

The Harriet Lane Compassionate Care Program: *Providing interdisciplinary pediatric palliative care in Baltimore*

The Challenge:

Pediatric palliative care is an under-funded and often overlooked element of the U.S. health care system. (Palliative care reduces or relieves pain from serious illness regardless of the diagnosis or prognosis. Although it can be part of hospice care, it also can be provided to those with non-terminal conditions – and includes physical, mental, emotional, and spiritual support for the patient and their family.)

Goal:

Improve interdisciplinary care for children living with life threatening conditions and for their families through education, clinical practice and research.

Where To Learn More

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An Innovative Solution:

A nurse-directed holistic approach to interdisciplinary, pediatric palliative care at the Johns Hopkins Children's Center in Baltimore.

What It Is

- The Johns Hopkins Children's Center (JHCC) program serves dying children and those with life threatening conditions – and their families – and coordinating and supporting the interdisciplinary work of teams of health care professionals. (At JHCC, 120-130 children die each year.)

What It Does

- Provides education, support and renewal with a unique focus on building confidence and competence in interdisciplinary health care professionals.
- Dr. Cynda Hylton Rushton and her colleagues focus on developing innovative, experiential education and support systems, including regular debriefings with professionals after each death. The program also includes an 85-member interdisciplinary network and an interdisciplinary leadership Committee.

Edge Runners



How It Stands Out

- One of the first pediatric palliative care programs in the country and uniquely led by a doctorally-prepared nurse.
- Monthly palliative care rounds on areas with frequent deaths and a palliative care series for residents have made participation in a variety of palliative care planning processes routine.
- The team facilitates or participates in 20-30 interdisciplinary patient care conferences per year on the most complex patients. Other changes from conventional care include weekly care planning conferences between pediatric critical care and oncology, a neonatal ICU resources team, and regular palliative care clinical rounds to identify infants with unmet palliative care needs.
- Staff debriefings are offered after each patient death; formal debriefing sessions are provided 2-3 times a month.
- The bereavement program serves more than 250 families each year. Examples of the services provided include: support groups for siblings as well as parents and grandparents, annual retreats for families, referrals and resource provision, including funeral assistance, and follow-up for families for two years after a child dies. Annual tribute and memorial services for families and health care team members honor patients who have died.
- Though a collaborative program with the Maryland Community Hospice the Harriet Lane Compassionate Center (HLCC) medical director provides medical oversight for pediatric patients.
- The HLCC team now is preparing a grant proposal to a private foundation for a demonstration project that will provide integrated pediatric palliative care services to infants in the first year of life.