

Capital Caring Kids; Concurrent Hospice and Palliative Care 101

Developmental Epileptic Encephalopathy Presentation



Capital Caring Kids; Our Why



Who We Are: Capital Caring Kids Overview

- ***When a Child Has an Advanced Illness***

- Every child is precious, and every moment with them matters.
- We serve children from infants to young adults who are facing chronic, life-limiting medical conditions.
- We recognize that children and teens require a specially tailored approach with compassionate, nurturing support.

- ***Surrounding Families with Care and Support***

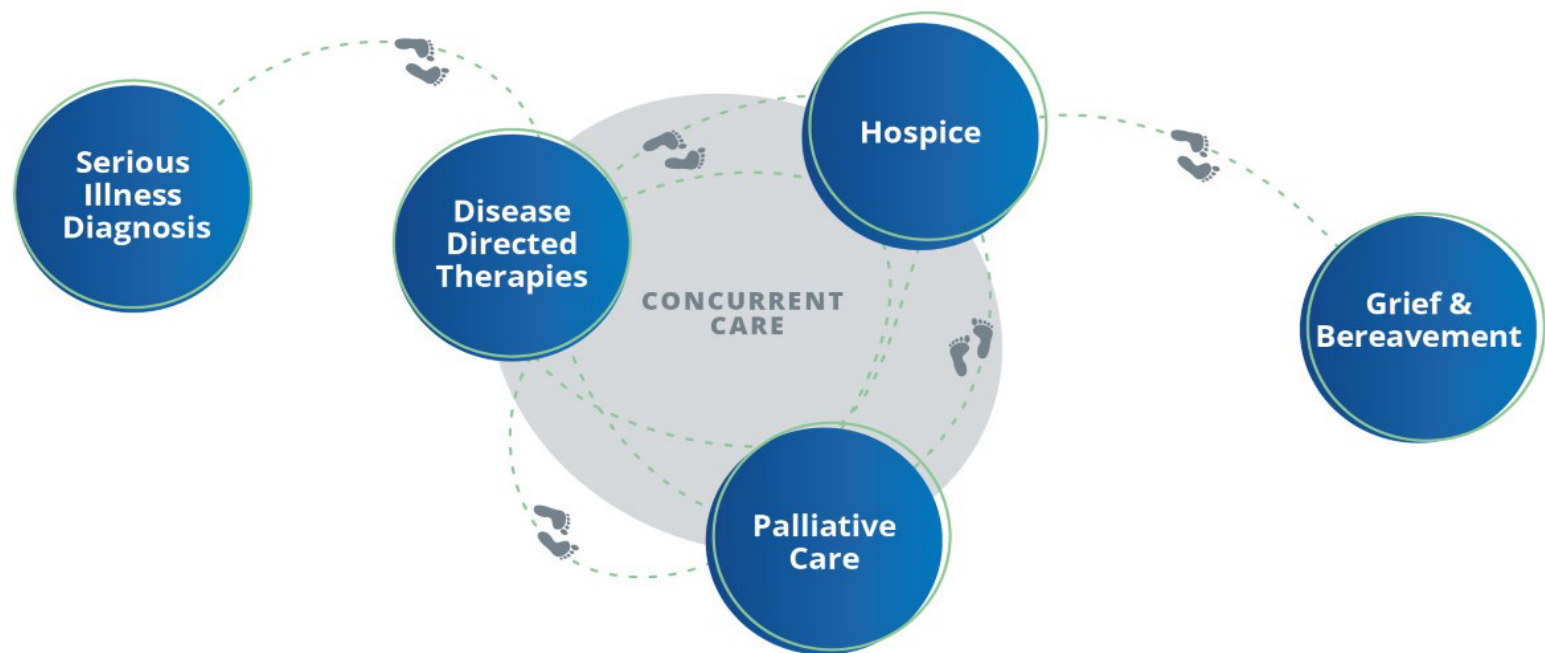
- We support families from the time of the child's diagnosis—even before birth—through treatment and end of life.
- Capital Caring Kids provides holistic symptom-directed care encompassing the social, emotional, psychological, and spiritual needs of children facing serious illness wherever they call home, anytime, day or night.
- Palliative (advanced illness) care or hospice care may be an appropriate intervention depending on illness trajectory
- Patients under the age of 21 fit under the umbrella of Capital Caring Kids.
- We help the whole family create meaning no matter how long the child is with us.

Capital Caring Kids; Overview of Support

Child/Family Directed Programs	Hospital/Community Partners
<ul style="list-style-type: none">• Perinatal Palliative Care• Palliative care• Concurrent (Hospice) Care• Loss, Grief, and Bereavement Support	<ul style="list-style-type: none">• Discharge planning• Provider consultation and guidance;<ul style="list-style-type: none">~<i>Determining/assessing eligibility</i>~<i>Case consultations</i>~<i>Approaching difficult conversations with parents</i>• Ongoing education offerings• Staff support groups

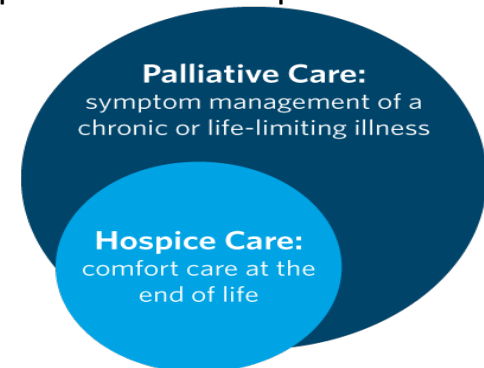
Pediatric Care Continuum; Complex Medical Illness

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Introduction to Pediatric Concurrent Hospice Care

- Concurrent hospice care is intended for children diagnosed with an advance illness **whose life expectancy is six months or less even while the child continues to receive disease-directed treatment**
- The Affordable Care Act (Section 2302) passed in 2010 allows for concurrent care. Unlike adults, this enables children with life limiting illnesses to receive curative treatment and hospice care at the same time. Because of concurrent care, we collaborate continuously with the patients' outside providers.
- Many families are relieved to experience the support hospice can offer, often earlier than expected.
- A DNR order is not required to receive support from hospice.
- We help families sort through the difficult decisions regarding the scope of services and treatments and their impact on the quality of life and the values for child and family



Introduction to Pediatric Concurrent care(continued)

- Hospice benefits are paid by the child's insurance on a per diem basis and include all visits and services, also including medications, supplies, and equipment related to the hospice dx.
 - As a not-for-profit provider of services, Capital Caring Kids is committed to care for all who need our services. In most cases, Medicaid or private insurers will cover the entire cost of care. With some private insurances, there may be small contractual copayments.
 - If the family has insufficient funds or no payer source, our Pediatric Patient Care Fund may be able to provide financial assistance.
- Children receiving concurrent care at home experience
 - Improved quality of life
 - Decreased patient costs
 - Decreased parental stress
 - Increased likelihood of dying at home

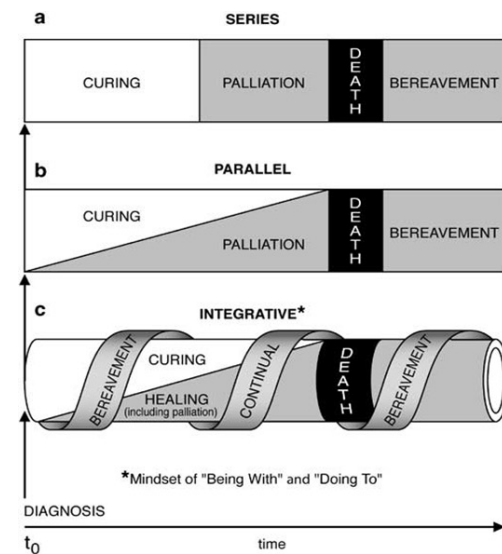


Concurrent Care; In Practice

- For Capital Caring Health (CCH), this means we admit children with a life-limiting prognosis receiving curative treatments including surgeries, chemotherapies, rehabilitative therapies, and DME that potentially prolongs life such as ventilators.
- The curative treatments are covered under the patient's insurance program. In collaboration with HMD, AMDs and specialists order and approve treatments and the patient's Medicaid or private insurance company pays for them separately from hospice services.
- CCH is paid the normal hospice daily rate based on the level of care provided. We cover all medicines and treatments typical under the hospice benefit to include all medicines related to comfort, all routine DME needed to ensure patient's comfort and adequate care, and all other treatments, such as some therapies to teach families how to safely transfer and position patients, relieve contractures, or improve quality of life.
- CCH is required to keep in close contact with the insurer when a child is receiving concurrent care
- We are also required to have a joint Plan of Care (POC) with the patient's other medical providers

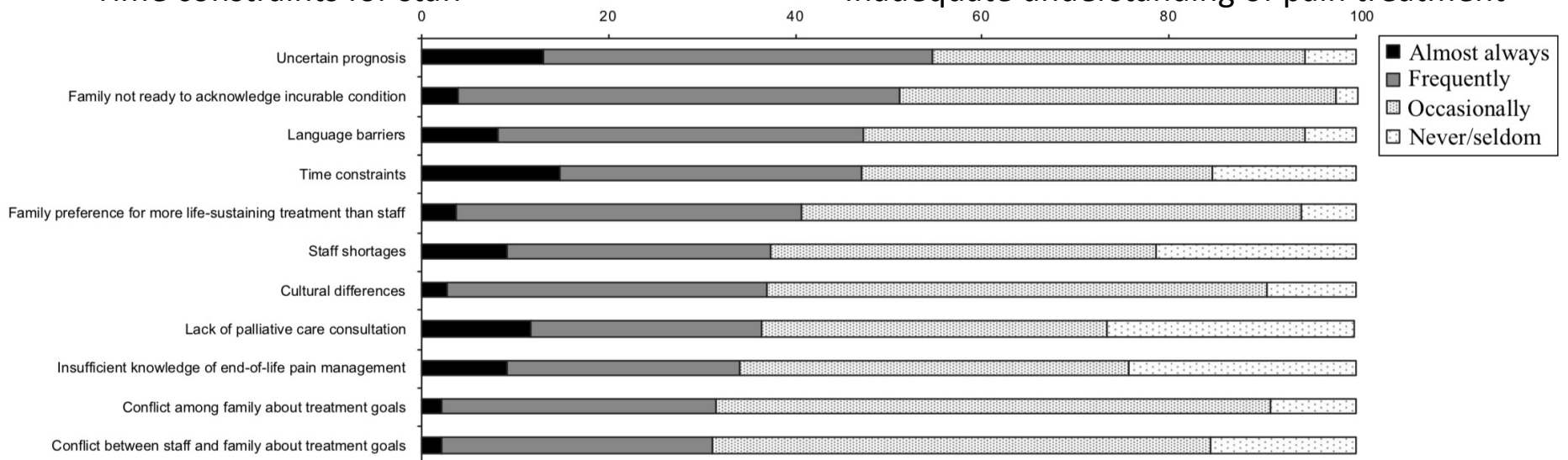
Barriers for Timely Access of Concurrent Care

- Poor understanding of pediatric palliative and hospice services
 - Fail to consider community care following hospital discharge
- Pediatric specialists form deep relationships with patients/families
- Belief that they can provide all the care needed
- No understanding of reimbursement allowances
- Out of sight, out of mind



Barriers for Children and Families

- Uncertainty of prognosis
- Family doesn't acknowledge incurable illness
- Language and cultural barriers
- Time constraints for staff
- Lack of community resources
- Family: Poor understanding of palliative care
- Staff: Poor understanding of palliative care
- Inadequate understanding of pain treatment



Davies B et al *PEDIATRICS* 2008; 121:282-88

Benefits of Concurrent Care – Medical

- Wrap around services for children w/ potentially incurable conditions
- Dedicated, community-based team – resources of hospice team for children receiving attempts at cure
 - Nurses and physicians
 - Social worker
 - Child Life
 - Chaplain
- Expert children's pain and symptom management
- Liaison between medical specialists
 - Bi-weekly virtual team rounds
 - Care coordination



When is it a good time to elect concurrent care for your child?

Hospice eligibility is typically based on whether or not a child has 6-months or less life expectancy based upon natural, untreated course of illness and progressive loss of function over the ensuing time.

Concurrent care has modified the course and extended the lives for all of these children through medical interventions.

One of the questions many parents ask is: Is each day a greater blessing or burden for my child?

Indicators of Disease Progression

- loss of function
- neurodegeneration
- increasing seizure med needs
- progressive heart or renal failure without a transplantation option (or even if listed for transplant and waiting)
- failure to respond to chemo
- relapse with high risk for incurability
- failed stem-cell transplantation
- progressive weight loss
- increased need for respiratory support (e.g. nasal cannula, BIPAP at night, BIPAP 24-hrs/day)

Cardiac: Increasing heart failure, needing home milrinone infusion, decreased exercise tolerance, more shortness of breath, listed for transplantation

Respiratory: Decreased exercise tolerance, increased oxygen and support requirements

Cancer: relapse with poor prognosis for remission, failed stem-cell transplant, incurable cancers (many CNS malignancies), progressive inanition associated with underlying cancer.

Renal: Renal failure without transplant option, failing dialysis

GI: Intestinal failure with TPN dependence

Metabolic/Genetic/Neurodegenerative: loss of function, neurodegeneration, increasing seizure med needs

For all groups: Increased frequency of hospitalizations or ED visits

Has there has been a change from full code to DNR status?

How do I talk to my child's physician about concurrent care?

- We are really struggling at home. I've heard that my child is eligible for concurrent care at home whether it is palliative or hospice. Do you believe that my child meets the criteria?
- i.e. loss of function, treatments not as effective, quality of life is suffering for child and family
- We really need an extra layer of support at home due to medication regimens, sleep issues, etc. Do you think it might be time to discuss palliative care at home to augment what we're doing to keep my child stable?

Benefits of Concurrent Care - Humanistic

- Pediatric palliative care recognizes that an ill child deserves a childhood
 - Celebration of birthdays and holidays
 - Recognize impact of developmental stage on child's reaction to illness
- Expert child and family centered care
- Understanding of challenges faced by a child with serious illness
- Understanding of stress on siblings and parent stresses of an ill child
- Approach family with nurturance, understanding, and softness while providing rigorous, evidence-based healthcare



Referral Indicators

- **General Guidelines for Concurrent Hospice Care**

- A child diagnosed with a chronic, progressive illness may be eligible for hospice if any of the following are present, even while continuing to pursue disease directed therapies;
 - Multiple trips to the doctors/ER/hospitalizations
 - Lack of response to treatment and/or worsening symptoms/disease
 - Treatment is having a negative impact on quality of life
 - Unintended weight loss
 - Decrease in cognitive abilities
 - Patient/family desires “comfort care”

Capital Caring Kids is always available to offer guidance and consultation for any child, even if a referral is not initiated.

Introduction to Pediatric Palliative Care

- Palliative care is designed for children with an advanced illness who are receiving disease directed treatments and **whose prognosis is expected to be more than one year.**
- Palliative care is an appropriate intervention at **any stage of a child's illness.** A child diagnosed with a chronic, progressive disease experiencing pain or other symptoms that impact quality of life will qualify.
- Our palliative care approach consists of a visit from a Pediatric Nurse Practitioner once or twice a month with an occasional visit from our Pediatric Palliative Care Physician to manage symptoms and coordinate care with the child's providers.
- Our Pediatric Social Workers make occasional visits for support and connection to outside resources.
- Insurance bills directly for individual palliative care visits (not the hospice per diem)
- Children on our palliative care service may transition to concurrent hospice service if the family and medical team decide that this is the most appropriate course based on the trajectory of the child's illness.

Summary of Benefits and Challenges; Pediatric Palliative Care

- Palliative care allows for **earlier and continual intervention** to children with serious illness and their families throughout the disease progression;
 - Helping to ease decision making regarding care interventions and goals
 - Enhancing QOL throughout trajectory
 - Establishing trust
- Barriers to care;
 - Resources vary significantly by state due to;
 - Difference of presence in care settings (i.e. hospital, LTC, community)
 - Lack of government priority or legislation
 - Limited availability of trained staff
 - Challenging funding structure and landscape



Capital Caring Kids Hospice Home Services Include;

- Board certified Physician/Nurse Practitioner consultation in coordination with child's physicians and other health care providers
- Nurse visits to manage pain and other symptoms
- 24/7 support for questions and after-hours nursing visits for urgent needs
- Home delivery of all medications and equipment
- Hospice Home Health Aides who assist with care needs and light house keeping
- Social Worker to help families navigate the health system and connect to outside resources
- Child and Family Clinical Specialist to help the whole family adjust to illness and express emotions
- Chaplain for spiritual support, respecting all belief systems
- Grief Counselor who helps educate families on grief and loss
- Specially trained volunteers to assist with companionship, light housekeeping and errands

Capital Caring Kids: Inpatient Hospice

- When a child's needs go beyond what can be managed at home, we provide pediatric intensive inpatient symptom management one of our specialized units.
 - Washington, DC
 - Aldie, VA
- Each unit can accommodate overnight stays for family members.
- We also provide respite care for children in our inpatient units on a case-by-case basis for a limited number of days depending on availability.
- We have in-house "general inpatient care" (GIP) beds at INOVA FFX Children's Hospital and other locations.

Complex Care Coordination; Virtual Pediatric Consultative Rounds

- **Regional Virtual Pediatric Consultative Rounds** led by our Capital Caring Kids Pediatric Clinical Supervisor and leadership team
- **A seamless program between in-patient and community-based care:**
 - **Bi-weekly virtual rounds coordinate care with pediatric specialists** from Children's National Medical Center and INOVA FFX .
 - Provides a platform for collaborating with specialists elsewhere
 - Improves communication among providers and provides expert consultation based on best practice in unique pediatric cases.
 - **Assures family everyone is on the same page**
- **Virtual Rounds have led to:**
 - Improved pain and symptom management
 - Fewer hospitalizations

Capital Caring Kids Referral Process

- Contact Capital Caring Kids Team at **703-213-7902** to begin referral process with a verbal discussion.
- Fax the following referral documents to 703-485-0926 ATTN Pediatric Patient on cover sheet OR send consult through EPIC.
 - Demographic Sheet
 - History and physical
 - Most recent clinic notes
 - Order for hospice or palliative care consult
- Within a 24-hour window of receiving a referral, the Capital Caring Kids Team will schedule a time to meet to discuss goals of care for family and determine if concurrent hospice or palliative care is appropriate.

Resources

- Beveridge, Christiana & Vesel, Tamara. From Fear to Confidence: Changing Provider's Attitudes about Pediatric Palliative and Hospice Care. *J Pain Symptom Manage*. 2018 Aug; 56(2) 205-214 DOI:<https://doi.org/10.1016/j.jpainsymman.2018.03.019>
- Dingfield, L., Bender, L., Harris, P., Newport, K., Hoover-Regan, M., Feudtner, C., Clifford, S., & Casarett, D. (2015). Comparison of pediatric and adult hospice patients using electronic medical record data from nine hospices in the united states, 2008-2012. *Journal of palliative medicine*, 18(2), 120-126. <https://doi.org/10.1089/jpm.2014.0195>
- Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington (DC): National Academies Press (US); 2015 Mar 19. Appendix F, Pediatric End-of-Life and Palliative Care: Epidemiology and Health Service Use. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK285690/>
- Goldman, L. (2014). *Life & loss: a guide to help grieving children*. New York: Routledge.
- Huitt, W., & Hummel, J. (2003). *Piaget's theory of cognitive development*. *Educational Psychology Interactive*. Retrieved from <http://chiron.valdosta.edu/whuitt/col/cogsys/piaget.html>
- Johnson K, Allen KE, West W, Williams-Kirkwood W, Wasilewski-Masker K, Escoffery C, Brock KE. Strengths, Gaps, and Opportunities: Results of a Statewide Community Needs Assessment of Pediatric Palliative Care and Hospice Resources. *J Pain Symptom Manage*. 2020 Sep;60(3):512-521.e7. doi: 10.1016/j.jpainsymman.2020.04.009. Epub 2020 Apr 20. PMID: 32325166
- Knapp, C. A. & Contro, N. (2009). *Family Support Services in Pediatric Palliative Care*. *American Journal of Hospice & Palliative Medicine*, 26(6), 476-482.
- Lindley LC, Shaw SL. Who are the children using hospice care?. *J Spec Pediatr Nurs*. 2014;19(4):308-315. doi:10.1111/jspn.12085

Resources

- Lindley LC. Health Care Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis. *J Hosp Palliat Nurs*. 2011;13(2):81-88. doi:10.1097/NJH.0b013e318202e308Dingfield, L., Bender, L., Harris, P., Newport, K., Hoover-Regan, M., Feudtner, C., Clifford, S., & Casarett, D. (2015). Comparison of pediatric and adult hospice patients using electronic medical record data from nine hospices in the united states, 2008-2012. *Journal of palliative medicine*, 18(2), 120-126. <https://doi.org/10.1089/jpm.2014.0195>
- National Hospice and Palliative Care Organization (2020). NHPCO Facts and Figures 2020 Edition. Retrieved from <https://www.nhpc.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf>
- National Hospice and Palliative Care Organization (2019). NHPCO Pediatric Facts and Figures. Retrieved from https://www.nhpc.org/wp-content/uploads/2019/04/Pediatric_Facts-Figures-1.pdf
- National Hospice and Palliative Care Organization (2019). Concurrent Care for Children, Implementation Tool Kit. https://www.nhpc.org/wp-content/uploads/2019/06/CCCR_Appendix1.pdf
- National Hospice and Palliative Care Organization. Pediatric Concurrent Care; Standards of Practice for Pediatric Palliative Care. Retrieved from <https://www.nhpc.org/palliative-care-overview/pediatric-palliative-and-hospice-care/pediatric-concurrent-care/concurrent-care-for-children/>
- McLeod, S. A. (2018). *Erik Erikson's stages of psychosocial development*. Retrieved from <https://www.simplypsychology.org/Erik-Erikson.html>
- Pollin, I., & Kanaan, S. B. (1995). *Medical crisis counseling: Short-term therapy for long-term illness*. New York: W.W. Norton.
- Rogers, Fred. (2005). *Life's Journeys According to Mister Rogers: Things to Remember Along the Way*. New York: Family Communications, Inc.