

Palliative Care:
Moving to a Natural Medical Home
for Children with Chronic and
Complex Health Needs

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A Palette of Care

Haslinger Pediatric

Palliative Care Center



Today's Roadmap

- A short summary of Pediatric Palliative Care and The Palette of Care Program
- Recognizing the needs of Medically Complex Children
- How Palliative Care can meet patient and family needs across health care settings
 - Palliative care as a medical home
- Supporting the caregivers of medically fragile children
 - Family
 - A Unique Partnership
 - Institutional



What is Palliative Care?

- *Palliative care* seeks to **prevent or relieve the symptoms** produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decision making.



Field, M.J. & Behrman, R.E. When Children Die: Improving Palliative and End-of-life Care for Children and their families. [Report of the Institute of Medicine Task Force.] Washington, DC: National Academy Press, 2003.

Palliative Care for Children

- Holistic and extensive care for a child with a complex, chronic condition or who is not necessarily going to “get better”
- Focuses on child and family
- Most effective when combined with cure-oriented, disease-modifying care at or near diagnosis
- Intensifies as appropriate, with changing goals of care
- Entire team approach of care to prevent and relieve child’s suffering and improve conditions of child’s living and dying
- Empathic, developmentally- and culturally-sensitive support



The Relationship Between Curative and Palliative Care



- Many pediatric disorders are incurable but not immediately fatal
- Children may live for many years with no possibility of cure (palliative care)
- May seem impossible to pinpoint the beginning of end-of-life care; however, at some point, the goals of therapy begin to change
- At diagnosis of a complex, chronic or life-threatening condition, the course is unclear and families need support for their journey

The Haslinger Family Pediatric Palliative Care Center



Established at
Akron Children's Hospital
July 2002



Akron, Ohio

- Where's that?
- 45 mi south of Cleveland
- North of Columbus
- Rubber capital of the world
- Home of girl scout cookies, hamburgers, AA, dodgeball, Chryssie Hynde (name the band...), and LeBron James





MICHIGAN

Lake Erie

PENNSYLVANIA

Toledo

Cleveland

Youngstown

Akron

OHIO

★ Columbus

Dayton

INDIANA

Cincinnati

WEST VIRGINIA

KENTUCKY



Akron Children's Hospital

- Free-standing tertiary care children's hospital
 - Established in 1890
- 253 beds+++
 - Cares for over half a million patients annually
 - Most pediatric surgeries in NE Ohio
 - Peds trauma center
- Only children's hospital in area
 - Large amount of community support
 - NICUs in 2 other hospitals
 - New pediatric hospital in Youngstown, Ohio
 - Other regional expansions
- Regional burn center (adult + peds)
- Affiliated home care agency
- Network of "satellite" primary care offices



PPC at ACH

THE
HASLINGER FAMILY
PEDIATRIC
PALLIATIVE
CARE CENTER

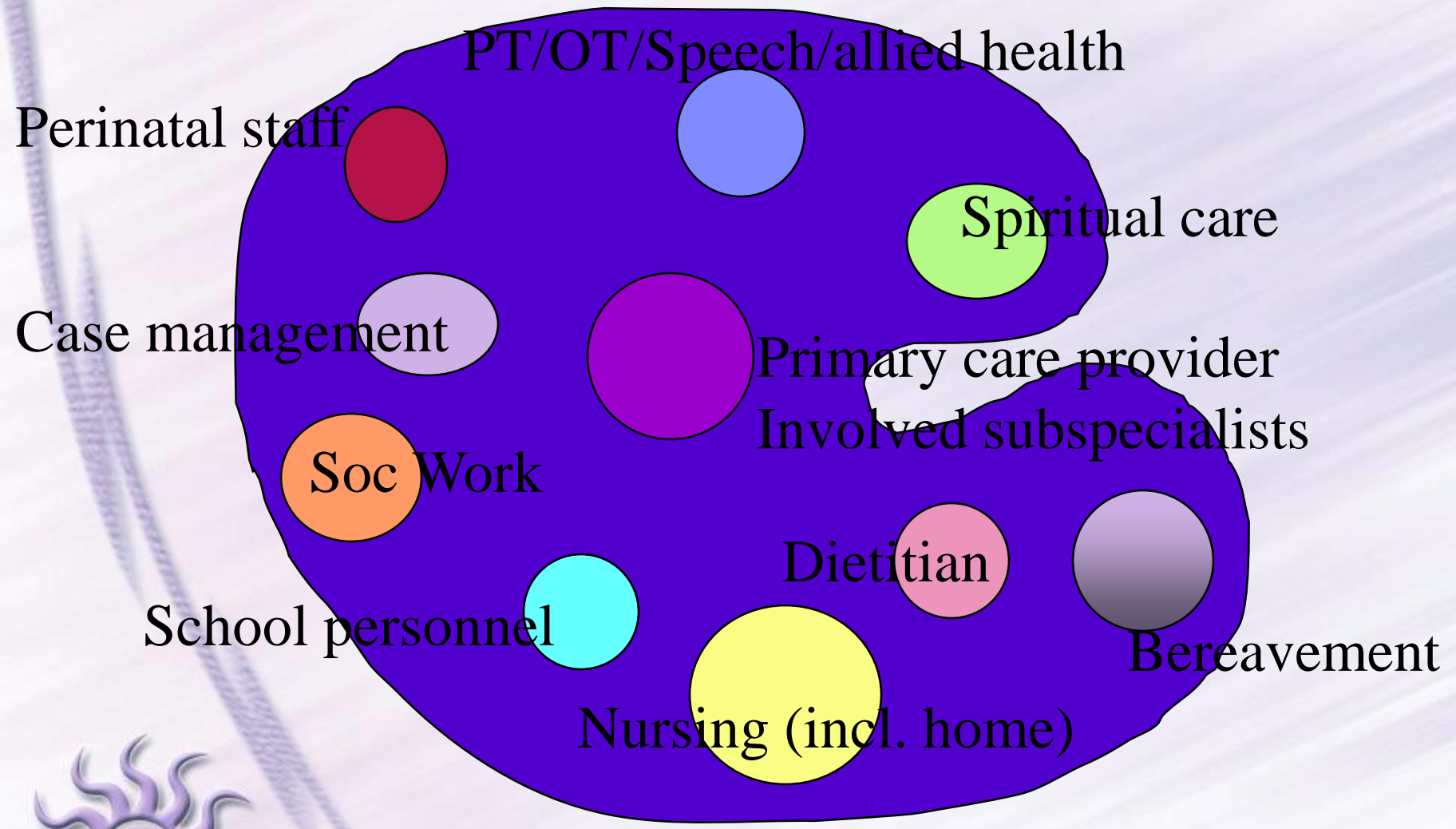
- Academic Division of Pediatrics
- Any age with pediatric diagnosis or specialist
- Any chronic, complex or life-threatening condition, any age
- Hospital-based team:
 - Inpatient consultation
 - Inpatient primary medical service
 - Outpatient services designed to fit family
 - Collaboration with PCP
 - Transition to home with comfort care
 - Coordination with local/regional home care and hospice agencies
 - Home visits



Our Palette Mission

- To bring legendary pediatric palliative care to any patient, in the perinatal period, infancy, childhood, adolescence or young adulthood, facing a chronic, complex or life-threatening condition
- To provide leadership in education, research, and advocacy initiatives in pediatric palliative care locally, regionally and nationally





PT/OT/Speech/allied health

Perinatal staff

Case management

Soc Work

School personnel

Nursing (incl. home)

Primary care provider

Involved subspecialists

Spiritual care

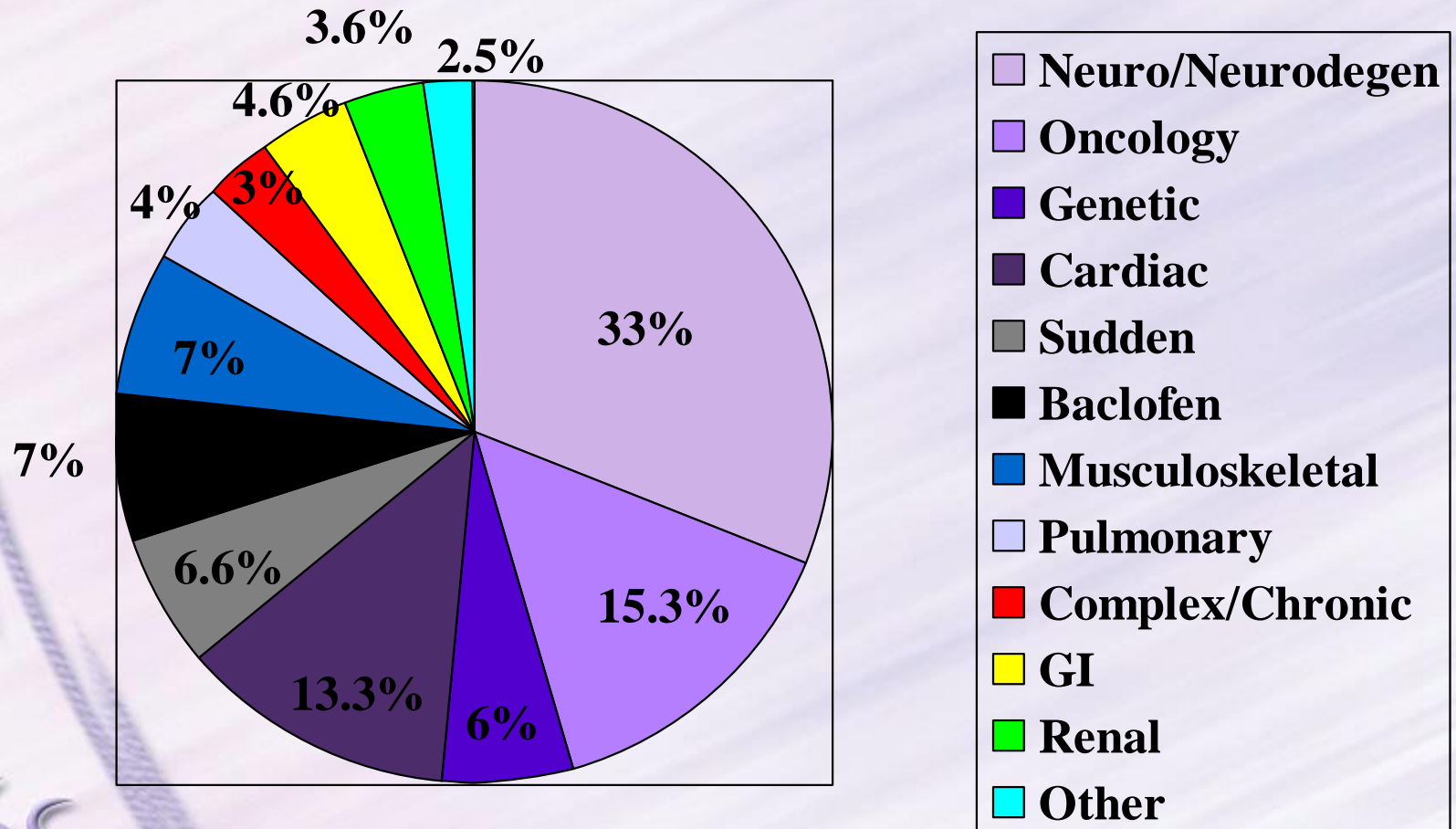
Dietitian

Bereavement

Patient/family: whole canvas



Diagnoses served in 2008



Baclofen pump patients not in total, so total greater than 100%

OTHER: Hematologic, ID, in utero, metabolic

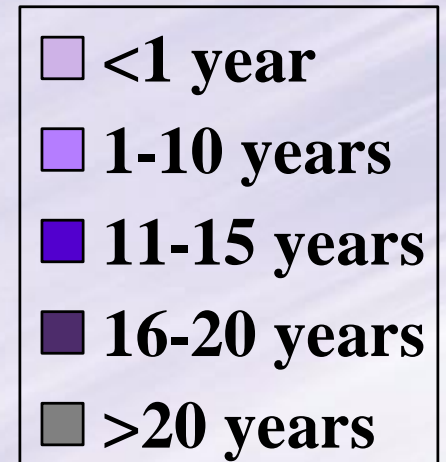
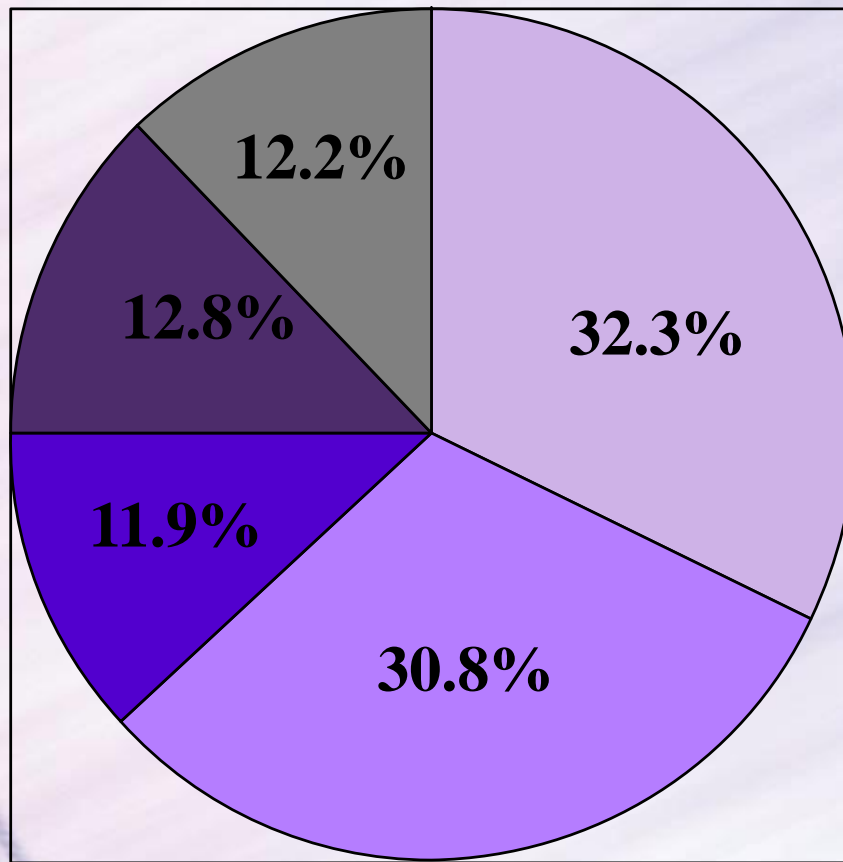


Referral Sources 2008

- PICU 31%
- Hematology/Oncology 13.8%
- Outside (CHCG, HL) 8.8%
- Neurosurgery 8.2%
- FTC/MFM 7%
- PMD/CHPA 7%
- NICU 5%
- Pulmonary, Neuro 3.6%
- Cardiology 3%
- Surgery, Family 1.5%



Age Breakdown



We are not typical...

- Every child with a complex, chronic or life-threatening illness deserves quality palliative care, but we are not there yet.
- Approximately 58% of Children Oncology Group hospitals have **Palliative Care Services** (Johnston DL, Nagel K, Friedman DL, Meza JL, Hurwitz CA, Friebert S. J Clin Oncol. 2008 Oct 1;26(28):4646-50.)
- Many programs address pain and symptom control at end of life or service inpatient consults only.



Etiology

- What makes a child medically complex?
 - A **medically fragile child** is one who, because of an accident, illness, congenital disorder, abuse or neglect, has been left in a stable condition, but is dependent on life-sustaining medications, treatments, equipment, and has need for assistance with activities of daily living.



Who is medically complex?



- **Medically fragile crosses all diagnoses**
- Diagnosed medically fragile by a medical physician, this child may:
- Have chronic health care conditions such as diabetes (CF), oxygen dependency, cerebral palsy (CP)
- Be a transplant recipient and/or require special health care support, such as tube feedings, suctioning, tracheostomy care, ventilatory support
- Have limited mobility and require special health care support and/or equipment due to paralysis or chronic disease



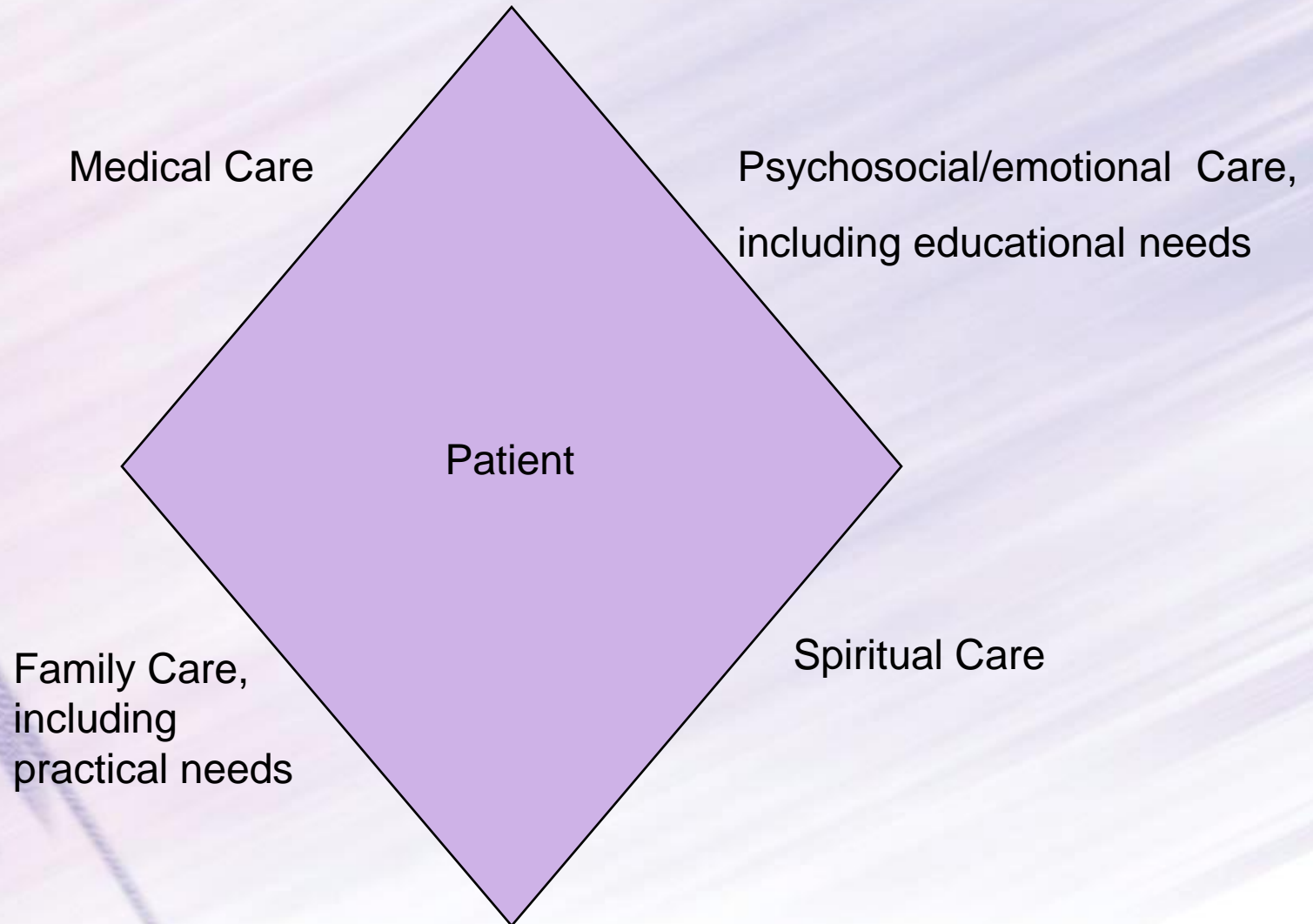
What is “normal”



- Profoundly developmental and intellectually handicapped children have a level of wellness that is normal to them.
 - Even if we cannot understand it, their parents and caregivers do
- Often we have to discover “new normals” as a child gets older or faces slow decline.



Dimensions of complexity



The Statistics part

Did you know?

- Children with special health care needs (CSHCN) comprise 12.8 % of all children under the age of 18 in the United States.
- A special health care need may result from premature birth, illness, injury or congenital conditions.
- Many children will require life-sustaining technology, extensive treatments and medications throughout their lives.
- Severely medically fragile children more likely to need intensive care, long-term care facilities, inpatient hospitalization; death rate higher

<http://www.childrensmemorial.org/newsroom/complexmedical.aspx>



Medical Advances

- Medications
- Airway Support
- Mobility and Communication
- Long-Term Care Facilities
- Nutrition
- Other supportive care
 - Especially for families with non-verbal and profoundly delayed children



The numbers are growing

- 53-55,000 children die/year in US
- Children with chronic, complex life-threatening illness: 0.5-2 million
 - Death rate decreasing slightly
 - Population increasing slightly
 - Increasing # of previously fatal illnesses/conditions now chronic
 - You do the math...



Increasing #: Increasing challenges

- Advances in medical treatments have prolonged life-span into adulthood
- These children continue to have difficulty in accessing care, experiencing limited resources upon reaching adulthood. They rely upon their families as care providers, often experiencing uncoordinated care, while seeking out multiple health care sources
- Institutions providing care for these children express dissatisfaction with the current system
- Fragmentation of care = #1 complaint of families whose children die



The Unfortunate Truth

- Medically complex children die
- What do children and families need?
 - Support for anticipatory grief, and during death and bereavement from a team of professionals who have walked the path with the child
 - Trust that is built over time
 - Celebrating the child's life, not just accommodating his/her death
 - A commitment to decreased suffering during life and during the dying process
 - Help for the family to understand they are not choosing what is killing their child
 - Medically complex children usually do not die of “disease progression” alone



What is the hallmark of a medical home?

- According to the Center for Medical Home Improvement, a medical home provides team-based care coordination, delivered from the centralizing resource with physician leadership and by experienced nurses, social workers, and/or comparable professionals.

• <http://www.medicalhomeimprovement.org/>



Capability of a medical home

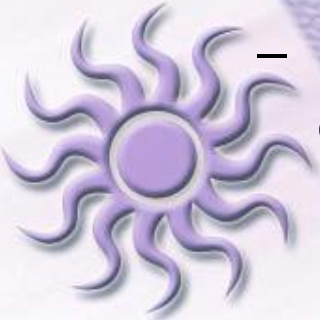
- The AAP Medical Home Advisory Committee in 2002 stated that a centralized medical home is a critical resource, especially for children with chronic and complex health needs.
- Care Coordination is the essence of a medical home
 - Complex
 - Time consuming
 - Necessary to facilitate optimal outcomes and prevent confusion for families
 - Resource-heavy
 - The AAP Committee on Children with Disabilities in 1999 recommended reimbursement for this labor-intensive role
 - In all medical settings for medically fragile children, care coordination is an essential element to ensure quality and continuity of care (Horst, Werner, and Werner,2000)



Care Coordination

- Practice-based care coordination within the medical home is a direct, family/youth-centered, team-oriented, outcomes-focused process designed to:
 - Facilitate comprehensive health promotion and chronic condition care;
 - Ensure a locus of ongoing, proactive, planned care activities;
 - Build and use effective communication strategies among family, the medical home, schools, specialists, and community professionals and connections; and
 - Help improve, measure, monitor and sustain quality outcomes (clinical, functional, satisfaction and cost)

(McAllister, et al, 2007)



An answer...

- Palliative care as a medical home for medically complex children
- A natural fit...



A special relationship

- We are fortunate to partner with families, primary care providers, specialists and with Hattie Larlham Center for Children with Disabilities
- Sharing our unique knowledge with each other for the betterment of the lives of our patients



A bit about “Hatties”

- 126-bed chronic care facility
- Located 40 minutes from Akron Children’s; also admits to 3 pediatric hospitals in Cleveland area
- All ages
- Tertiary care wing
- Nursing, habilitation assistants, therapists, social work, mobility experts
 - Aqua therapy, sensory room
- Single full-time medical director
- On-site school, off-site workshops
- On-site “typical” mainstreaming day care



Statistics: Shared care

- 35 active mutual patients
- 15 deaths
- Admit patients up to 35 years of age



The marriage of services

- Palliative Care is the primary medical admitting team for patients with complex medical needs who are over 21 and serves as a consult service for care coordination and support along with other admitting services.
- Primary pediatricians receive frequent communication about their patients when the children are hospitalized.
- Homecare services and supplies
- It's a true partnership among healthcare providers

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**"Do you, Jason, take Karyn to have and to hold,
to E-mail and fax, to page and beep,
until death do you part?"**



Combining strengths

- Palliative care team
 - Expertise in pain and symptom mgmt
 - Expertise in EOL care/ imminent death
 - Depth of spiritual and psychosocial resources
 - Cutting-edge education programs
 - Intensive medical treatment
 - ?increased involvement with family of origin
- Primary & Long Term Care
 - Expertise in chronic disease mgmt
 - Long-term relationship w/pts, families
 - Extensive resources for educational, mobility, therapy and practical support
 - Dedicated staff
 - Tremendous community support & reputation



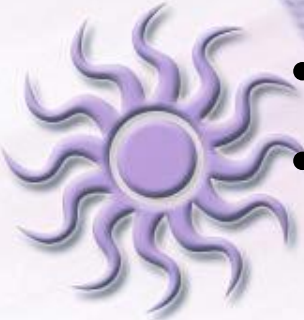
Continuity

- Palliative care NP makes house calls and rounds at HLCCD quarterly on all mutual patients
 - Updates care plans, med lists
 - Educational offerings to facility staff and home care staff
- Education offered quarterly for community-based home-care hospice staff
- Phone consultation with known patients
- Quick exchange of information between PMD and hospital
- Educational experiences for residents, students of all disciplines, first responders
 - EMS transfer according to the care plan



What has this relationship done for our patients?

- Improved patient well-being and enhanced access to medical care
- Single admitting service to coordinate care in a safe and efficient manner
 - Quick access to acute care setting
 - Direct admission possible
- Improved pain control, symptom control, wellness
- Fewer interruptions to facility services, routines (including school, therapy)
- Improved “personhood” at the hospital
- Able to stay “home” at end of life



Benefits for family, caregivers

- Assurance that child is being treated according to family's wishes
- Transparency of information
 - Helps family set and reach attainable goals of care
 - Helps facilitate goals of care discussions over time
- Enhanced grief & bereavement services
 - Help with funeral arrangements
 - Memory making
- Enhanced spiritual care



Benefits for health care teams

- Palliative care team/hospital
 - Full histories, information
 - Caregivers see fullest potential of clientele (more than “frequent flyers”)
 - Education re chronic care issues
- Community/LTCF
 - Seamless to & fro transitions of care
 - 24/7 access to same care team who gets to know pts well
 - Free access to in-hospital information
 - Education re palliative care/acute care issues
 - Consultation for non-admission issues
 - Bereavement support & memory-making



Benefits Providers

- Flow of information is seamless
 - Access to pts for ongoing assessment in or out of hospital
- Research collaborative opportunities
 - Current study: facility caregiver responses to death with HLCCD
- Enhanced trust of providers
 - ACH: families trust us more if we're vetted by the child's "home" team
 - Families trust their MD, we have trust by proxy
 - Helps facilitate goal-based decision making



Challenges

- Culture and ethical environment of LTCF and homes
 - Nutrition and hydration
 - Morphine at the end of life
- Transition for patients over age 35
- Boundary issues at facility
- Attitude toward chronically ill at hospital
- Availability of subspecialty consultation hampers continuity



Outcomes

- Decreased length of stay
- Decreased admission rate to hospital
 - Remain in facility setting instead of transfer
- Family satisfaction with care at both locations
 - Communication with families enhanced and trust built with both facilities
- Consistency of information given to family
- Decreased medical errors
- Improved pain and symptom control
- Improved EOL care for facility patients



Take-home messages

- Pediatric palliative care = best quality care, not second-best or after-thought
- Truly is a location-independent philosophy and practice
- Medically fragile children are a growing constituency
- Palliative care is a natural medical home for medically complex children
- Palliative care/LTCF partnerships are beneficial and rewarding for patients, staff and caregivers



Questions?

- mfarrar-laco@chmca.org or sfriebert@chmca.org
- www.akronchildrens.org/palliative
- More information on pediatric resources: www.nhpco.org/pediatrics
 - ChiPPS Project
- CAPC: Center to Advance Palliative Care – Pediatric PCLC
 - www.capc.org

