

Pediatric Palliative Care

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for Children[™]

Agenda

- Philosophy of Pediatric Palliative Care
- Understanding carepoints in pediatric neurology
- Serious communication tools
- Useful language when the news is bad
- Useful experience from other pediatric specialties
- Resources for symptom management
- Meaning making for family and provider
- Template for a family-centered review of autopsy results

A black and white photograph showing a woman and a young child sitting on a lawn. The woman is on the right, wearing a dark, long-sleeved top and a light-colored skirt, looking towards the child. The child is on the left, wearing a light-colored dress with dark sleeves, gesturing with their hands. They are sitting on a patterned blanket or rug. In the background, there is a large tree with broad leaves, possibly a magnolia, and a grassy lawn. The overall mood is peaceful and intimate.

The First Question

What is palliative care?

Charon and the River Styx



Hospice



Palliative care....

The art and science of lessening physical, psychosocial, emotional, and existential suffering.

A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions



Who is eligible for
palliative care?

Any child not expected
to survive to adulthood

And when?

From time of diagnosis

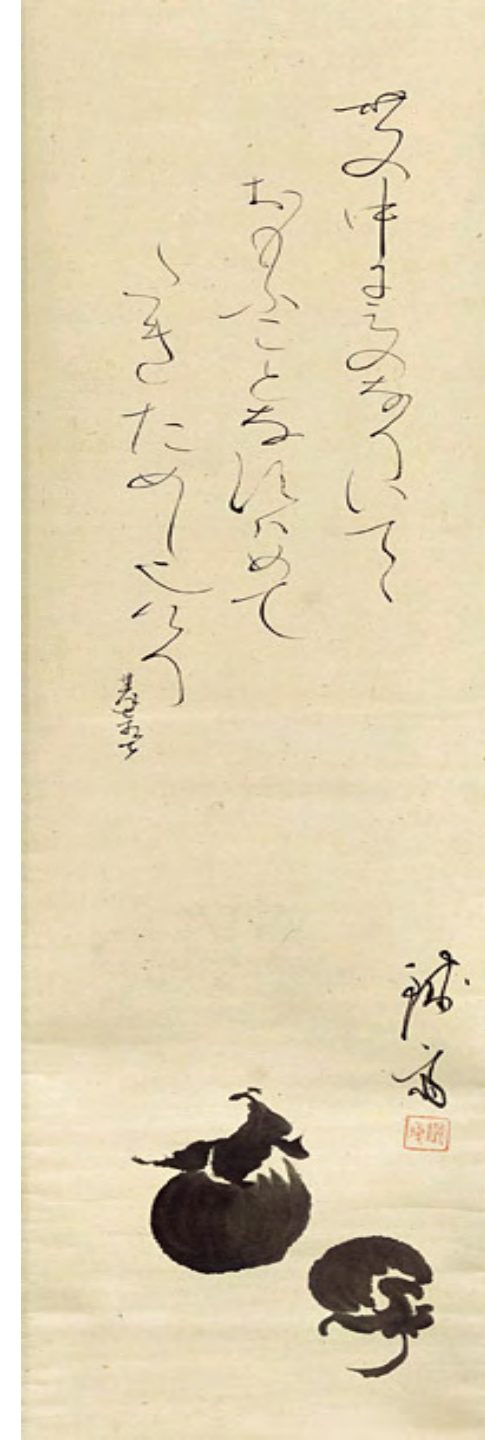
American Academy of Pediatrics

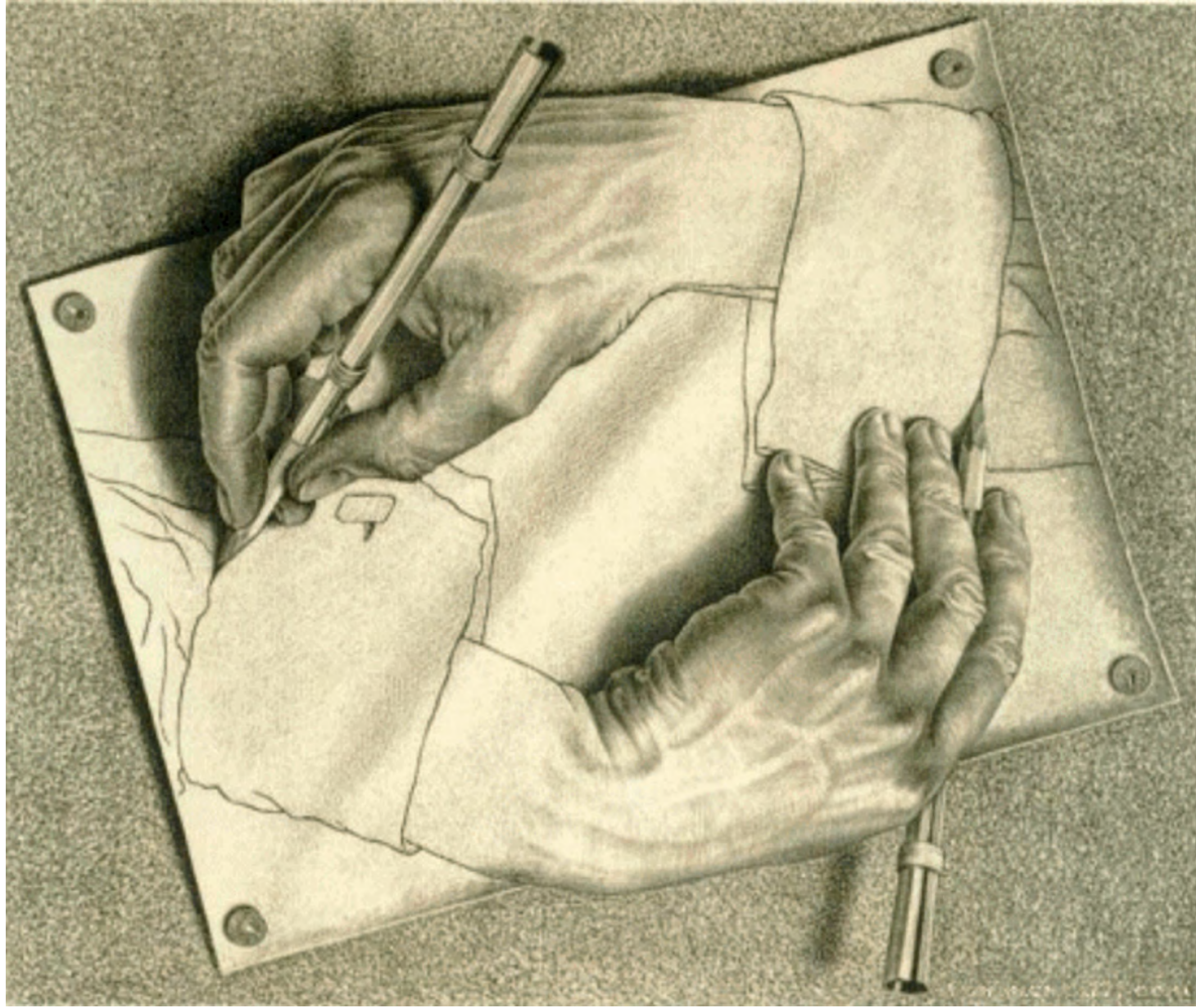


Pediatric palliative care puts all our medical
knowledge and technology
to the service of enhancing
a child's joy, autonomy, comfort,
safety, and meaning.



Family-centered
Interdisciplinary
Goal directed
Based on patient experience
Calls for creative reframing





Consider involving Pallcare...

- When a child faces a lifespan limiting condition
- When symptoms are interfering with quality of life
- When you recognize there are some things you can't fix
- When a change in health status prompts a review and potential reprioritizing of goals



Consider involving Pallcare...

- When the family or health care team would like help interpreting goals or choices
- When the family or health care team would like the space to consider goals other than curative without having the sense that they are giving up



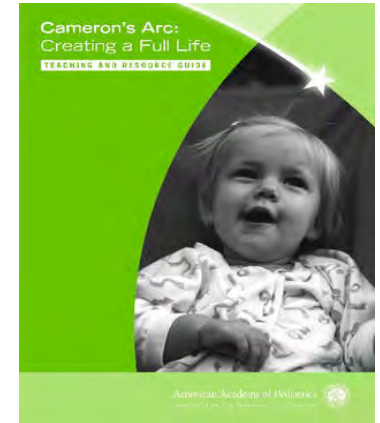
Palliative care

lets the child's spirit

shine through..



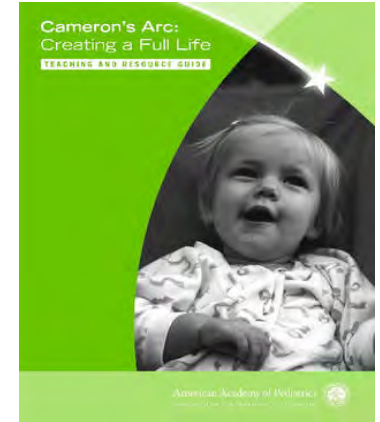
Carepoints: from “Cameron’s Arc”



Carepoints are junctures in care when:

- An unmet need is recognized
- The need is met by timely provision of the appropriate resources

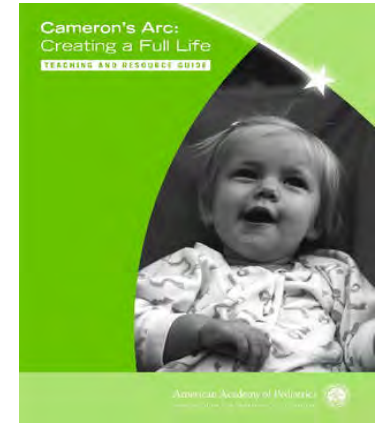
Carepoints: from “Cameron’s Arc”



Some examples:

- Breaking the news of a diagnosis
- Building a team around a child with a lifespan limiting condition
- Discussing life-extending treatments
- Giving anticipatory guidance about end of life care

Carepoints: Delivering the diagnosis



- Be conscious of the waiting period of uncertainty
- Describe beforehand what will happen at the meeting
- Ask family whom they would like present
- Understand the tempo of information flow, for 1/3 of parents less than 50% retention
- Prepare yourself--what makes it tolerable for you when you are giving what feels like a “death sentence”

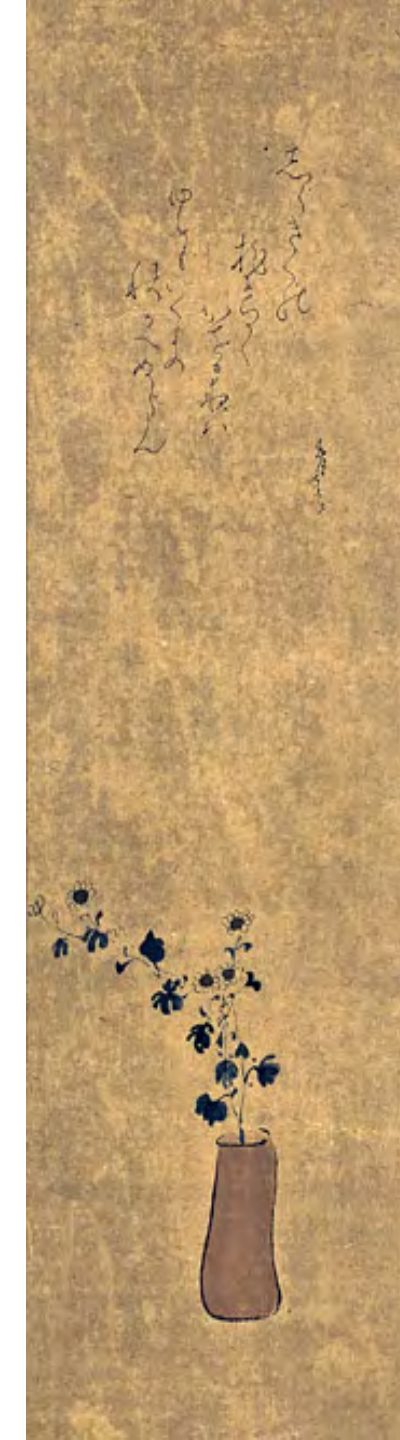
SPIKES Tool

1. Setting	Find a quiet location, private if possible Invite the important people to be present Have tissues available Have enough chairs Turn off the ringer on your phone/pager
2. Perception – what the patient knows already	“Tell me what you understand about your illness.” “What have the other doctors told you about your illness?” Look for knowledge and emotional information while the patient responds
3. Invitation – information sharing preferences	“Would it be okay for me to discuss the results of your tests with you now?” “How do you prefer to discuss medical information in your family?” “Some people prefer a global picture of what is happening and others like all the details, what do you prefer?”

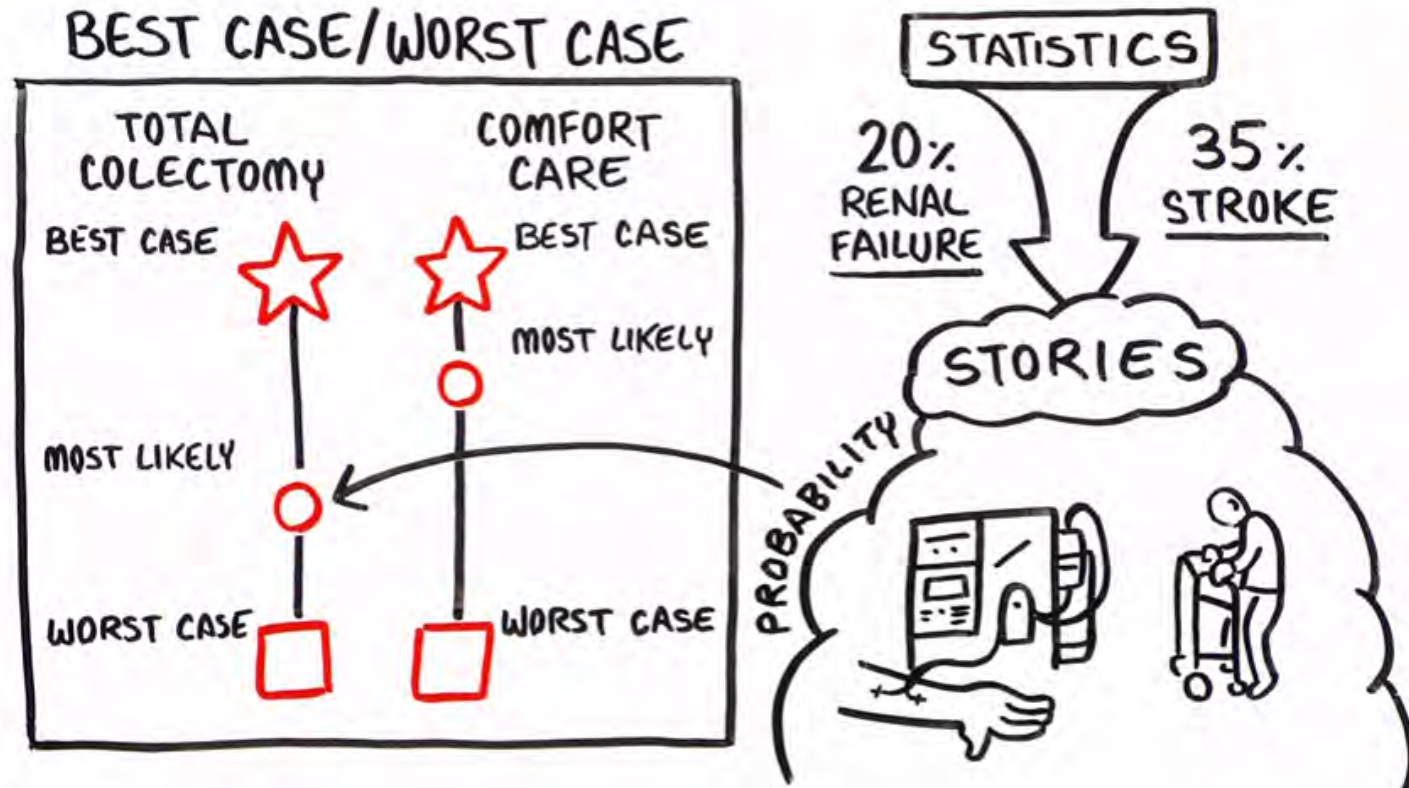


SPIKES Tool

4. Knowledge – give the information	Give a warning... “I have something serious we need to discuss” Avoid medical jargon. Say it simply and stop. (e.g. “Your cancer has spread to your liver. It is getting worse despite our treatments.”)
5. Empathy – respond to emotion	Wait quietly for the patient. “I know this is not what you expected to hear today.” “This is very difficult news.”
6. Summary – discuss next steps and follow up plan	“We’ve talked about a lot of things today, can you please tell me what you understand.” “Let’s set up a follow-up appointment.”



Best Case/Worst Case Tool



Kruser, J. M., Nabozny, M. J., Steffens, N. M., Brasel, K. J., Campbell, T. C., Gaines, M. E., & Schwarze, M. L. (2015). "Best Case/Worst Case": Qualitative evaluation of a novel communication tool for difficult in-the-moment surgical decisions. *Journal of the American Geriatrics Society*, 63(9), 1805–1811. <http://doi.org/10.1111/jgs.13615>



Experience from Other Specialties

- Oncology: The Day One Talk, Mack and Grier
- Neonatology: The neonatal diagnosis experience, Skotko



Ways to Improve Parent Experience with Neonatal Diagnosis



Birth mother informed:

- By a physician
- As soon as possible, except in cases of maternal ill health
- With the partner present
- In a private place
- With the infant present

Continued...



- With provision of a private place for the parents directly after the conversation
- With the indication that a follow-up interview with the pediatrician would be arranged 24 hours later
- With as much time as needed for questions
- With the indication that a specialist would talk to the parents again as soon as they wanted

Skotko adds....

- Ability to connect with other families, website, resources
- Up to date information
- Positive comments
- Be aware of differences in providers' views

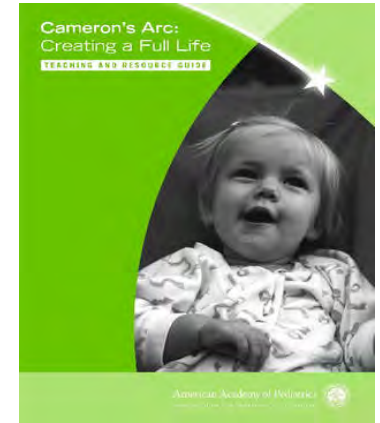


Different Provider Responses



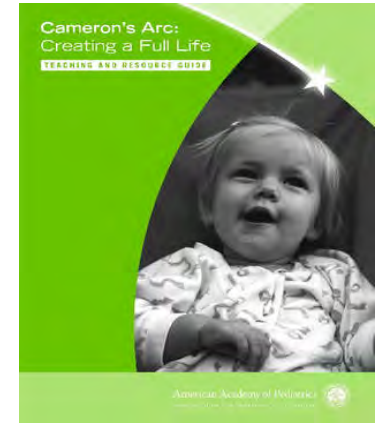
- “Having a baby with DS is a mother’s worst nightmare:” *L&D nurse to the mother*
- “Having a baby with DS is like a death in the family:” *Social worker to the father*
- “The baby is fine, but he has DS and his low Apgars are due to a cardiac defect”
DR anesthesiologist to the family outside

Carepoints: Building the team



- Line up specialists—pulmonary, GI, social service, physiatry, OT/PT, pallcare
- Identify resources, other families, websites, organizations
- Using the language of teambuilding— “we” not “you”

Carepoints: Determining the values that will guide care



- Envisioning a full life for the child
- Anticipate likely events beforehand, so they can be discussed as “what ifs”
- Imagining a good death
- Hope for the best, plan for the worst

Useful Language When the News is Bad

- Wishing
- Hoping
- Worries
- What ifs



Families as Experts



- Families of CLLNC become the experts, not only in their child, but often in the rare condition that afflicts their child
- They frequently have mastered a huge number of details and manage a bewildering array of medications, schedules, personnel
- Coming to the hospital is terrifying (“we know more than the hospital staff do”)
- Coming to the hospital is loss of control
- Coming to the hospital may be decrement in care

Resources for management of common symptoms



- PCNA volume 2007
- Websites
- Frameshift in goals: support feeding goals that are realistic and compassionate
- “A Life with Grace: Caring for Children Who Have Severe Neurological Impairment” by Julie M. Hauer, M.D.

Ways that the neurologist adds meaning...

- Validating the personhood of the child, even the neurologically devastated child
- Bearing witness to the suffering endured by the family, respecting their goals of care
- Recognizing carepoints as an opportunity to develop a deeper bond



Meaning making...

- Tissue banking and autopsy information regarding contribution to knowledge
- Continued contact after the death of the child, reflecting with family on what care of that child has meant to you



Template for autopsy review



- Medical facts—these are often what we are most fluent in and comfortable with
- What should I know to protect the rest of my family
- What should I call it to the casual friend or acquaintance
- What should I call it to the medical provider

Template for autopsy review

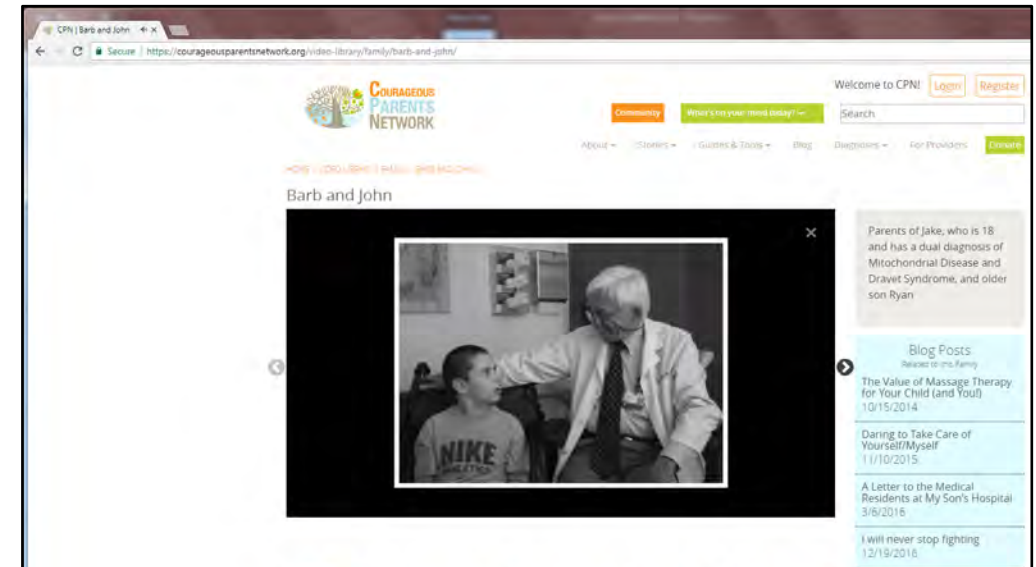


- Could I have done anything to prevent the condition
- Could we have done anything to prevent the child's death
- How will this information help other children and families
- Offer a written copy, and repeat visit to address any concerns raised by later readings of it

Some “must-sees” for the Pediatric Neurologist



- Cameron’s Arc
- Welcome to Holland
- The Day One Talk
- PCNA Volume on pallcare
 - Irritability
- Courageous Parents Network



Even if cure is not possible,
..healing is..



Thank You

