

Courageous Parents Network

A Palliative Care Resource for Every Pediatrician

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Every Pediatrician Does Palliative Care

You hold the long view

You follow these children, and their siblings, across years and across subspecialists.

Families learn from families

After their clinicians, caregivers trust other caregivers more than anyone. Pediatricians learn from families and hold their combined wisdom around coping and decision-making.

You're a shared decision-maker

Eliciting and applying values is the first step in discerning goals of care. Goals of care drive functional shared decision making.

Founded by a bereaved parent

Blyth Lord started CPN in 2014, thirteen years after her daughter and nephew died of infantile Tay-Sachs disease.

She drew on a career in television production and distance learning to put parent and clinician voices in front of families still in the thick of it.

What helped her family

- 1 A pediatrician who practiced palliative care
- 2 A grief counselor, during her child's life and after
- 3 A sense, from other families, of what lay ahead

To orient, equip and empower families caring for a child with a serious medical condition, and the clinicians who care for them



Education

Videos, podcasts, guides and curated topic pages, free and open around the clock



Community

Monthly “In the Room” events, a parent and clinician blog, hospital rounds presentations



Advocacy

Raising awareness of, and demand for, pediatric palliative care

WHO THEY ARE • AT A GLANCE

A free, curated library of lived experience

500+

Short videos and podcasts of parents, siblings, grandparents and clinicians

\$0

Free to families, open 24/7 on phone, tablet or computer

3

Curated initiatives: Medical Complexity, NeuroJourney, Coping with Loss

6

Languages on NeuroJourney, including Spanish and Arabic

Content is reviewed and vetted by a Medical Advisory Board; the governing board includes both parents and clinicians.

Built by parents and clinicians together

Staff (selected)

Blyth T. Lord, Executive Director; bereaved parent

Chrissy Salley, PhD, Director of Clinician Education; pediatric psychologist

Blair Young-Whitworth, Director of Family Education; parent of a child with a rare neurological condition

Laura Will, MSN, RN, Story Curation; nurse and parent

Board (selected)

Diane Meier, MD, Director Emeritus, Center to Advance Palliative Care

Becky Aures, MD, Pediatric Critical Care, Mass General Brigham for Children

Sarah Burnett, NP, Pediatric NP, St. Louis Children's Hospital

Also, parent advocates and leaders from law, finance and patient advocacy

How the site is organized

Three curated initiatives, each a guided path through the illness journey

Navigating Medical Complexity

Any serious condition, any diagnosis;
three phases and 23 topics

NeuroJourney

Severe neurological impairment:
medical and social-emotional content
across a life

Coping with Loss

For parents and families after a child
dies

Underneath, shared by all three

Media Library (search
everything)

Blog by parents and clinicians

Events: monthly “In the Room”

Clinicians / Educators portal

WALKTHROUGH 1

Navigating Medical Complexity

courageousparentsnetwork.org/medical-complexity

A journey map in three phases



Shaded = topics where a primary care pediatrician is often part of the conversation

Anatomy of a topic page: Baseline

1

Plain-language framing

Baseline as a “new normal” that shifts down in steps over time

2

“Your Team”

Who can help, and with what. The **primary physician** is listed first

3

Practical tools

Questions for tracking change; how baseline ties to goals of care

4

Related resources

Parent and clinician videos, a downloadable guide, blog posts

Every topic page follows this pattern, so once you know one, you can find your way around all of them.

Questions a family can bring to your visit

- How does my child compare to six months ago? A year ago?
- After an illness, does my child return to the same place?
- How much of the day is my child comfortable and happy, and how has that changed?
- Is my child sleeping more, or doing less of what they enjoy?
- How much has our household changed to keep up?



Each shift in baseline is an opening to revisit goals of care.

Parents usually notice change first. Asking them to track it makes them partners in the conversation.

What CPN offers us

Clinician—Educator portal

Free sign-up as a provider. Videos, audio stories and guides for self-education and for teaching colleagues

“Power of Family Voice” curriculum

Open-access teaching sessions built on parent video narratives, with Cleveland Clinic Children’s and MassGeneral Hospital for Children

Tools for introducing CPN

A short guide on when and how to mention CPN to families, plus a referral card

Research and recognition

Parent-partnered studies in Pediatrics, JPSM and JAMA Network Open; an annual Courageous Provider Award

WALKTHROUGH 2

NeuroJourney

For families of children with severe neurological impairment, children many of us follow closely for years

courageousparentsnetwork.org/neurojourney

The arc of a life, in four phases

Adapting to Diagnosis

Gathering information, care and support as issues emerge; setting goals of care

Goals of Care

Building Strengths

Maximizing core skills and family resilience

Caregiver Well Being

Adjusting to Changes

Decisions as the baseline evolves, and a new baseline after each intervention

Sleep/Obstructive Sleep Apnea

Navigating Decline

Re-orienting goals and preparing for the end of the child's journey

Regret

Two tracks in every phase: Medical, and Social & Emotional

Six languages: English, Spanish, French, Arabic, Portuguese, Chinese

Medical topics, by system

Neurology

Irritability and Pain

Gastrointestinal

Nutrition and Growth

Pulmonary

Sleep

Musculoskeletal

Urology

Endocrine

Cardiology and Heart Rate

Vision

Plus 16 social and emotional topics, from siblings to out-of-home placement

Four core concepts

Palliative care supports every option, curative to comfort, through shared decision-making

Baseline is the new normal, shifting down in steps

Goals of care carry a family's values and change over time

Anticipatory grief is normal, and worth naming

WALKTHROUGH 3

After a death

Grief and bereavement

When the child has died, the family is still yours

Understanding Grief

The grief experience; identity as a parent

Grief

Coping with Loss

Partnership, siblings, grieving with others

Identity as a Parent

Maintaining Connection

Pregnancy after loss; a continuing bond with the child

Maintaining Connection

Where a pediatrician meets this

The siblings' well visits · the next pregnancy and newborn · the parent who shows up with a sibling and wants to talk

Five moments to mention CPN

Moment	What to point toward
At diagnosis, gently	Practical pages: working with the team, goals of care, shared decisions
Along the way	When a family sounds isolated, frightened, or is grieving ahead of time
At a decision point	G-tube, trach, spinal fusion, a trial, out-of-home placement
“Surprise question” is no	Baseline and goals of care, before the next crisis
Considering palliative care	Families describing what palliative care actually gave them

CPN Needs You—Few Parents Make Full Use of the Site Without a Clinical Interpolator

“Every family is different, but a lot of parents tell me other parents are the ones they trust most on this.”

“There’s a free site where parents and doctors talk about exactly what we’re discussing. Want me to send you one page?”

A few habits

Follow their cue. Start from a worry the family has named.

One page, not the site. A single topic or video is easier to open.

Preview it. Some videos are emotionally strong.

Ask next visit. “Did any of that land?”

Mention, don’t prescribe. Not every family is ready for every topic.