

# Filling The Space: An Alternative Pediatric Model for End of Life Care in The USA

Judith Dunlop, MA, M.Div.

Barbara Beach, MD

Claire Vesely, RN, BSN

George Mark Children's House



# Objectives:

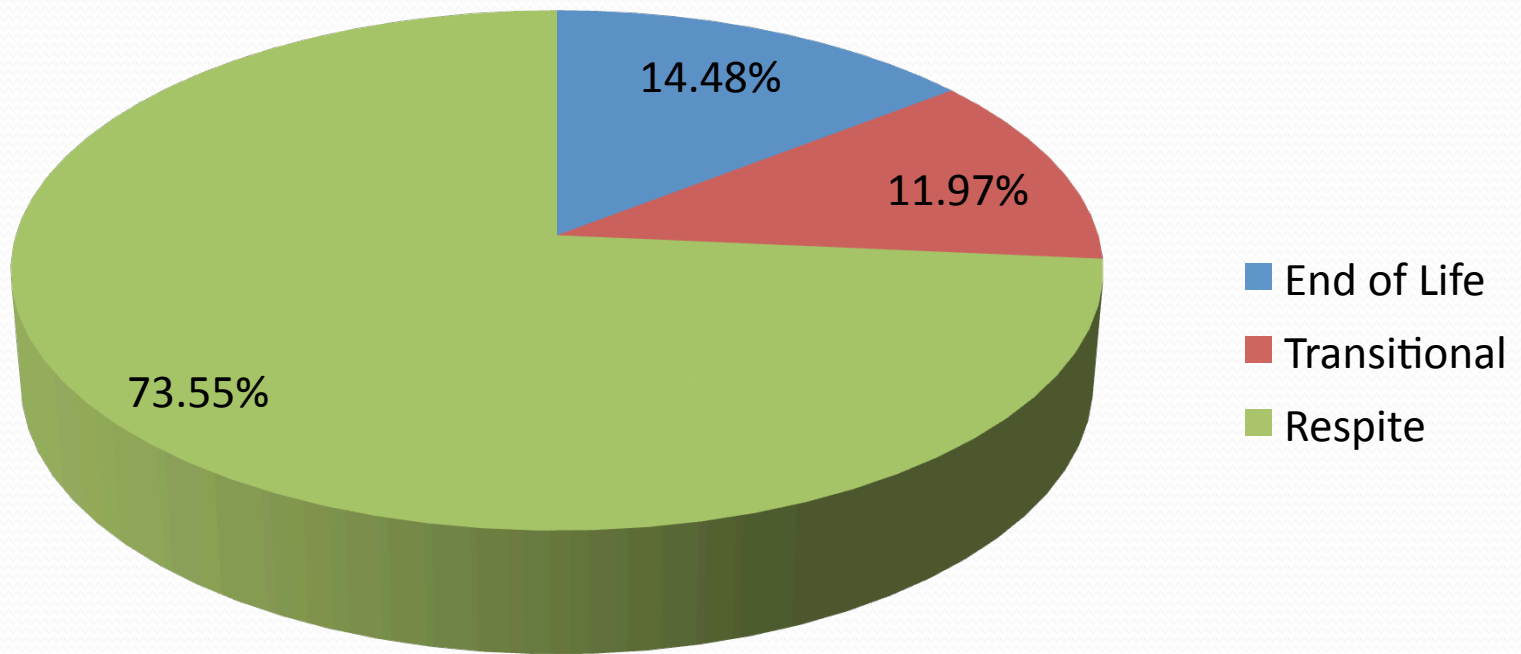
- **Describe at least two distinctive aspects of end of life care at GMCH**
- **Identify at least two interdisciplinary goals for the child and family admitted to GMCH for compassionate extubation**
- **Discuss at least two essential components of an open ended bereavement care program**



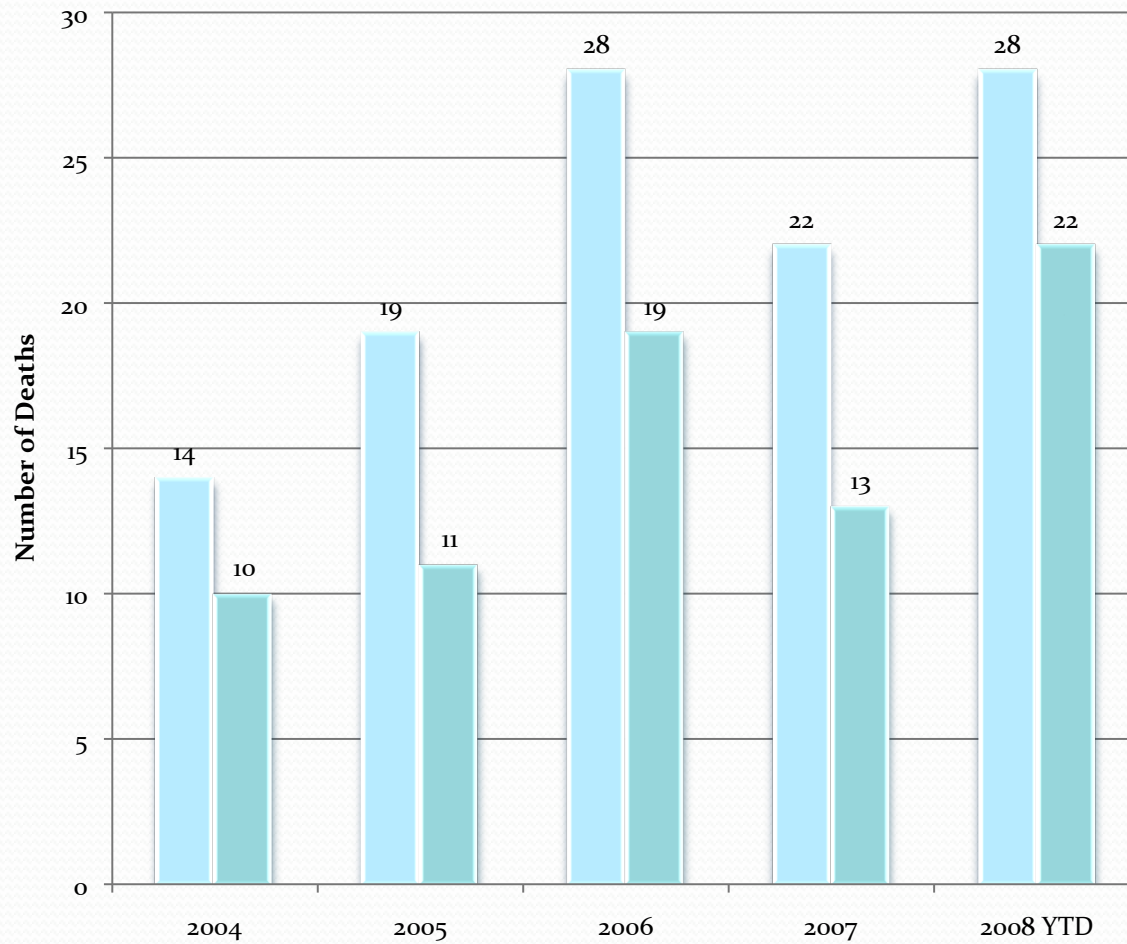
# George Mark Children's House

- **Opened in April 2004**
- **The first freestanding respite and end of life care facility in the country**
- **Dedicated to helping the entire family before, during and after their child's illness, and life, is over**
- **Services are provided free of charge**

## Admissions by Type: 4/1/04-8/31/08, n=532



## Deaths of GMCH Patients, April 2004 through November 1, 2008



	All Deaths	Death at GMCH
<b>2004</b>	14	10
<b>2005</b>	19	11
<b>2006</b>	28	19
<b>2007</b>	22	13
<b>2008 YTD</b>	<u>28</u>	<u>22</u>
	<b>111</b>	<b>75</b>

■ All Deaths  
■ Death at GMCH

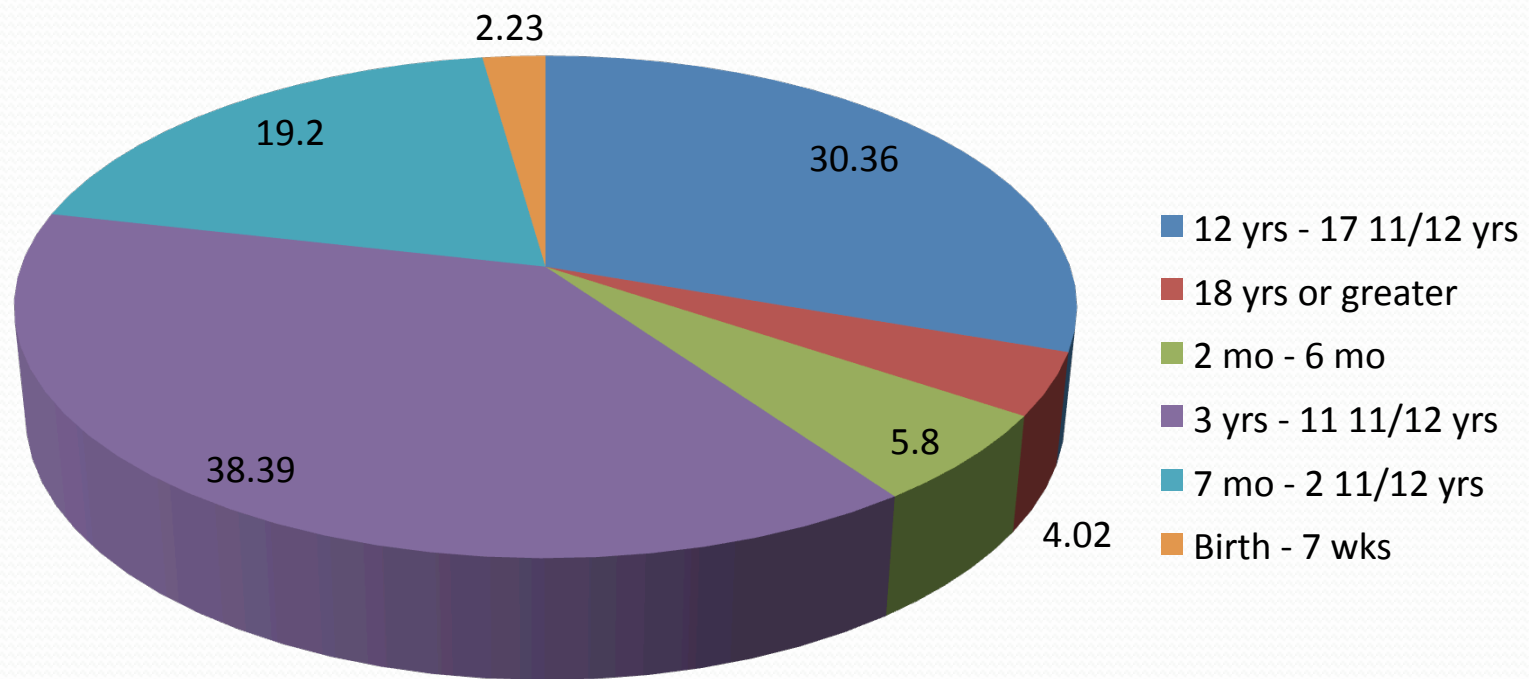
	Count	% of Total
Death at GMCH	75	67.57%
Off-Site: Came for GM Care	6	5.41%
Off-Site; D/C'd from GMCH Same Day	4	3.60%
Off-Site	26	23.42%
<u>Total Deaths</u>	<u>111</u>	



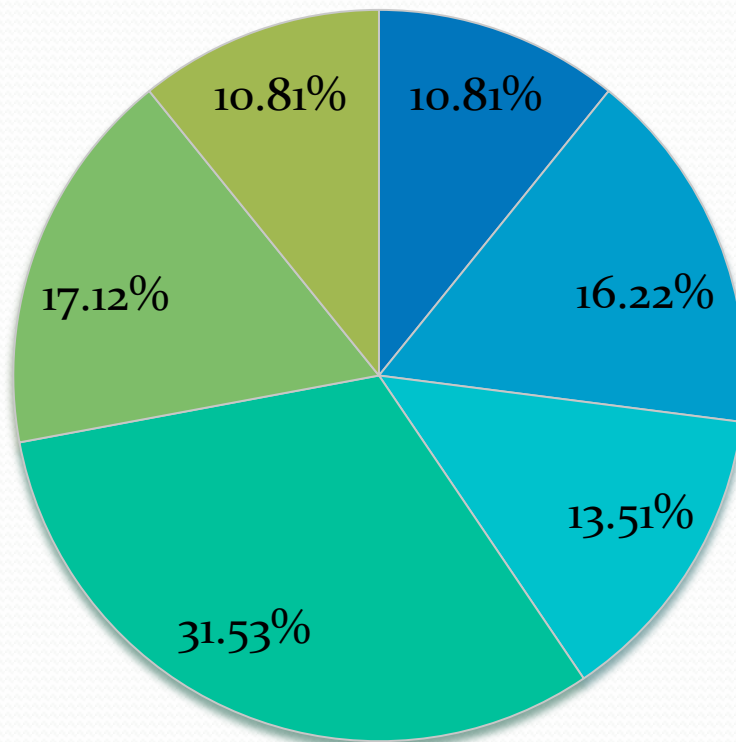
# Who Do We Care For?

- **Children with life-limiting illnesses such as:**
  - **Birth Asphyxia/Encephalopathy**
  - **Cardiac failure/Inoperable defects**
  - **Progressive cancers/Brain tumors**
  - **Congenital abnormalities**
  - **Neurodegenerative/Neuromuscular diseases**
  - **Respiratory conditions**

## Patient Age (All Patients), 4/1/04-8/31/08: n=224

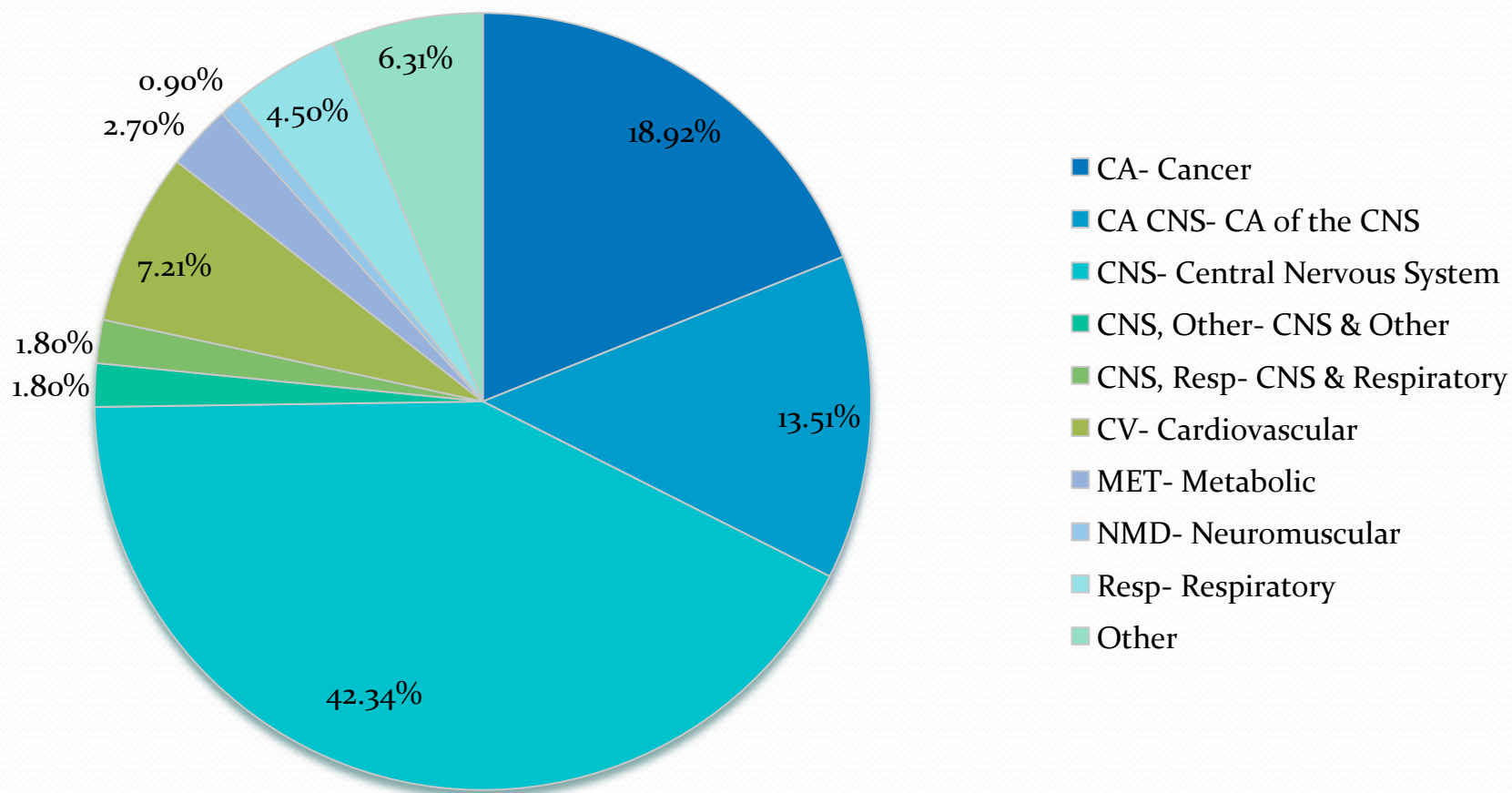


## Age of Children Who Have Died; April 9, 2004 through November 1, 2008



- Birth to 7 weeks
- 2 months to 6 months
- 7 months to 2 years
- 25 months to 11 years
- 12 to 17 years
- More than 18 year

## Diagnosis Types of Children Who Have Died; April 9, 2004 through November 1, 2008



# The Facts

- **Approx. 55,000 children die in the U.S., 50% in the 1<sup>st</sup> year of life (Meyer, et al, 2006)**
- **Approx. 80% children die in the ICU (Feudtner, et al, 2007)**
- **Approx. 7% Pediatric ICU patients die (Zwerdling, et al, 2006)**
- **Approx. 2/3 PICU deaths follow WWLSMT and/or compassionate extubation (Meyer, et al, 2006)**
- ***Initial* discussion addressing palliative care happens late(Stark, et al, 2008)**



# Out of the Box

- **Classic- Pediatric Intensive Care Unit**
  - Open plan
  - Private rooms
- **Innovative**
  - Home
  - Inpatient hospice facility, e.g. George Mark Children's House

# Innovative Approach

## Benefits

- Environment
- Involvement of extended family/social network
- Expert pain and symptom management
- Decreased medical costs
- Memory making activities
- Funeral planning
- Wake room
- Bereavement support

## Burdens

- Coordination of d/c supplies and transportation
- No crash cart/emergency supplies
- No 24/7 physician
- Unfamiliar surroundings (inpatient hospice)
- Unfamiliar medical team
- Organ donation limited

# Compassionate Extubation

## Specific: Statistics

- Total 6 patients
- Patient Age- range 2mths to 25 yrs, average of 6.4 years
- Admitting Diagnosis-
  - 2x Severe Encephalopathy secondary to hypoxia related to aspiration
  - 2x Restrictive Lung Disease secondary to Campomelic Dysplasia and Rhizomelic Dwarfism
  - 1x Cerebral Palsy with complications of PNA
  - 1x brain tumour

# Compassionate Extubation

## Specific: Statistics

- Length of Stay- 1 day to 19 days, average of 4.67 days
- “George Mark Care”- 4 out of 6 families chose, average LOS 2 days

# Compassionate Extubation

## Specific: Medical Management

- **IV Access- 5/6 patients**
- **Pain/Dyspnea- Dilaudid x1, Morphine Sulphate x5**
- **Agitation/Irritability- Lorazepam x5**
- **Secretions- 1% Atropine x3, Levsin x2, Robinul x1**
- **Terminal Restlessness- Phenobarbital x4**

# **Compassionate Extubation**

## **Specific: Psychosocial Management**

- **Immediate family present and involved**
- **Siblings involved x5**
- **Families stayed in suites, “a home away from home”**
- **Most participated with memory making activities**
  - **Handprints/footprints**
  - **Scrapbooking**
  - **Moment by Moment**

# Case Study: Emma

- **Age- 25 years**
- **Diagnosis- Cerebral Palsy since birth, spastic quadraplegia, scoliosis; complicated by irreversible lung damage secondary to Klebsiella PNA in left lung, sepsis, pleural effusion and abscess cavity**
- **Failed extubation/weaning; in ICU for 3 weeks**
- **Tracheostomy proposed**
- **Family goal = palliative care**

# Case Study: Emma

- **Planning**
  - **Family tour of GMCH**
  - **Discussed palliative care goals, pain and symptom management regimen**
  - **Coordinated transfer from adult ICU to GMCH for compassionate extubation**

# Case Study: Emma

- **Psychosocial- parents and brother, 23 years old, present; used family suite**
- **Pain and symptom management**
  - **Morphine Sulphate, 1-2mg, q 10 min's, IV, prn SOB/pain**
  - **Ativan, 1-2mg, q 10 mins, IV , prn agitation**
  - **Atropine 1%, 1-2 gtts, q 1-2 hours, SL, prn secretions**
  - **Phenobarbital, 130mg, IV, q 12 hours ATC after loading dose of 310mg, for terminal restlessness**
  - **NPO**

# Case Study: Emma

- **LOS – 2 days**
- **Funeral Home Pick Up– 6 hours later**
- **Memorial Service- English Tea Party**
- **Bereavement- f/u phone support, family has attended various family picnics, “Tiles and Tales” day and other GMCH events**
- **Dad joined the GMCH Board 😊**

# Case Study: Issac

- **Age- 5 months**
- **Diagnosis- Rhizomelic Dwarfism; restrictive lung disease; h/o GT and Nissen fundoplication; respiratory failure secondary to aspiration PNA/ Klebsiella**
- **Failed multiple extubations secondary to aggressive lung disease; in ICU for 3 weeks**
- **Family goal = palliative care**

# Case Study: Issac

- **Planning**
  - **Family tour of GMCH**
  - **Discussed palliative care goals, pain and symptom management regimen, need for interpreter services- Mum's primary language = Spanish**
  - **Coordinated transfer from PICU to GMCH for compassionate extubation**

# Case Study: Issac

- Psychosocial- parents present with maternal Grandmum and maternal Aunt; used family suite
- Pain and Symptom Management
  - Morphine Sulphate, 0.4mg, q 4 hours, IV ATC
    - Advanced to Morphine via PCA, 0.14mg/hour basal with 0.05mg bolus q 30 mins prn B/T pain/SOB
  - Lorazepam, 0.2mg, q 4 hours, IV ATC and q 2 hours prn agitation/irritability/SOB
  - Phenobarbital, 35mg, q 12 hours, IV, prn terminal restlessness
  - Levsin, 2-3 gtts, q 4-6 hours, po/sl, prn secretions
  - Advanced to PO feeds as tolerated: ½ str. Prosobee 24kcal/oz mixed with Pedialyte

# Case Study: Issac

- **LOS – 19 days**
- **George Mark Care – 2 days**
- **Memorial service in sanctuary**
- **Funeral Home Pick Up – after memorial service**
- **Bereavement – family attended ‘Tiles and Tales’ day; psychosocial support by phone; home visit scheduled**

# Eligibility

- **Severe heart or lung disease**
- **Severe brain injury**
- **Severe irreversible weakness or an abnormal respiratory drive**



## **Planning: Medical (Before Transfer)**

- **Current history and physical**
- **Confirmation of terminal diagnosis and an AND order**
- **Determine need for interpreter services**
- **Confirmation if a coroner's case or if tissue donation requested**
- **Current medication regimen, applicability in homelike setting**



# Planning: Medical (Before Transfer)

- **Determine parenteral access for meds**
- **Current LOC of child**
- **Adequate symptom management established prior to compassionate extubation**
- **Availability of medicines and equipment from homecare pharmacies/DME**



# Medical: Specifics (Before Transfer)

- **Goal = pain and symptom management for a comfortable death**
  - **Hold neuromuscular blocking agents for 2-3 hours prior**
  - **Hold any enteral feeds for 2-3 hours prior**
  - **D/C IV fluids/hydration, unnecessary meds (limit polypharmacy)**



# Formulating Treatment Plan

- **Respiratory Status**
- **Cardiovascular Status**
- **Neurologic Status**



# Formulating Treatment Plan

- **Respiratory Status**
  - Ventilator settings
  - Recent blood gas
  - Risk of upper airway obstruction



# Formulating Treatment Plan

- **Cardiovascular Status**
  - Inotropic support
  - Shock



# Formulating Treatment Plan

- **Neurologic Status**
  - **LOC**
  - **Cranial nerve function**
  - **Muscle strength**
  - **Seizure disorder**



# Planning: Psychosocial

- **Prior to transfer and again upon arrival**
  - **Who makes the medical decisions?**
  - **What does the family understand?**
  - **Determine need for interpreter services**

# Planning: Psychosocial

- **Family review, upon arrival:**
  - **Reiterate clinical findings and prognosis**
  - **Confirm the treatment plan**
  - **Review wishes and expectations**
  - **Determine who is to be present**
  - **Determine any spiritual/religious needs**
  - **Review need for Medical Examiner or autopsy**
  - **Introduce available memory making activities**



# Planning: Psychosocial

- **Upon arrival:**
  - **Anticipatory Guidance- review s/s at time of death**
  - **Review what to expect- avoid prognostic timing**
  - **Establish sibling support and level of involvement**
  - **Prepare staff receiving child- clear communication of family centered care plan**



# Medical: Recommendations

- **Pain and Dyspnea-**
  - **Morphine Sulphate**
  - **Fentanyl**
  - **Hydromorphone (Dilaudid)**
  - **Methadone**

# Medical: Recommendations

- **Anxiety and Sedation-**
  - **Benzodiazepines,**  
e.g. Midazolam (Versed), Lorazepam (Ativan)
  - **Barbiturates, e.g. Phenobarbital**
  - **Neuroleptics, e.g. Haloperidol**
- **Other Considerations- Oxygen, oral secretions/  
death rattle**



# Medical: Additional Comfort

- **Goal: Maximize comfort and minimize psychosocial distress**
  - Suctioning
  - Turning
  - Fans
  - Music/Expressive Therapies
  - Pet therapy
  - Massage therapy
  - Hydrotherapy
  - Sucrose water drops (infants)



# Bereavement Services

- **Currently, bereavement services at George Mark Children's House include:**
  - **Cards sent at**
    - **holiday times**
    - **child's birthday**
    - **anniversary of his/her death**



# Bereavement Services

- **Phone calls to family are made at regular documented intervals**
- **Home visits, when possible ,within first 3 to 5 months after death or, families come to GMCH to see a member of psychosocial staff**
- **Home visits are made by the Chaplain, Social Worker or Nurse Case Manager , and by the Child Life Specialist as needed**



# **Bereavement Services**

- **Tiles and Tales days -3 to 4 times per year**
  - **Families come to GMCH and make a tile in memory of their child for our memorial tile wall**
- **Annual Remembrance Day -the second Sunday in December**



# **Bereavement Services**

- **All families are invited to our annual family picnic and other events, i.e. Pumpkin Day**
- **Special days for siblings led by our Child Life Specialist**
- **Referrals are made to our Clinical Psychologist when the psychosocial staff determines an acute need**



# Bereavement Services

- **GMCH has just begun the initial steps to building a secure web site designed for parents and siblings to provide peer support. This innovative program has several features:**
  - **a site for each family to “tell the story” of their child/teen in words, pictures, video**
  - **be able to connect with other parents using the site to exchange help and support**
  - **to post questions and appeal for help for clinical staff member response**



# Bereavement Services

- **About 12 to 15 families have been recruited to pilot the site –hopefully by the end of the year**
- **Eventually, it will be open to all CFK/GMCH families, and perhaps for families from other local children’s hospitals**




# **Bereavement Services**

- **Plans to develop a newsletter for bereaved families and an educational and informational introductory support group are in the formation stages**
- **GMCH will offer an introductory educational and informational program for newly bereaved families that will be a regular offering about every four months**



# Bereavement Services

- **Open to the greater community, the program will have three sessions:**
  - **An overview of what parents, other adult members of the family, close supportive friends can expect related to grieving in the first year or so**
  - **A session for couples only**
  - **A session for siblings and parents**
- **If a support group naturally emerges from these sessions, staff will provide leadership**



We need, in love, to practice only this;  
Letting each other go.  
For holding on comes easily;  
We do not need to learn it.

Rainer Maria Rilke