

Putting Pediatric Palliative Care in Prime Time

Benefits, Value Proposition, Messaging, and Resources

Starter Statement

Modern medicine has helped thousands of seriously ill infants and children live longer lives.

Pediatric Palliative Care (PPC) is essential to bring the same level of attention to the **quality** of these longer lives – for both the affected children and their families.



Putting Pediatric Palliative Care in Prime Time

PALLIATIVE CARE VALUE PROPOSITION

Drawing on a Decisive Moment

- Health system facing unprecedented growth of an aging population, and seriously ill adults, infants, and children are living longer with complex conditions
- Documented failure to recognize and treat pain and other distressing symptoms
- Exponential cost increases in care without improved value
- Value-based care is taking over as the new mantra while MACRA implementation starts taking hold
- Dissatisfaction and confusion about medical care and the health system

What if we intensify our focus on what matters to people?

Palliative care is an essential
health care innovation

Palliative Care is a Solution

It delivers on the IHI triple aim framework:

- Improves quality of life and prognostic understanding
 - ✓ Relieves pain, distress, uncertainty
 - ✓ Helps clarify and address patient and family goals and associated treatment preferences
- Strengthens communication, decision-making and family satisfaction/well-being
- Coordinates medical and practical needs across settings
- Reduces resource utilization and costs by matching treatment to patient and family goals



Describing palliative care

Palliative care is a team-based specialty devoted to **improving quality of life** for seriously ill patients and families through:

- Expert pain and symptom management
- Skilled communication about what matters most to patients and their families
- Well-coordinated care over the course of illness

Palliative care = quality care

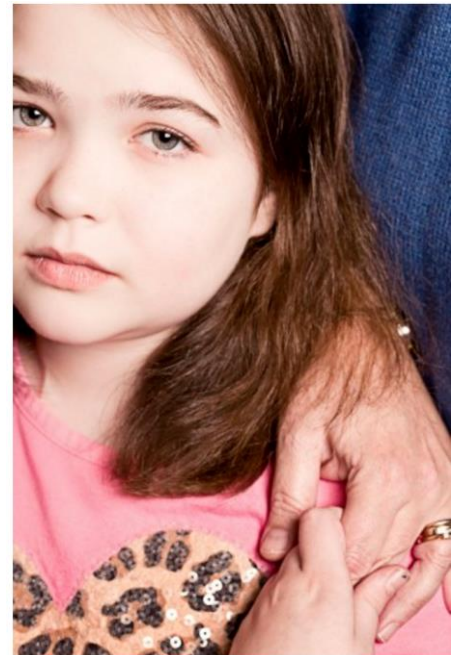
It's an essential aspect of providing the **best care possible at any age**, and should be delivered at the same time as curative or disease directed treatments.

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

The transplanters are the people who put the layer down, then palliative care 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.”

- Gwen Lorimer, *The New Yorker* Jan 2014



Bring Palliative Care Everywhere

- It's one of the fastest growing healthcare specialties for adult care in the US
- It's imperative to bring these same benefits to all seriously ill infants, children and families
- It's got to be reliably available in all the settings where children and families need care – inpatient, outpatient, home



PPC Improves Outcomes

- Helps parents and children have a voice in identifying and realizing their care goals – essential to improved quality of life, experience and satisfaction
- Enhances well-being, strength, and resilience – all required to have the reserve to undergo disease-directed treatment successfully
- Makes it more likely that seriously ill children and their families have fun and meaning

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.

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.

Shown Also To Reduce Costs

California Home-Based PPC Pilot Findings:

- High satisfaction scores from caregivers – improved children's pain and other symptoms and parents' own experience and quality of life
- Health care cost savings of \$3,331 PEPM
- Most savings were realized through a dramatic reduction in inpatient costs of \$4897 PEPM
- Enrollees experienced a nearly 50% reduction in average number of inpatient days per month (dropped from 4.2 to 2.3)
- Average LOS per hospitalization dropped from average 16.7 days before enrollment to 6.5 days while in the program
- Overall savings totaled nearly \$7 million. Pilot data spanned Jan 2010 to Dec 2012



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.

Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *J Pain Symptom Manage*. 2016;52(3):329-335.

Sizeable Numbers Need PPC

- Infants and children with medical complexity are increasing in prevalence
- Childhood deaths in US total 40,000 annually, and more than half occur in infancy
- Estimates on numbers of US children currently living with complex conditions range from 400,000 and up
- As many as 17 million adults are caregivers for a seriously ill child

Caring for Infants and Children: Unique Qualities and Challenges

- Patients' ages range from infants to young adults
- Present with wide-ranging diagnoses, developmental stages and symptom burden
- Course of care may stretch many months or years, and also supports siblings, parents and extended family
- Parents are integrally involved in decisions in best interest of child with child's involvement in process increasing with age

Who delivers it? Everyone



Generalist palliative care

Basic symptom management and communication all clinicians should provide to achieve goal concordant treatment and QOL

Specialized team consultation

For more complex cases – refractory symptoms, challenging care planning and communication

TE Quill and AP Abernathy. Generalist plus Specialist Palliative Care —
Creating a More Sustainable Model. N Engl J Med 2013; 368:1173-1175

Action step: Prioritize professional education and training in primary palliative care core competencies for all clinicians

- Communication skills (prognosis, goals of care, transitions)
- Pain & symptom management
- Sensitivity to cultural and spiritual beliefs
- Grief and bereavement care

The Challenges of Palliative Care for Children

So much about treating seriously ill children is different from caring for adults



Addressing barriers to implementing PPC in practice:

- **Improve communication** about what it is and its benefits
- **Align research and resources** with patient and family needs
- **Build specialist and generalist workforce through training**
- **Expand access to services in all settings**, including community-based (e.g., outpatient and home) where most seriously ill children receive care

EFFECTIVE MESSAGING ABOUT PALLIATIVE CARE

What's in a name? Messaging matters.

Palliative care...

Focuses on relieving symptoms, pain and stress of serious illness.

Improves quality of life for both patient and family.

Provided by a team who works with a patient's other doctors to **provide an extra layer of support.**

Appropriate at **any age and any stage** and can be provided **along with curative treatment.**

People Want Palliative Care:

95% say education is important for patients & their families about palliative care options available to them as part of treatment.

92% report they would be likely to consider palliative care for themselves or their families if they had serious illness

92% also said they believe patients should have access to palliative care at hospitals nationwide

CAPC Public Opinion Strategies research and national survey of 800 adults age 18+ conducted June 2011.

Give parents the words to use

October 2014 American Childhood Cancer Organization online survey (n=275 parents) used these same messages:

- **86%** would be likely to consider PPC for their child during cancer treatment
- **89%** think its important that PPC services are available in all hospitals caring for children

Q: Considering this definition, how likely, if at all, would you be to consider pediatric palliative care for your child during cancer treatment?

Not too likely	2%
Undecided	9%
Somewhat likely	14%
Very likely	72%

Q: How important do you think it is that designated pediatric palliative care services be made available at all hospitals in the U.S. caring for children with cancer and their families?

Not too important	1%
Undecided	8%
Somewhat important	12%
Very important	77%

Helping chronically ill children

- PPC adds an extra layer of support for seriously ill 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 complex care waters by improving communication and collaboration to deliver better care for the child and family.

Hope has many constellations

“Once I found out we were dealing with EOL care, I did have hope.

Hope changes along the continuum.

When hope for a cure went out the window, then we hoped for a more sound, humane, and less painful death.

Empowerment and communication go hand in hand.”

Victoria Sardi-Brown
Mattie’s Mother
Mattie Miracle Cancer Foundation



EXPAND INTEGRATED PROGRAMS AND ACCESS

PPC Access Affirmation

American Academy of Pediatrics

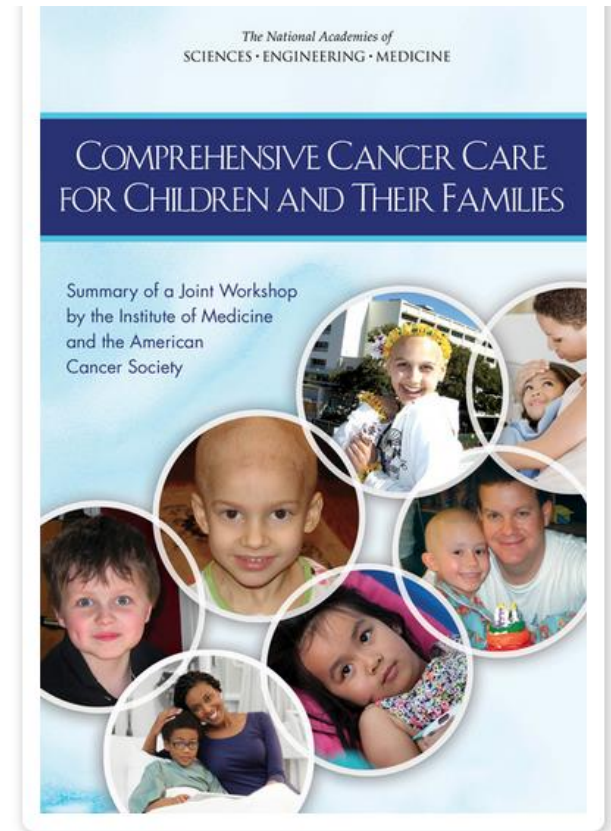
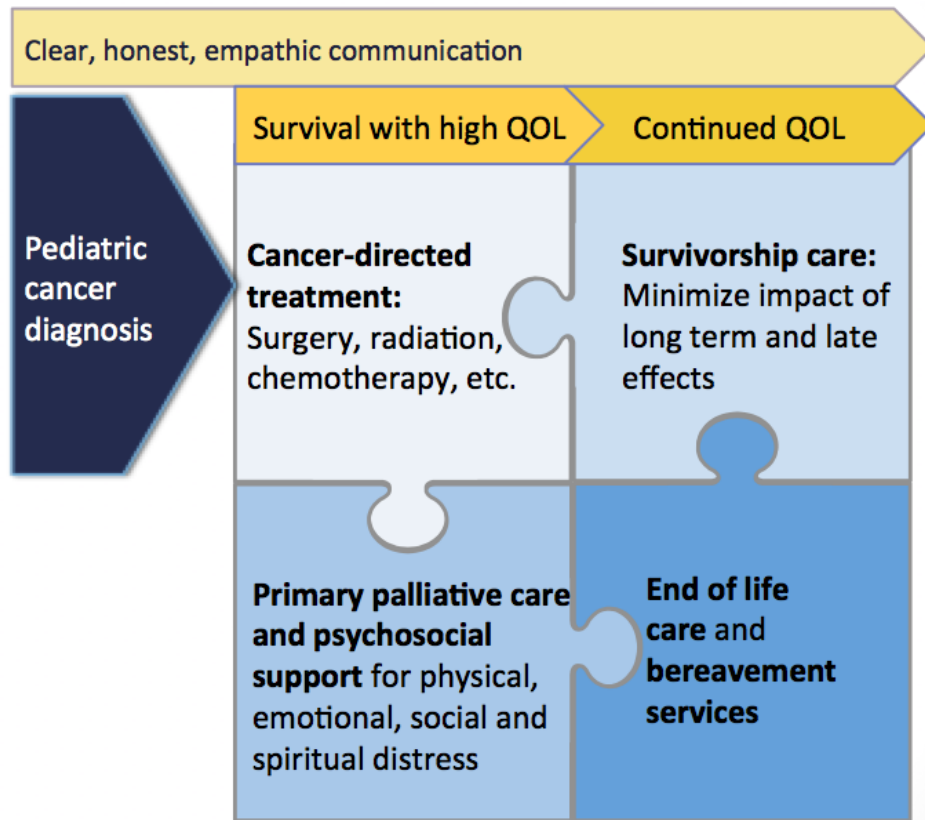
DEDICATED TO THE HEALTH OF ALL CHILDREN™



Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations (October 2013)

- **PPC is an essential aspect of medical care** for patients who have life-threatening conditions or need end-of-life care
- **All clinicians should provide basic palliative care** initiated at diagnosis and consult PPC-PHC specialists in a timely manner to deliver “collaborative integrated multimodal care” (i.e., concurrent curative care)

Comprehensive Cancer Care



Kirch R, Reaman G, Feudtner C, et al. Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps. *CA: A Cancer Journal for Clinicians* 2016 Sep;66(5):398-407.

Rising number of PPC teams

PPC 2013 cross-sectional national survey revealed that 69% of children's hospitals have a team (112/162)
(Feudtner et al. Pediatrics 2013)

BUT...

- Nearly one-third hospitals still lack PPC
- Most only offer inpatient service during work week and are highly dependent on hospital funding
- Need to also expand community-based access and develop sustainable financial models
- Number of consults annually varied substantially across programs, positively associated with hospital bed size and number of funded staff

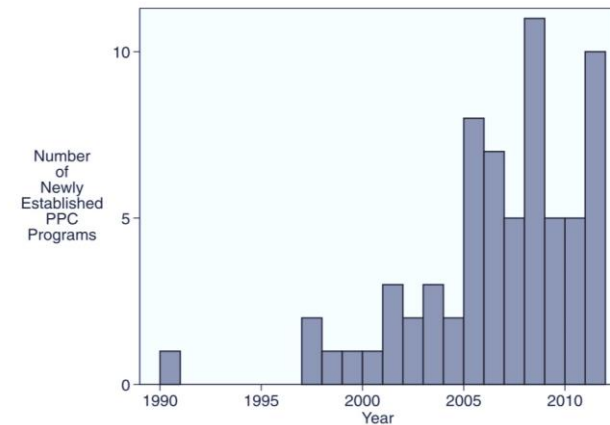
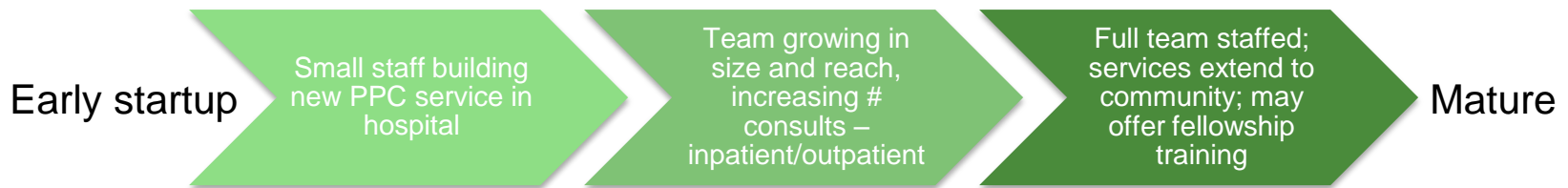


FIGURE 2
Establishment of new hospital-based PPC programs over time.

Culture of Quality



To ensure quality and safety, PPC teams should strive to:

- Include physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists, and child life specialists
- Have an adequate number of dedicated, trained staff who are available for consultation 24-7 and are paid specifically to provide PPC
- Bridge their consultative activities across multiple physical locations to support patients, ranging from provision of services in homes or schools to clinics, hospitals, and other partnering facilities
- Conduct ongoing quality improvement reviews and projects aimed at improving patient and family experiences and outcomes

(AAP Guidelines, Pediatrics 2013)

ADDITIONAL RESOURCES

New PPC Resources Field Guide



CAPC PPC Field Guide digital tool includes links to key info from multiple organizations and sources covering:

- PPC's Value Proposition: Making the Case
- Building and Expanding Integrated Programs
- Collaboration with the Research Community
- Advocacy for System Level Change



Access PPC Field Guide at www.capc.org

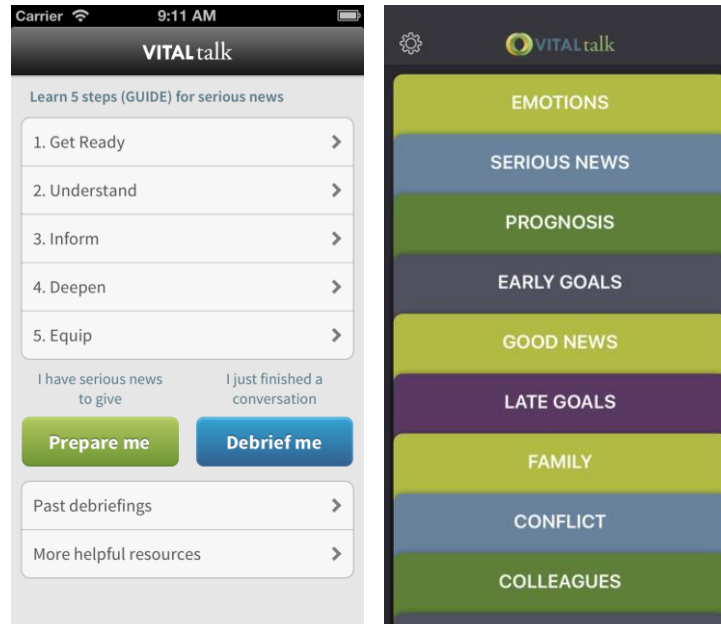
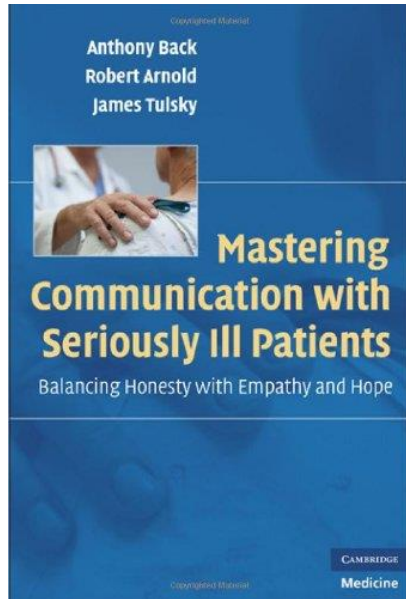
New CAPC PPC Content

- **This slide deck and field guide** – use these to update your colleagues and other audiences
- **National Palliative Care Registry** includes PPC-specific reports capacity to compare programs

capc CENTRAL™


- **CAPC Pediatric Toolkit** online tools and technical assistance for CAPC members
- **PCLC-Pediatric** will be expanding to more sites with updated and expanded content in 2017

Skills Development Scaffolding



EPEC[®]
Education in Palliative and End-of-life Care

**Pediatrics Online
Communication & Planning**
Access at:
epec.net/epec_pediatrics.php

**ELNEC**
END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

**Pediatric Module 3 Online:
Communication in Pediatric
Palliative Care**
Access at:
www.reliaslearning.com/courses/elne-pediatric-module-3-communication-in-pediatric-palliative-care

CAPC's Communication Curriculum

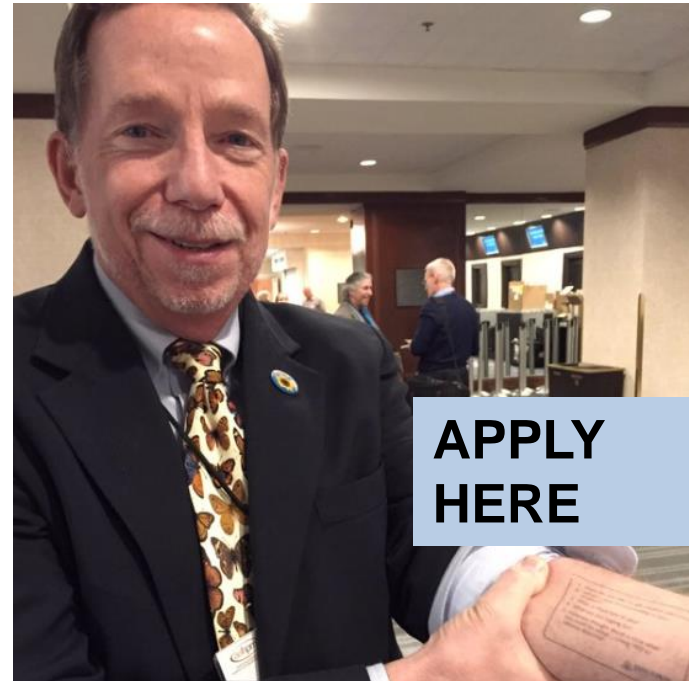
<https://www.capc.org/capc-central/courses/>

Access free online tools for clinicians
and faculty at www.vitaltalk.org

Always Ask Tattoo

Pick a Few QOL Cues:

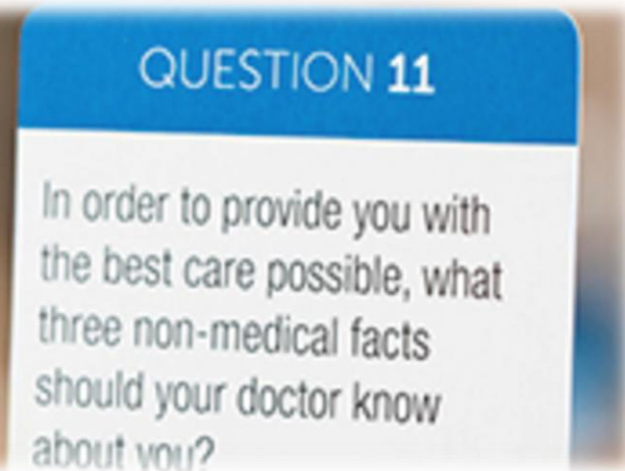
1. Tell me about your child as a person
2. How do you like to get medical information?
3. What is your understanding of your child's situation now?
4. **What is important to you?**
5. What are you hoping for/what are your worries?
6. Where do you find your strength/comfort?



Giving people the words to use



Transforming anxiety about dying into *conversations about living*



Access helpful videos and other info at common-practice.com

Rx: Playing the game creates a safe place for everyone to talk about QOL priorities and goals

Additional Resources



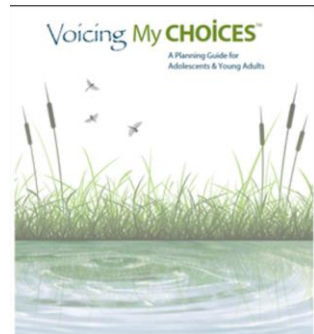
COURAGEOUS PARENTS NETWORK

Empowering parents caring for children with life-limiting illness.



**PALLIATIVE CARE
Conversations Matter®**

Easing symptoms and enhancing lives



- **Courageous Parents Network** (courageousparentsnetwork.org)
- **Get Palliative Care** consumer information (getpalliativecare.org/whatis/pediatric/)
- **Voicing My Choices** (agingwithdignity.org/shop/product-details/voicing-my-choices)
- **NIH/NINR Conversations Matter** campaign (ninr.nih.gov/newsandinformation/conversationsmatter/pccm-about-7-2015#.Vjktf66rRPM)
- **Parent's Guide to Enhancing QOL** in Children with Cancer family handbook (acc.org)

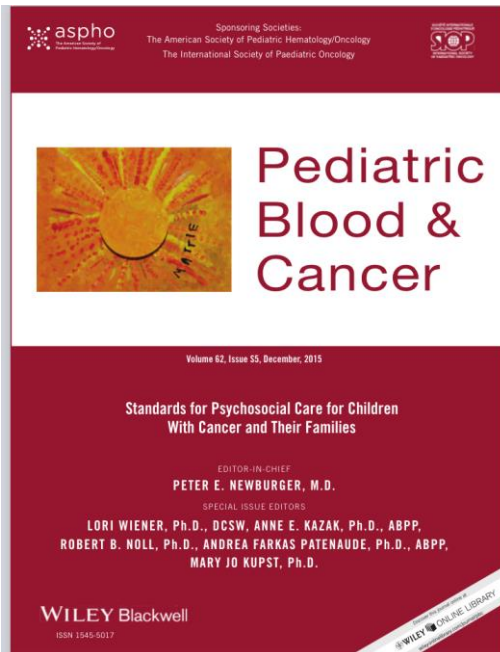
**GET PALLIATIVE
CARE**

capc Center to Advance Palliative Care

Psychosocial Care Standards

15 STANDARDS OF CARE

<http://www.mattiemiracle.com/downloadstandards>



1. Psychosocial Assessment
2. Monitoring and Assessment of Neuropsychological Outcomes
3. Psychosocial Follow-Up in Survivorship
4. Psychosocial Interventions and Therapeutic Support
5. Assessment of Financial Burden
6. Standards of Psychosocial Care for Parents of Children with Cancer
7. Anticipatory Guidance and Psycho-education
8. Procedural Preparation and Support
9. Providing Children and Adolescents Opportunities for Social Interaction
10. Supporting Siblings
11. Academic Continuity and School Reentry Support
12. Assessing Medication Adherence
- 13. Palliative Care**
14. Bereavement Follow-Up After the Death of a Child
15. Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology

Link to full issue:

http://www.mattiemiracle.com/?utm_campaign=2016%2BMay%2BNewsletter&utm_medium=email&utm_source=Mattie%2BMiracle%2BMay%2BNewsletter%2B2016#!downloadstandards/c1dja

Care Camps: Healing happens here



“It’s a lot of fun
once you get
here, and you feel
like you’ve never
had cancer.”

— Hannah Zarr
Age 12



Care camps = a powerful palliative care prescription that boosts QOL for children, families, *and health professionals*

Camp locator map:

<http://www.cocai.org/index.php/component/geofactory/?view=map&id=4>

Insurance Coverage and Financial Assistance Advocacy



Families can contact PAF at 1-800-532-5274 or [email an online case manager directly](#)

- 200 caring case managers provide individualized and sustained services by phone
- Active liaisons between the patient or parent and their insurer, employer and/or creditors
- Free assistance to resolve insurance, job retention and/or debt crisis matters