**Pediatric Palliative Care’s Value Proposition: Making the Case**

**The following document has been excerpted from the *Pediatric Palliative Care Field Guide* included in this Toolkit.**

**Pediatric Palliative Care is Unique and Essential**

There are [significant differences](http://www.wsj.com/articles/the-challenges-of-palliative-care-for-children-1424145655) in what constitutes effective palliative care for adults versus infants and children across a number of dimensions. Infants and children needing palliative care range in age from prenatal to young adult, and interdisciplinary PPC teams care for patients and families with wide-ranging diagnoses and disease trajectories, often for many years. PPC teams must involve parents in decision-making and are adept at addressing the diverse developmental stages of the children they serve. Perinatal palliative care has evolved to serve women with high-risk pregnancies and families in need of support after the diagnosis of a life-limiting condition in utero.

The [American Academy of Pediatrics recommends](http://pediatrics.aappublications.org/content/132/5/966) by expert consensus the initiation of PPC at diagnosis and its integration throughout the illness course to help improve quality of life (QOL), reduce suffering[[1]](#footnote-1) and support goals of care[[2]](#footnote-2) for the more than [400,000 pediatric patients and families](http://www.nationalacademies.org/hmd/Reports/2002/When-Children-Die-Improving-Palliative-and-End-of-Life-Care-for-Children-and-Their-Families.aspx) estimated to be living with life-threatening or serious health conditions in the US.[[3]](#footnote-3)

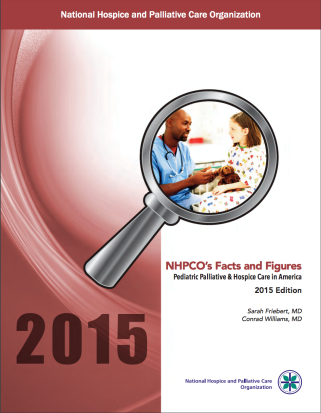
Given limitations in our data stratifying age and disease categories, it’s challenging to characterize with precision the full range of infants, children and families who might be appropriate or eligible for PPC services. Consequently, estimates of the population in need of PPC services vary widely.

Yet we do know that the numbers are sizeable:

* **Children with medical complexity are increasing in prevalence** because of increased survival rates of infants born prematurely, with congenital anomalies,and/or with chronic conditions, as well as improved treatments for acute illness in fields such as intensive careand oncology.[[4]](#footnote-4)
* **More than half of childhood deaths occur in infancy**, and approximately half to two-thirds of these deaths occur in the neonatal period – most due to congenital and chromosomal anomalies and/or prematurity. In 2014, the infant mortality rate was 5.82 infant deaths per 1,000 live births in the U.S.– a total of 23,215 deaths occurring in children under age 1 year.[[5]](#footnote-5)
* **Estimates on the prevalence of US children currently living with life threatening or chronic, complex conditions such as congenital and chromosomal abnormalities, diseases of the nervous system, or cancer, range from 400,000 and up, and** **more than 40,000 infants and children die annually**.[[6]](#footnote-6)
* **As many as 17 million adults are serving as caregivers to a seriously ill child.**[[7]](#footnote-7)

These statistics, and the stories behind them, underscore the priority of investment in PPC research, professional training, and program expansion that meet rising demand for high quality palliative care to support infants, children and families across all care settings and transitions.   
  
**Trends in Pediatric Serious Illness and Palliative Care**

[NHPCO's 2015 Facts & Figures Report](http://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf) on *Pediatric Palliative & Hospice Care in America* describes the current state of PPC in the US, identifies children who may be in need of support, and details existing gaps in service.

Some key trends detailed in the report:

It’s a useful go-to document for providers, payers, policy makers, funders and the media, summarizing information about epidemiology, eligibility for PPC services, program demographics, service availability and usage, payment models, and cost-related outcomes of PPC, referencing several seminal PPC studies and findings throughout.

→ **Children with chronic illness and complex health care needs are living longer**

* The overall prevalence of children with life-threatening conditions is increasing due to advances in pediatric medical/surgical care; meanwhile, the number of deaths in children with complex chronic conditions declined between 1989 and 2003.[[8]](#footnote-8)

→ **Numbers of children with special health care needs that could potentially benefit from PPC continue to increase**

* Approximately 27% of children with special health care needs have conditions that affect their activities usually, always or a great deal,[[9]](#footnote-9) and an estimated 8,600 children with complex chronic conditions are eligible for and would benefit from palliative care on any given day.[[10]](#footnote-10)

→ Growth in service capacity enables provision of grief and bereavement support services to patients and families affected by trauma or sudden serious illness and death, which account for about one-fourth of childhood deaths.

* PPC traditionally has served only the three-quarters of pediatric deaths classified as not preventable.[[11]](#footnote-11)

→ Parents who planned a location for their child’s death were more likely to be comfortable with that setting and less likely to have preferred a different location.[[12]](#footnote-12)

* The place where death occurs is not an appropriate quality of care indicator for PPC,[[13]](#footnote-13) and existing data do not currently indicate whether children are dying in their family’s preferred location.

→ PPC teams have increased over the past decade, but expansion is essential to include all [pediatric hospitals](https://www.childrenshospitals.org/Directories/Hospital-Directory), general hospitals where children are cared for, and [community-based care settings](http://www.ncbi.nlm.nih.gov/pubmed/25955682).

* Only about half of all US children’s hospitals have a PPC program; staff composition and services are highly variable.[[14]](#footnote-14)
* NHPCO’s 2013 national summary of hospice care showed that only about 14% of participating hospice agencies had formal PPC services with specialized staff.

**Messaging Matters**

**A. What’s in a name: Explaining Pediatric Palliative Care**

Using consistent and clear messages to explain PPC really matters. A [consumer research study](https://www.capc.org/media/filer_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care_237.pdf) commissioned by CAPC in 2011 revealed that 7 in 10 Americans are “not at all knowledgeable” about palliative care. Yet an overwhelming majority of people polled (92%) said that they would want palliative care for themselves or their loved ones and believe it should be accessible in our nation’s hospitals when it was explained using key messages that were developed through focus groups and interviews with patients and caregivers:

* Palliative care helps to provide the best possible quality of life for patients and their families.
* Palliative care helps patients and families manage the pain, symptoms, and stress of serious illness.
* Palliative care is a partnership of patient, all of the medical specialists, and family.
* Palliative care provides an extra layer of support for families and patients with serious illness.
* Palliative care is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

Ninety-two percent of respondents in the above study also said they believe patients should have access to this type of care at hospitals nationwide. Using these same consumer-derived messages to describe PPC, the American Childhood Cancer Organization informally surveyed its pediatric parent constituency in October 2014 to reveal [similar findings](http://meetinglibrary.asco.org/content/103464?media=vm&poster=1). Among 275 responding parents:

* **86%** would be likely to consider PPC for their child during cancer treatment

* **89%** think it’s important that PPC services are available in all hospitals caring for children

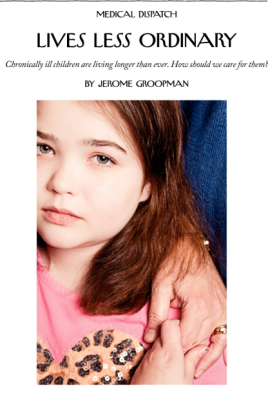
Not only does the term “palliative care” remain relatively unfamiliar to lay people, many clinicians still associate palliative care with terminal prognosis and believe it to be primarily useful near the very end of life. The erroneous association of palliative care with “giving up hope” or hospice remains one of the largest barriers preventing patients and families from accessing the benefits of palliative care. Using consistent messages from the consumer-driven research highlighted above can help the field address this [identity problem](http://www.nejm.org/doi/full/10.1056/nejmsb1305469).

A particularly poignant and relatable patient description of PPC appeared in *The New Yorker* ["Lives Less Ordinary"](http://lordfoundation.org/wp-content/uploads/2014/01/The-New-Yorker-_-Jan-20-2014.pdf) January 20, 2014 medical dispatch article by Jerome Groopman. Then 11 year-old Gwen Lorimier, cared for by the Boston Children’s Hospital and Dana-Farber Cancer Institute Pediatric Advanced Care Team (PACT), explained succinctly what PACT meant to her:

“It’s like when you’re filling in concrete.

The transplanters are the people who put the layer down, then PACT are the people who go after and fill the holes, so the whole thing doesn’t start to crumble.

But if it does start to crumble they’re the people who actually go with the hard hats and fix it.”



A related public radio interview featuring Drs. Groopman and Joanne Wolfe, “[Helping Chronically Ill Children](http://www.wbur.org/radioboston/2014/01/22/helping-chronically-ill-children),” describes the history behind the field’s emergence and expansion, highlighting effective messages about PPC benefits:

* PPC adds an extra layer of support to these children and their families, using an interdisciplinary team approach to provide holistic, compassionate, and individualized care.
* Through this partnership, PPC adds value not only to the children and families, but also to the multiple primary and subspecialty clinicians caring for them. A key part of PPC expertise involves knowing how to negotiate those complex waters to improve communication and collaboration to ultimately better care for the child and family.

[Courageous Parents Network](https://courageousparentsnetwork.org/) (CPN), an organization dedicated to bringing PPC everywhere, has created a powerful visual depicting PPC’s national reach that is updatable in real time as information is added. This [interactive map](https://courageousparentsnetwork.org/map/) helps families caring for a seriously ill child find others in their community in similar situations, as well as locate PPC professionals/services in their area.

PPC professionals can use the link below to add their individual and institutional information to the growing network of professionals and parents. Entering data takes just a couple minutes, and populating the map helps demonstrate how the field is making its mark on the national landscape. It is also a useful tool to help illustrate for institution administrators, policymakers, and potential funders the need for increased investment in PPC to extend the field’s reach.



Put PPC on the Map!

Use this link to [Join CPN network](https://community.courageousparentsnetwork.org/login) and put your institution/yourself on the PPC network national map



The CPN website is a superb resource to share with families. The table below features other helpful resources available to explain PPC to families, professional colleagues, and any other audience interested in PPC principles, themes, or resources.

|  |  |  |
| --- | --- | --- |
| Organization | Resource description | Links |
| National Institute for Nursing Research Palliative Care: Conversations Matter® Campaign | NINR developed these web resources to raise awareness of and improve communications and understanding about PPC | [Conversations matter campaign materials](http://www.ninr.nih.gov/newsandinformation/conversationsmatter/conversations-matter-newportal#.V7zzn2Xnvdk) for health care providers and for families that have children living with serious illnesses  [Spanish campaign materials](https://www.ninr.nih.gov/newsandinformation/conversationsmatter/cuidados-portal#.V7z0dGXnvdl) |
|  |  |  |
| Courageous Parents Network | CPN provides web and mobile resources that educate and support parents caring for seriously ill children, providing on demand access to coping tools, community, and resources that promote family resilience | [Provider resources](https://courageousparentsnetwork.org/providers/)  [Free CME Module on PPC for pediatric practitioners](https://media.capc.org/filer_public/0b/61/0b616f5d-84db-4730-b131-474a11951806/courageous_parents_network_peds_cme_course_flyer.pdf) One hour on demand course includes 4 sections plus parent perspectives: What is Pediatric Palliative Care; Advanced Care Planning; Initiating Difficult Conversations; Transitioning to End-of-Life/Bereavement  [Online video library](https://staging.courageousparentsnetwork.org/video-library/)  includes 260+ videos of parents talking about their experiences and of therapists addressing end-of-life issues – helpful for parent support and as teaching tools for clinicians  [Guides for Parents](https://courageousparentsnetwork.org/guides/) topics include helping siblings cope; navigating the hospital; parent self care; strengthening parenting partnership |
|  |  |  |
| Get Palliative Care | CAPC’s consumer-focused website provides specific content explaining PPC, its definition, benefits, and more | [Pediatric palliative care information for families](https://getpalliativecare.org/whatis/pediatric/)  [Distinctions: adult and pediatric palliative care](https://getpalliativecare.org/whatis/pediatric/adult-vs-pediatric-palliative-care/)  [PPC team members](https://getpalliativecare.org/whatis/pediatric/the-pediatric-palliative-care-team/) |
|  |  |  |
| American Childhood Cancer Organization (ACCO) “Parent’s Guide to Enhancing Quality of Life in Children with Cancer” | Written by PPC experts and with parents’ personal perspectives, this 261-page paperback is available to families for free through ACCO | [Parent's QOL Guide order info](http://www.acco.org/books/)  **Healing happens here.** For families facing childhood cancer, consider recommending camp! [Care camps map](https://koacarecamps.org/camps-map/) or [Children's Oncology Camps locator list](http://www.cocai.org/index.php/cocai-camps/cb-user-list) |
|  |  |  |
| National Hospice and Palliative Care Organization | NHPCO website information and support for families about advance care planning, talking with child about serious illness, talking with doctors, caregiving, hospice and palliative care, grief and loss | [Brochures for families - in English and Spanish](http://www.nhpco.org/childrenspediatricschipps/brochures-families) – print on demand free pediatric-focused resources series that is part of NHPCO’s [Caring Info](http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1) program |
|  |  |  |
| PerinatalHospice.org | Website with professional information and resources for parents facing pregnancy affected by a life-limiting diagnosis | [Perinatal PC caregiver resources](http://www.perinatalhospice.org/resources-for-caregivers.html)  [Perinatal PC resources for parents](http://www.perinatalhospice.org/resources-for-parents.html)  [List of US and International Programs](http://www.perinatalhospice.org/list-of-programs.html) |

**B. PPC Delivers Value That Warrants Focused Investment**

Palliative care has become one of the [fastest growing medical specialties](https://reportcard.capc.org/) in the United States, spurred by its ability to meet patients and families where they are and to accompany them as they move through the labyrinth that is a serious illness. This approach demonstrably and measurably improves care quality and clinical outcomes – and by helping patients and families avert the need for 911 calls and repeated hospitalization, it also reduces costs – benefits recognized by hospital administrators, policymakers, payers, and providers for their value in achieving the Institute for Healthcare Improvement’s [Triple Aim Framework](http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx) to improve the patient experience of care and health of populations while reducing the per capita cost of health care.

PPC can use this momentum in the broader field to also expand its reach.

With increasing health system focus on value-based care and associated payment reforms, communicating about PPC and its benefits to various audiences is becoming a bigger part of every inter-professional clinician’s job. Successfully embedding PPC services into organizational culture will take effective advocacy, backed by evidence, to support staffing and resource requests required to meet current PPC program needs and foster future growth potential.

**Philanthropic support continues to be the fundamental funding stream supporting PPC, which is neither a sufficient nor sustainable model.** The sections below feature resources available to help build and make the business case for PPC programs, including evidence-based talking points the field can use as a consistent message to expand and amplify understanding of PPC’s ability to improve quality and meet the triple aim in the context of caring for infants, children and families. The advocacy section of this field guide identifies public policy and coalition activities currently underway to help address these system-level shortfalls.

Pitch Points: PPC Helps Deliver the Best Care Possible Aligned with Achieving the Triple Aim

* **PPC provides an evidence-based solution supporting QOL and improved clinical outcomes** for seriously ill infants, children and families throughout the care continuum,[[15]](#footnote-15) [[16]](#footnote-16) [[17]](#footnote-17) including improving the likelihood that children and families have fun and enjoy experiences that add meaning to life.[[18]](#footnote-18)
* **Provision of PPC improves patient and family experience and satisfaction**, helps reduce parent caregiver burden, reduces needless hospital admissions through effective care coordination and symptom management, and **through these gains in quality, also reduces costs.**[[19]](#footnote-19) [[20]](#footnote-20)
* **PPC programs are becoming more common in children’s hospitals** but most programs only offer inpatient services, and most only during the workweek.[[21]](#footnote-21) Many are now also expanding to provide perinatal palliative care services.[[22]](#footnote-22)
* **Despite this steady program expansion, millions of infants and children in the US still lack access to quality PPC** from the point of diagnosis throughout the course of illness, and PPC team staffing and capacity vary tremendously.22
* **Resources for PPC program development and** [**fellowship training**](http://aahpm.org/uploads/membership/communities/Pediatric_Palliative_Care_Fellowships_and_Pediatric_Tracks_updated_5-6-15.pdf) **of the next generation are essential** to build teams and their capacity to improve care quality for infants, children and families.
* **Outpatient and community-based PPC services are just beginning to develop.**[[23]](#footnote-23) [[24]](#footnote-24) Investment in building community-based PPC is essential to bridge from hospital to home.
* **PPC research funding lags far behind** **what is invested in adult palliative care.** Outside of pain, there are relatively few studies that can guide clinicians in the treatment of common symptoms in children (e.g., fatigue, nausea, breathlessness, anxiety, depression). Key research priorities for PPC have been identified.[[25]](#footnote-25) [[26]](#footnote-26)
* **Educating and training all pediatric professionals in pain and symptom management, communication, and care coordination is also important** so that all clinicians caring for children with serious illness and their families in the community and hospitals have a uniform set of core (“generalist”) palliative care knowledge and skills, and refer to PPC specialty teams for the more complicated or nuanced situations.[[27]](#footnote-27)

1. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol.* 2008;26(10):1717-1723. [↑](#footnote-ref-1)
2. American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. Pediatrics 2013; 132:966-72. [↑](#footnote-ref-2)
3. Field JF, Behrman RE. When children die: Improving palliative and end-of-life care for children and their families. Washington, DC: National Academies Press; 2003. [↑](#footnote-ref-3)
4. Cohen E, Kuo DZ, Agrawal R, et al. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics.* 2011;127(3):529-538. [↑](#footnote-ref-4)
5. KD Kochanek, SL Murphy, J Xu, B Tejada-Vera. Centers for Disease Control and Prevention National Center for Vital Statistics. Deaths: Final Data for 2014 (65) 4 (June 30, 2016). <http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_04.pdf> [↑](#footnote-ref-5)
6. J Xu, SL Murphy, KD Kochanek, and BA Bastian. Centers for Disease Control and Prevention. Deaths: Final Data for 2013 (64) 2 (February 16, 2016). Available at: <http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf> [↑](#footnote-ref-6)
7. Kuhlthau K. Kahn R. Hill KS. Gnanasekaran S. Ettner SL. The wellbeing of parental caregivers of children with activity limitations. Matern Child Health J. 2010;14(2):155–63. [↑](#footnote-ref-7)
8. Feudtner C, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. JAMA 2007; 297(24): 2725-32. [↑](#footnote-ref-8)
9. US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2009-2010. Rockville, Maryland: US Department of Health and Human Services. [↑](#footnote-ref-9)
10. National Hospice and Palliative Care Organization. ChiPPS White Paper: A call for change: recommendations to improve the care of children living with life-threatening conditions. October 2001 [↑](#footnote-ref-10)
11. Osterman MJ, et al. Annual summary of vital statistics: 2012-2013. Pediatrics 2015; 135(6). [↑](#footnote-ref-11)
12. Dussel V, et al. Looking beyond where children die: determinants and effects of planning a child’s location of death. JPSM 2009; 37(1):33-42. [↑](#footnote-ref-12)
13. American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. Pediatrics 2013; 132:966-72. [↑](#footnote-ref-13)
14. Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric palliative care programs in children’s hospitals: a cross-sectional national survey. Pediatrics 2013; 132(6):1063-70. [↑](#footnote-ref-14)
15. Wolfe, J, Hammel, JF, Edwards, KE, et al. (2008). Easing of suffering in children with cancer at the end of life: Is care changing? Journal of Clinical Oncology, 26(10), 1717–1723. [↑](#footnote-ref-15)
16. Hays, RM, Valentine, J, Haynes, G, et al. (2006). The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. Journal of Palliative Medicine, 9(3), 716–728. [↑](#footnote-ref-16)
17. Gans D, Hadler MW, Chen X, et al. Impact of a pediatric palliative care program on the caregiver experience. J Hosp Palliat Nurs 2015;17:559-565. [↑](#footnote-ref-17)
18. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med. [↑](#footnote-ref-18)
19. Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *JPSM 2016 (in press)* DOI: <http://dx.doi.org/10.1016/j.jpainsymman.2016.02.020> [↑](#footnote-ref-19)
20. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. *J Palliat Med.* 2014;17(2):183-188. [↑](#footnote-ref-20)
21. Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric palliative care programs in children’s hospitals: a cross-sectional national survey. Pediatrics. 2013 Dec;132(6):1063-70. [↑](#footnote-ref-21)
22. Denney-Koelsch E, Black BP, Cote-Arsenault D, Wool C, Kim S, Kavanaugh K. A Survey of Perinatal Palliative Care Programs in the United States: Structure, Processes, and Outcomes. *J Palliat Med.* 2016. [↑](#footnote-ref-22)
23. Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE. Pediatric palliative care in the community. *CA: A Cancer Journal for Clinicians.* 2015;65(4):315-333. [↑](#footnote-ref-23)
24. Rabow MW, O’Riordan DL, Pantilat SZ. A statewide survey of adult and pediatric outpatient palliative care services. J Palliat Med. 2014;17(12):1311-1316. [↑](#footnote-ref-24)
25. Ullrich C, Morrison RS. Pediatric Palliative Care Research Comes of Age: What We Stand To Learn from Children with Life-Threatening Illness. *J Palliat Med.* 2013;16(4):334-336. [↑](#footnote-ref-25)
26. Baker JN, Levine DR, Hinds PS, et al. Research Priorities in Pediatric Palliative Care. *The Journal of Pediatrics.* 2015;167(2):467-470. [↑](#footnote-ref-26)
27. Quill TE, Abernethy AP. Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. *New England Journal of Medicine.* 2013; 368(13): 1173-1175. [↑](#footnote-ref-27)