

Rounding Third: Bringing Pediatric Palliative Care Home

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Background:

Community Based Pediatric Palliative Care (CBPPC) is a much needed resource in communities throughout the country. Raleigh, NC has three level 1 children's hospitals within a 15 mile radius, two of which have inpatient pediatric palliative care teams. However, there were no hospices that served pediatric patients in the Raleigh/Durham Triangle prior to 2015. In September 2015, Transitions LifeCare started the Transitions Kids (TK) program and began providing hospice care, both at home and in the inpatient hospice unit, to pediatric patients. Over the first year the TK program has developed a care model that meets not just the needs of children at end of life, but the needs of any child, and their family, who are facing a life limiting or life threatening illness. The following are the three most valuable lessons learned in the development and growth of the program.

Funding

CBPPC Does Not Generate Revenue

- Philanthropic support is essential for a successful and sustainable program.
- States that have successfully implemented concurrent care sometimes have funding or partnership to support CBPPC, however generally this is not enough to run fully staffed CBPPC programs.

Funding is Not an Insurmountable Barrier

- The TK program is fortunate to have an excellent VP of Development who has been instrumental in securing sustainable funding.
- If your organization has a development or foundation department, use them.
- If your organization doesn't have one, don't despair. Anyone can raise funds for a pediatric program. TK's Development VP is skillful not because she creates money out of thin air, but because she learns the community and goes to where the money is.
- People want to donate money to sick and dying children, they just need to be pointed in the right direction.



Partnerships Are Essential

- A large part of TK's success is due to the partnerships that have been established with providers and teams within the three local hospitals.
- Search out advocate partners within the community. Start small, only one or two are needed initially.
- One of the most valuable partnerships TK has created is with a local funeral home. They provide all services to TK families at no cost. Beyond the financial aspect, the care and consideration they give families provides comfort and confidence not just to families but to the TK staff as well.

Collaboration

Be Creative and Have Patience

Innovation

- The way the TK program looks a year after its inception is barely recognizable to its beginning.
- Learning from successes and challenges and making changes in real time is essential.
- There is no idea too crazy. The only way to be a leader and innovator is to think outside the box. Then jump into another box and think outside of that one too.

Patience

- Even if change happens quickly, the acceptance of change does not. Sick children often make people uncomfortable. Dying children are unspeakable to many. Even within a hospice or palliative care organization, people often do not want to participate in anything dealing with children.
- Reinforce the goals of palliative and hospice care being available across the life continuum.
- Support staff with education and reinforce importance of mission. Repeat.

