP's
- Nurses are responsible for a large geographic area
- See patients in their homes, hospital
- Are supervised by HMD

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Child Life

- Therapeutic play
- Expressive arts
- Memory making/Legacy building
- Preparation
- Education
- Sibling support

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Legacy Building

Goal:

To provide opportunities for the patient to create meaningful and unique projects which focus on how they would like to be remembered.

Intervention:

Letters
Songs
Living will
Autobiography
Video Interviews

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Memory Making

Goal:

To engage the patient, family and friends in memory making activities

Intervention:

Anything with handprints
Garden stones
Hand molds
Handwriting
Photo projects
Scrapbooking

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Social Work

- Goals of care conversations- attending to emotional and social responses to family choices
- Resource connection and financial assistance
- Funeral arrangements and advanced care planning
- Interacting with other agencies working with family such as DSS or school system
- Bereavement services and follow up- connection to counseling as needed

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Pharmacy

- Contract Pharmacy
- Dedicated Pediatric Pharm D.
- Available for consultation 24/7
- Rounds with us q2 weeks

Nutrition

- Consultative
- Pediatric Expertise
- Rounds with us q 2weeks

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Hospice Medical Director

- Hospice and Palliative Medicine Boards
- Responsible for the hospice services provided to all the patients. Supervises the "hands on" team
- Symptom control!!
  - Pain, N/V, Seizures
- Communication
- Goals of care

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Barriers to Hospice Care

- Children are not supposed to die!
- Perceived as "giving up"
- Concerns for siblings
- Medical community lack of awareness of hospice services
- Late referrals

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So….,who should take care of dying children?

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So…..,who should take care of dying children?

Ultimately it's up to you *to decide*!

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Case 1 (continued)

- Gradual increased dosing over time to:

  Ativan 7.5 mg prn
  Dilaudid 150 mg q1h w/ 30 mg bolus q10 min
  Lyrica 50 mg daily
  Methadone 105 mg q4h
  Phenobarbital 150 mg q8h

STILL having pain at 8/10, awake at times and conversant

What do you do now?

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- Started Dexmedetomidine (Precedex)
  - Central alpha-2 Adrenergic Agonist
  - Pain control
  - Palliative sedation?
  - Eventually achieved pain control.
  - Patient died ~ 1 week later

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Case #2

- 5 yo with Lennox-Gastaut syndrome
- Intractable seizures- "hundreds" per day despite maximal medical therapy, vagal nerve stimulator. Apnea with some seizures, lasting as long as 20 seconds
- Vomits most feeds
- Multiple episodes of "neuroirritiability" throughout day
- Parents wish to withhold nutrition and hydration.

What do you do now?

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- American Academy of Pediatrics Policy on Forgoing Medically Provided Nutrition and Hydration in Children -- http://pediatrics.aappublications.org/content/124/2/813.full
  - "Decisions about whether medical interventions should be provided to a child, including medically provided fluids and nutrition, should be based on whether the intervention provides net benefit to the child.""Medically provided fluids and nutrition can be withdrawn from children when such measures only prolong and add morbidity to the process of dying. In these situations, continued fluids and nutrition often provide very limited, if any, benefit and may cause substantial discomfort."
- Taken from the Bioethics page from the United States Conference of Catholic Bishops website.
  - "There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, *as long as this is of sufficient benefit to outweigh the burdens involved to the patient."* (Emphasis mine)

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- Nutrition to be weaned over a period of 8 days
- Anxiolytic and analgesics provided for use prn
- Seizure meds continued.
- Child died peacefully at day 6 of wean, when feeds were being given at 4 hours per day.
- Pt likely was dying at the time of the initial consult.

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Case #3

- 9 yo with multiply relapsed osteosarcoma
- Multiple previous chemo regimens, including phase 2 trials. Parents have been very aggressive in seeking "curative" therapy
- Hospitalized for sx control.
- You are making rounds on her with the nurse while parents are out of the room and she asks you: Am I going to die?

What do you do now?

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- Don't let this question surprise you!
- Have a discussion with the parents before this to ask them their wishes about how much to discuss with the child.
- Advise them that the child has a right to know what is happening to them.
- Turn the question around- ask the child why they are asking you this now.
- Be honest.

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Conclusion

- Dying children are in need of "subspecialty" type care.
- Extensive training in Pediatrics is important for Hospice Providers.
- Refer early!
- Be involved!- Don't be afraid, your patients and their families want you to help them.
- I'll help YOU!

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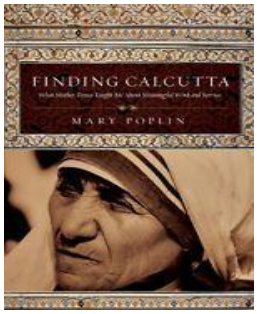

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Well, I've had a wonderful morning,

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Well, I've had a wonderful morning,

But this wasn't it.

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Well, I've had a wonderful morning,

But this wasn't it.

Questions ???

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