

# Complex Care for *Your Child*



# *When a Child Has an Advanced Illness*

Every child is precious, and every moment with them matters. At Capital Caring Kids, 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.

We offer comprehensive non-hospice palliative care as well as hospice care for children in Virginia, Washington, DC and southern counties in Maryland.



# *Surrounding Families with Care and Support*

We support families from the time of your 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.

Our philosophy is to care for the entire family as serious illness has a profound impact on everyone who loves your child.

We help families sort through the difficult decisions regarding the scope of services and treatments and their impact on quality of life and the values of your child and family.

Palliative (advanced illness) care or hospice care may be an appropriate intervention for your child no matter where they are on their journey with illness.

## **Capital Caring Kids home services include:**

- Board certified Physician/Nurse Practitioner consultation in coordination with your 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



### Capital Caring Kid's home services include (continued):

- 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 also provides periodic respite care and pediatric intensive inpatient symptom management at our four specialized facilities which have accommodations for overnight stays for family members. Visitors are welcome.*

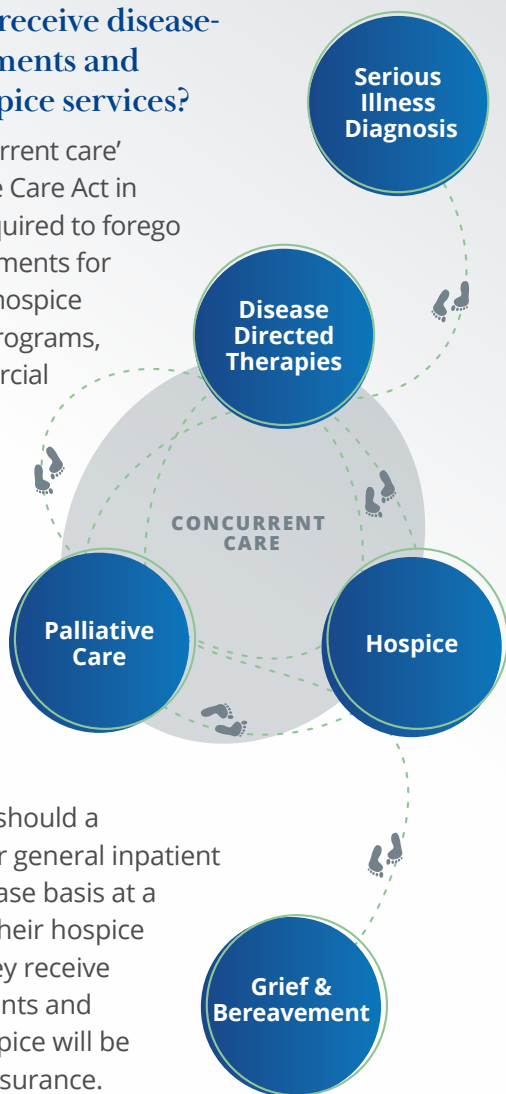
**With your family at the center of our care, we listen carefully to your needs and wishes while respecting your unique cultural and belief systems.**

### **Can my child continue to receive disease-directed, aggressive treatments and medications while on hospice services?**

With the adoption of the 'concurrent care' legislation under the Affordable Care Act in 2010, parents are no longer required to forego curative or life prolonging treatments for their children to be eligible for hospice benefits. Now state Medicaid programs, followed by most other commercial insurers, enable access to curative treatments and the full scope of hospice benefits.

Your child is able to continue any current treatment or medications and they are welcome to begin new treatments and medications while receiving palliative care or hospice care.

Your child can be hospitalized should a need arise. We are able to offer general inpatient care to children on a case-by-case basis at a growing number of hospitals so their hospice services can continue while they receive hospital care. Curative treatments and hospitalizations outside of hospice will be billed to your child's primary insurance.



## What is the difference between Capital Caring Kids palliative care and hospice care for my child?

Children with advanced illness surprise us every day and their needs can change rapidly. We offer a full spectrum of care, starting with pediatric palliative care given while a child has an unknown prognosis. Some children improve and “graduate” while others transition to hospice services.

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. 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 your child’s providers. Our Pediatric Social Workers make occasional visits for support and connection to outside resources. We bill your insurance directly for individual palliative care visits.

Children on our palliative care service may transition to our hospice service if your family and medical team decide that this is the most appropriate course based on the trajectory of your child’s illness.

Our hospice service is intended for children whose life expectancy is six months or less even while your child continues to receive disease-directed treatment. Hospice service includes comprehensive support from our entire interdisciplinary team including a Physician, a Pediatric Nurse, Social Worker, Chaplain, and Nurse’s Aide. Your child’s dedicated pediatric nurse will visit at least once every two weeks to ensure your child’s needs are met. Additional team members visit based on the goals you’ve set for your child and the acuity of your needs.

## How do I know if my child is ready for hospice?

Your infant, child, teen or young adult may be ready for Capital Caring Kids hospice if they have been diagnosed with a life-limiting illness even if they are continuing to receive curative

treatment. If you, your child or your child's doctor feel that this is the right time for hospice, you can request a free evaluation by calling 703.213.7902. Many families are relieved to experience the support we can offer—often earlier than expected.

## **Where or when does your care take place?**

Our care takes place in your child's home. Many families with critically-ill children have several appointments to go to and other family needs to meet. One of the benefits of hospice is that we come to you around your schedule. However, if your child's needs cannot be managed in the home setting, we offer temporary symptom management at one of our inpatient units.

Our pediatric team is committed to working around your schedule and will be available for evening and weekend visits if needed. Our visit schedule is based on your child's plan of care and we adjust based on the ever-changing needs of your child and family.

We also offer innovative telehealth remote patient monitoring devices that include a Bluetooth-enabled tablet to record basic vital signs and medication usage. While not a replacement for in-person visits, this technology allows us to provide video-assisted visits to address issues such as pain and symptom management at any time without the need for internet services.

## **Who pays for Capital Caring Kids services?**

Benefits are paid by your child's insurance on a per diem basis and include all visits and services. 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 cost of care, with small contractual co-payments as outlined in your plan. If you have insufficient funds or no payer source, our Pediatric Patient Care Fund may be able to provide financial assistance based on your financial status. When your child is referred to our program, our Financial Case Managers will verify your child's hospice benefit and our team will assist you to make arrangements where necessary.

“A couple of years ago, we knew that major medical interventions were no longer possible for our son, it was just too much for his body. Being home, being cared for at home, is the best for him. Capital Caring Kids has been facilitating, coordinating and helping to care for our son since that moment. They have been the conduit to our son’s doctors and specialists. They help coordinate medical equipment and medications. Most importantly, the Capital Caring Kids staff is there for us, at any moment of any day, addressing our concerns, fears, medical needs and just about anything else.”

— Carrie Jenkins, Mother of Brayden



We serve all families within our diverse community and no one is turned away due to their inability to pay. Our Pediatric Care Fund ensures that every child and their family has access to our compassionate hospice care.

**We still wish to pursue all interventions including CPR. Are we still able to receive hospice care from Capital Caring Kids?**

Yes. With you and your child at the center of care, we respect and honor the decisions regarding your child's care.

**Once my child is on your service, will we still be able to see our pediatrician and other specialists?**

Hospice is an added layer of support for your child at home. We focus on understanding your individual needs, addressing your unique situation, and treating pain and other symptoms. Our staff is an enhancement to, not a replacement for, the care your child currently receives from others.

**Do children ever improve and get discharged from your care?**

Yes. It is our sincere hope that your child's illness stabilizes and can transition to our palliative care service so we can continue to monitor their progress and coordinate care with their other providers.

We are here to walk alongside you and your child for as long as it takes to ensure that they are finding meaning in every minute they are with us.

# *Complex Care Coordination for Your Child*

Capital Caring Kids hosts Virtual Pediatric Consultative Rounds led by our Capital Caring Kids Pediatrician. These weekly rounds allow us to coordinate the pediatric patients' care with children's specialists from Children's National Medical Center, INOVA and other pediatric providers across the region.

This complex care coordination improves communication among providers and provides expert consultation based on best practice for specific pediatric needs. Since initiating these virtual rounds, our patients have experienced improved pain and symptom management and have required fewer hospitalizations.

## **How do we help all of your children adjust to the serious illness and its impact on our family?**

Play is the universal language of childhood and especially important to children who are confined by their illness and the siblings who have often had to adjust their lives in a big way. We offer interactive play opportunities through our Child and Family Services Team and integrative therapy staff. Children and teens are encouraged to connect with their families to express their wishes and process their emotions through art, music, movement and imagination often alleviating pain and anxiety. Our therapy staff help children create lasting memories through hand and footprints, specialty jewelry and individualized art projects so their legacy and wishes are beautifully captured.

Our Social Workers help your child and family cope with emotional and practical issues of dealing with a serious illness, including keeping them connected to their school community for education and socialization. Spirituality is an important part of every child's life and our Chaplains help sick children and their siblings find meaning and purpose in the midst of illness and end of life.

We offer massage, acupuncture, professional photography, interpersonal healing, and pet therapy for your child and family at no cost to nurture your family along your journey with a seriously ill child.

**Sometimes we need a moment to ourselves as caring for a seriously ill child can be overwhelming. How can you help with that?**

Capital Caring Kids has a group of pediatric specialized volunteers available to offer companionship, assistance, and support for families. Our volunteers are able to help with light housekeeping tasks and can visit with your child while you take some time for yourself or run errands. Respite care at one of our four inpatient units is also available upon request.

**We would like to travel with our child to make meaningful memories. How do we continue to have the care we need?**

We are happy to set up a travel contract with a hospice at your travel destination so your child's hospice benefits can continue while you travel with them. We believe that travel is a key component of memory making and encourage you to take advantage of this service. If your family relocates, we will connect you to a palliative care or hospice organization to continue care for your child.

**I have learned that my baby will be born with a serious illness, can Capital Caring Kids help us?**

Yes. Capital Caring Kids is committed to providing support for families who have learned that their unborn child has a life-limiting illness. In addition to connecting our pediatrician with your obstetrician and specialists for birth planning, we can offer emotional and spiritual support. When your child is born, we will help you adjust to your child's condition and continue to provide care for your newborn and support you and your family no matter how long your child is with us.

# *Inpatient Hospice Services*

When your child's needs go beyond what can be managed at home, we provide pediatric intensive inpatient symptom management at our four specialized units. 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. This will give you time for self-care, time with your family or the ability to travel.

## **Can we tour the inpatient unit before we send our child for inpatient care?**

Yes, we believe it's important for you to tour our inpatient unit and get to know our staff before your child's stay. Your child's pediatric RN will share your child's routine with our inpatient unit staff to make sure your child's comfort needs are met.

## **What will it be like for my child during a respite stay?**

Our inpatient units feature private rooms with full bathroom in a setting that is comfortable and inviting for your child's stay. We have a gaming system, TV and DVD players available for our pediatric patients. Every effort is made to welcome your child including themed blankets and décor based on your child's wishes.

## **Can I accompany my child during a respite stay?**

Yes. Though it is not required, some parents choose to stay for a portion of their child's visit. There is a single bed chair in each room to accommodate an overnight stay for one parent.

## **May I travel outside the region while my child is having a respite stay?**

Yes, you are welcome to travel while your child is in our respite care.

## **What will I need to provide for my child during a respite stay?**

You will need to bring medications, equipment and supplies, special dietary items and comfortable clothing and pajamas. We encourage you to also send your child's favorite comfort item.



# *For Medical Providers*

## **General Guidelines for Palliative Care**

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.

## **General Guidelines for Hospice Care**

A child diagnosed with a chronic, progressive illness may be eligible for hospice if any of the following are present:

- 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"

**To initiate a referral for Capital Caring Kids care please fax the following information to 571.389.6832:**

- Order for concurrent care consult
- Demographic Sheet
- History and Physical
- Most recent clinic notes

Please ask a member of your team to contact the pediatric team directly at 703.213.7902 to discuss the case and ensure clinical documentation has been received for further follow-up.

# *Capital Caring Kids Team*



**Dr. David Steinhorn**  
*Pediatric Palliative and  
Hospice Physician,  
Capital Caring Kids*



**Dr. Catalina Ruiz-Mesa**  
*Pediatric Palliative and  
Hospice Physician,  
Capital Caring Kids*



**Allison Kuchar**  
*Director of Pediatric  
Care Coordination*

Questions or to access care:  
703.213.7902

[capitalcaring.org/children](https://capitalcaring.org/children)



3180 Fairview Park Drive, Suite 500  
Falls Church, VA 22042

[capitalcaring.org](https://capitalcaring.org)