

Pediatric Care during a Pandemic

Background: Established in 1977, Capital Caring Health (CCH) is one of the nation's largest non-profit hospice providers with one of the top pediatric programs. CCH offers hospice and palliative care for both adults and children, along with additional programs for seniors such as Primary Care at Home, Stay-at-Home Services and special offerings for military veterans. Altogether, CCH cares for an average of 2,000 patients each day through 10 different communities in the District of Columbia, Maryland and Virginia. Each year, it provides approximately \$3 million worth of charity care to families in need.

Capital Caring Kids (Pediatric Care): Palliative and hospice care for children can be provided simultaneously with care designed to cure disease or prolong life. Called concurrent care, 20 percent of CCH pediatric patients live longer with hospice's extra layer of care and support.

Fortunately, the need for pediatric palliative and hospice care is far less common than for adults. CCH typically has a daily census of 25 pediatric patients (approximately 50-70 patients total each year). With COVID-19, hospital referrals to home hospice have increased dramatically due to risk of infection to children at end of life and strict restrictions on family visits. CCH now averages 3-4 new patients weekly—more than double our previous average—with a daily census of up to 36. Over the next 2 to 3 months, CCH expects to care for up to 30 additional pediatric patients.

Approximately 80 percent of new patients have high-tech medical needs requiring home delivery and set up of mini-pediatric intensive care units with ventilators, feeding systems and more. Many families have no insurance or inadequate coverage, are low-income, and may be food-insecure due to recent job loss. Many of the children also require disease-specific special diets which cost more and require more advanced preparation.

Adapting to Pandemic Restrictions: Hospice care is by nature in-person and hands-on with specially-trained care team members including nurses, social workers and volunteers offering compassionate medical care, emotional support and practical help in the home.

With COVID-19 restrictions and concerns, only the initial assessment, weekly case manager visit, and visits for urgent needs may be made in-person. All other care and support is now being provided virtually or over the phone. Tele-health devices will monitor vital signs automatically; the Bluetooth-enabled tablets permit virtual conference check-in with real-time access and support. Counseling is available virtually or by phone; in-person pediatric support groups where kids meet their peers—temporarily suspended—will resume online in May.

Responding to COVID-19--More Patients, More Families in Need: A dramatic increase in pediatric patient referrals, greater financial needs of families, and the new services necessitated by COVID (tele-health, for instance) call for a substantial increase in resources to cover program costs. CCH is currently seeking institutional and individual donors including in-kind support for pediatric care costs including, but not limited, to:

- Delivery of at least two customized meals daily for those in need
- High-tech medical equipment for those with little or no insurance coverage
- Purchase and placement of tablets for tele-health remote patient monitoring, family video conferencing, remote care coordination and emotional support
- Purchase and delivery of custom Meaning Making Kits to support the emotional and recreational needs of sick children

Capital Caring Kids has an overall fundraising goal of \$200,000 to cover additional pediatric hospice care costs such as the care, support and services described above. To make a donation and learn more about specific donor opportunities for individuals and institutions, please contact Tara Hoit, Director of Children's Programs at thoit@capitalcaring.org or 540-295-7223.