



## Creating a Community Network of Support for Children with Life-Threatening Conditions and Their Families

In 2002, the Institute of Medicine published a report “When Children Die: Improving Palliative and End-of-Life Care for Children and their Families.” This groundbreaking study revealed that community-based care coordination was a fundamental step to providing comprehensive pediatric palliative care. The study highlighted fear of abandonment and isolation, especially during a child’s long illness, as a major concern to chronically ill or dying children and their families.

Children’s Hospice and Palliative Care Coalition has developed such a program which seeks to mitigate this problem and reassure the parents and child of the continued involvement and support of caring skilled clinicians and community throughout the child’s life, as well as after death. This community-based care coordination program is the cornerstone for a comprehensive pediatric palliative care benefit that is being developed in California.<sup>1</sup> What follows are their strategies for creating a community network of support:

1. **Build a Village:** When a child is diagnosed with a life-threatening condition, it impacts the entire family — mom, dad, brother, sister, grandparents — and quickly ripples out into the community at large. Assess what services are available in your community. Among the questions to ask:

- What home health and/or hospice agencies are currently caring for seriously ill children in your area?
- What community-based organizations currently provide the children and their families with emotional, psychosocial, spiritual, practical, and/or financial support?

Once you have a list of community resources, consider hosting a forum to discuss how together as a community you can work more collaboratively to support the families.

2. **Replicate Don’t Duplicate:** With limited resources and time, it is important for partners in the care community to collaborate and share information with one another. Duplicative programs and services are an inefficient use of the community’s limited resources and can create confusion and distress among community partners. This duplication is also confusing for families and can create unnecessary stress and at times undue hardship on the very families we are looking to serve.
3. **The Key is Communication:** Good community-based care is rooted in good communication — so create systems through which community partners can stay connected. Options include monthly conference calls, e-mail and/or phone chain, and monthly or quarterly gatherings. When establishing a system of communication, make sure that you are well-versed and in compliance with current regulations related to patient privacy, i.e. HIPAA.

- 4. Speak the Language:** It is important that if we are going to walk the journey with the families we serve that we have a base understanding of the language which families are experiencing as they navigate the medical system. This can include medical terms describing a multitude of conditions (i.e. genetic, neurological), infections and side effects (neutropenia, anemia), clinical titles (intern, primary care physician), medical specialties (i.e. oncology, cardiology) and acronyms like H&P, History & Physical. Visit the Partnership for Parents website ([www.partnershipfoparents.org](http://www.partnershipfoparents.org)) for a list of common medical terminology.

Consider convening a forum of local clinicians and physicians from the children's hospital(s) to discuss the intricacies of the unique ways children navigate the healthcare system.

- 5. Circle the Wagons:** We often mean well by saying “call me if you need anything,” but the reality is that it is best to offer something specific you can and will do and then just do it. This is especially true when a family is dealing with a serious illness or a death. There are tangible things that individuals and the community-at-large can do to help ease their burden.

Visit [www.partneringforchildren.org](http://www.partneringforchildren.org), [www.sharethecare.org](http://www.sharethecare.org) or [www.project-compassion.org](http://www.project-compassion.org) for information on how to create a care giving circle or support team.

- 6. Keep Your Eye on the Goal:** Establish clear, concise, and measurable goals for your community-based care coordination efforts. Together, assess the needs of the families in your area and chart unmet or underserved community services and resources. This information will help you establish your goals and delineate the activities necessary to meet those goals. (i.e. *Goal:* build the capacity of traditionally adult focused providers to care for children. *Activities:* conduct a series of trainings in pediatric palliative care; establish a resource library)
- 7. Intention, Intention, Intention:** When difficulties arise (and they will) always go back to your original intention — to improve community-based care for seriously ill children and families. To quote Margaret Mead, “A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has.” Together, you can make a significant difference in the lives of the children and families in your community.
- 8. Memories Last a Lifetime:** Establish a coordinated system among community partners to connect with families during holidays and birthdays, mother's/father's days, etc. Notes and letters that continue over time are priceless. Don't worry about “reminding them of their child” they are already remembering and often grieving for their child during these milestones and will be comforted to know that their child is remembered by others.

For more information about coalition building, go to [www.caringinfo.org](http://www.caringinfo.org) (under ‘Community’).

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<sup>i</sup> The program, which is called Partnership for Children, currently serves children with life-threatening conditions living in Central California. For more information about the program's details and design, visit [www.childrenshospice.org](http://www.childrenshospice.org).