



Pediatric Serious Illness Care: To Infinity and Beyond

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The Doctor by Luke Fildes, 1891

A Specialty Comes of Age

- ▶ 1950s & 1960s—just a twinkle in the eye
 - ▶ Increasing focus on death—experience of parents and child
 - ▶ Growing recognition of physical and emotional suffering
- ▶ 1970s—fetus/newborn baby
 - ▶ Cicely Saunders
 - ▶ “Constant pain needs constant control”
 - ▶ Total pain
 - ▶ “The care of the dying must be a shared work”
 - ▶ 1st US hospice
 - ▶ The Private Lives of Dying Children by Myra Bluebond-Langner



A Specialty Comes of Age

- ▶ 1980s & 90s—toddlerhood
 - ▶ 1982 Helen House, 1st pediatric hospice
 - ▶ Scope broadens upstream of death, closer to time of diagnosis
 - ▶ Persistent undertreatment of pain in infants and children
 - ▶ Inclusion of pediatrics in scholarly work of palliative care
- ▶ 2000s—adolescence
 - ▶ Joanne Wolfe: *Symptoms and Suffering at End of Life in Children with Cancer*
 - ▶ AAP Policy Statement
 - ▶ IOM *When Children Die*
 - ▶ Growing emphasis on barriers, outcomes, metrics, best practices, interventions
 - ▶ What do we want to be when we grow up?



National Scope

- ▶ **Professional Organizations**
 - ▶ American Academy of Pediatrics
 - ▶ American Academy of Hospice & Palliative Medicine
 - ▶ Center to Advance Palliative Care
 - ▶ National Hospice & Palliative Care Organization
 - ▶ Hospice & Palliative Nurses' Association
 - ▶ Social Work Hospice & Palliative Care Network
 - ▶ Pediatric Palliative Care Task Force
- ▶ **State Coalitions**
- ▶ **Child & caregiver voice**
 - ▶ Courageous Parents Network



SC work—Dum Spiro, Spero

- ▶ Hospital-based programs
 - ▶ Charleston
 - ▶ Columbia
 - ▶ Greenville
- ▶ Community-based program
 - ▶ Hands of Hope, Agape Care's Pediatric Program
 - ▶ Dedicated pediatric team with hospice and palliative care services
- ▶ State collaborative
- ▶ State Palliative Care & Quality of Life Collaborative



Looking Forward



Awareness & Education

- ▶ State Advisory Council
- ▶ Public education
- ▶ Continuing education opportunities
- ▶ Include serious illness curriculum in professional graduate schools
- ▶ Promote fellowship programs
 - ▶ None exist focused primarily on pediatrics
- ▶ Training centers of excellence



Policy & Advocacy Opportunities

- ▶ Do Not Resuscitate & Advance Care Planning
- ▶ Opioid policy
- ▶ Alternative payment strategies to enhance access
 - ▶ CAPC toolkits
 - ▶ Inadequate reimbursement of “non-medical” team members
- ▶ Home nursing/health support and respite care
- ▶ Paid caregiver program
- ▶ Concurrent Care & Hospice benefit



Policy Opportunities



- ▶ Telehealth
- ▶ Education—public and professional
- ▶ Workforce incentives
- ▶ Serious illness care planning



Lessons Learned

- ▶ Sustainability is your best ability
- ▶ Set boundaries
- ▶ One step at a time
- ▶ Invest in people
- ▶ Make connections
- ▶ Access, access, access



South Carolina Pediatric Hospice & Palliative Care Collaborative



Let's connect

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