

# GULF STATES PEDIATRIC PALLIATIVE CARE CONSORTIUM

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LA PEDIATRIC PALLIATIVE CARE CONSORTIUM,  
CHAIR



A scenic view of a bayou with large trees and cypress roots in the water. The trees have thick, textured trunks and dense green foliage. The water is calm, reflecting the trees and the sky. The ground is covered in brown pine needles and some green grass.

## WHO DAT?

- Bayous
- Alabama
- California
- Louisiana
- Mississippi
- Tennessee
- Boston
- HOME SWEET HOME
- @DrMoPPC (Twitter)
- amorva@lsuhsc.edu



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**NO  
DISCLOSURES**

# WHAT IS PEDIATRIC PALLIATIVE CARE?

Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers.



# Why is PPC needed?

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- 500,000-1 million children with complex, chronic illnesses – LIVING LONGER AND LONGER
- 10,000+ Dx with Cancer per year
- 40,000+ Dx with Complex congenital heart disease
- 80,000+ with severe prematurity
- 50,000 children die/year (~700-800 deaths in LA)
- 75-85% children die in an institutional setting = need inpatient programs!

Laurel Kitto, RN (Woman's BR), Lori Naquin, RN (Ochsner), Cori Morrison MD (CHNOLA), Sonia Malhotra MD (UMC)

Paved the Way, please stand

Summit last year

Many phone-calls for collaboration

I wanted to meet people

Partnered with LMHPCO (Jamey Boudreaux and Nancy Dunn)

Dinner at my home in January – what is going well and where are our growth opportunities discussion

The rest is history

**STORY  
OF PEDIATRIC  
PALLIATIVE CARE IN  
LOUISIANA/  
MISSISSIPPI**

**AND**

**OUR CONSORTIUM**



## **VISION**

All children and families in the gulf state region facing serious illness will have access to comprehensive support through the entire duration of serious illness both in the hospital and the home with the goal to prevent, anticipate and mitigate suffering in all its forms.

# MISSION

We will achieve our vision through an interdisciplinary workforce advocating for every child and family to have access to the support necessary to live as well as possible with serious illness.



Our interdisciplinary workforce will:

Provide quality clinical care both in our hospitals and in the home

Collaborate with our Gulf Coast community to advance education

Engage in advocacy

Provide leadership and expertise in the region

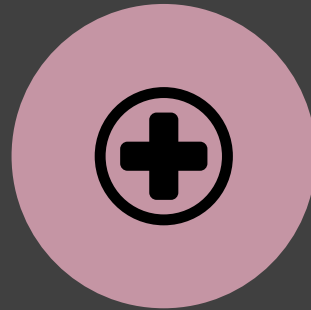
Identify utilization and gaps within hospice and palliative care in Louisiana



# WHO IS PARTICIPATING?



50 MEMBERS



5 HOSPITALS



MANY HOSPICE  
COMPANIES



9 DISCIPLINES

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# HOW DO WE HOPE TO EFFECT CHANGE?

Bring a voice to children and families living with serious illness

Dividing and Conquering

6 Subcommittees, led by incredible humans

**LA Pediatric Hospice and Palliative  
Care Professional Education and  
Community Outreach**

- Christy Heitmeier, RN and Sonia Malhotra, MD

**LA Pediatric Hospice and Palliative  
Care Literature and LMHPCO  
Newsletter Updates**

- Judy Zeringue, RN

**LA Pediatric Hospice and Palliative  
Care Utilization, Outreach and  
Resources**

- Ben Rothwell, MD, Annie Vaden, LCSW

**LA Pediatric Palliative Care  
Consortium Social Media, Website  
and Networking**

- Thad Hicks, RN

**LA Pediatric Hospice and Palliative  
Care Data Collection**

- Haritha Vellanki, MD, Catherine Buckingham, RNP, Kimberly Stewart, MD

**LA Concurrent Care Benefit**

- Melissa Salus, RN and Jamey Boudreaux, SW

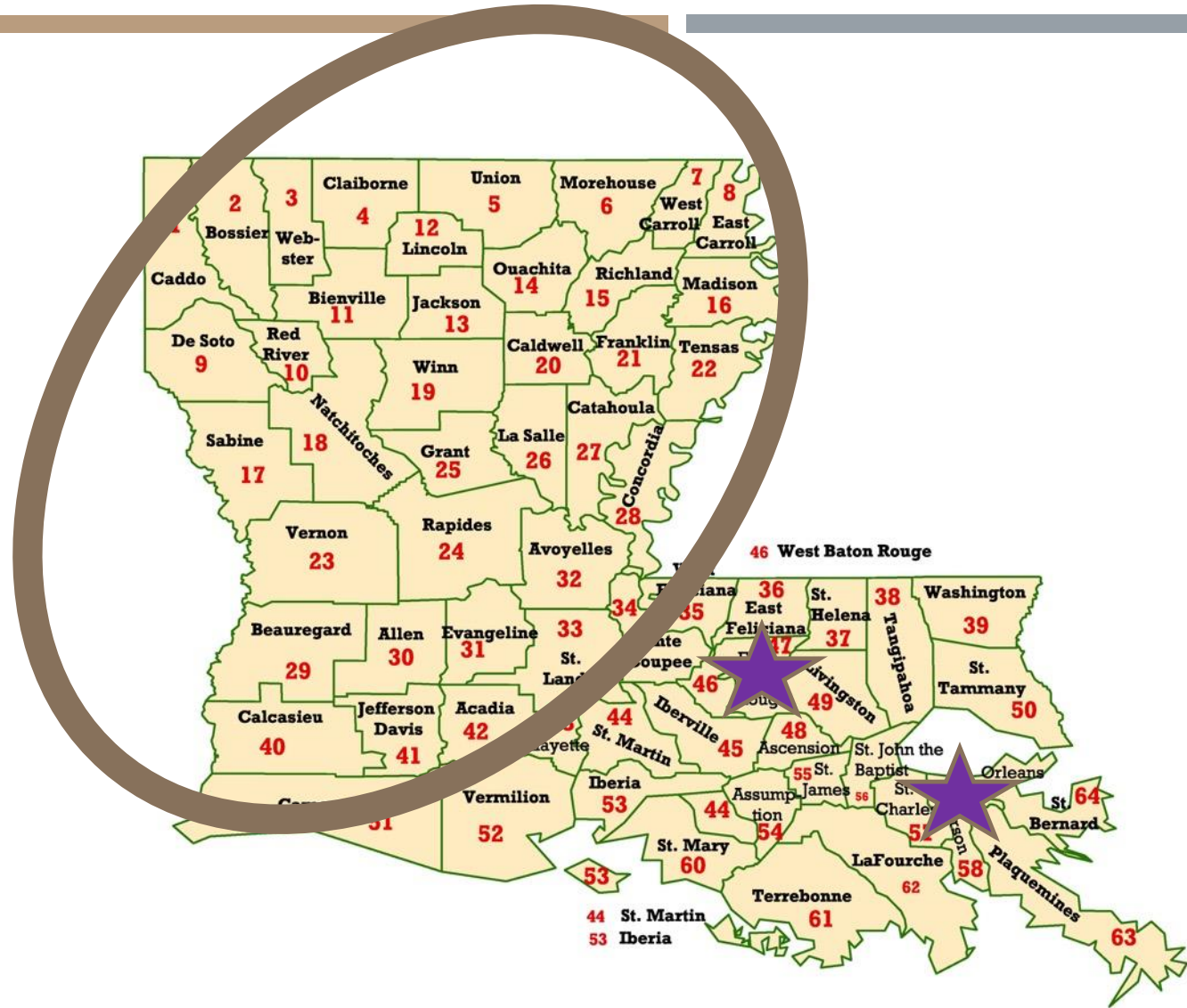
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# WHAT'S HAPPENING IN PEDIATRIC PALLIATIVE CARE WITHIN LOUISIANA?

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- Survey created by Drs. Vellanki and Stewart and Catherine Buckingham
  - CHNOLA, Ochsner Baptist NICU, Women's Baton Rouge NICU, OLOL – replied to our survey
  - UMC's adult palliative care program sees pediatric trauma cases
    - led by Dr. Sonia Malhotra who is med/peds trained and board certified in HPM
  - **Disclosure:** If there are other programs who exist! Please let us know!

## WHAT DID WE LEARN?

- Programs are between 1-8 years old
- ~8000 pediatric admissions with about ~320 consults per year= 4% penetration rate (~750 peds deaths/year)
- All programs are inpatient only at this time, no 24/7 availability
- 1 joint commission certification
- 1 program has formal relationship with hospice and the others informally collaborate
- 1 program sees all ages and diagnoses of pediatric patients
- 100% of programs worry about burnout for their team
- 100% hope for expansion of a formal team



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# SUPER TRAINED!

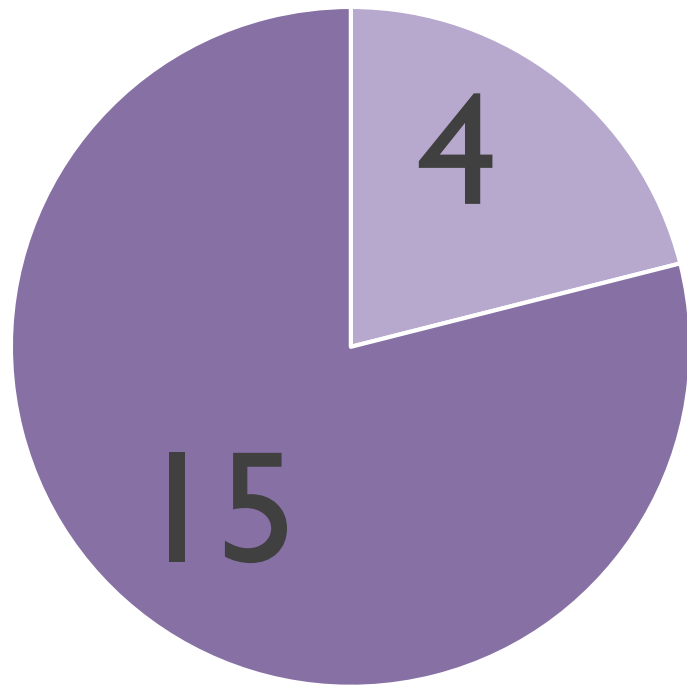
- **EPEC-PEDS** (train the trainer certified)
- **VitalTalk**
- Nursing and social work **certification** in palliative care
- **ELNEC-PEDS** certification (train the trainer certified)
- 2 completing **PCEP** this year
- By 2020, **3 HPM board certified** pediatricians who completed pediatric HPM fellowships and will be 100% dedicated to pediatrics

# WOO HOO



# LA PEDIATRIC PALLIATIVE CARE PROVIDERS

## Formal versus Informal Providers



■ Formal ■ Informal

## Disciplines Represented

- Social Work\*
- Physician\*
- Nursing\*
- Child Life
- Psychology
- Spiritual Care
- Respiratory Therapy
- Integrative Therapies
- No formal bereavement coordinators



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## **GOOD NEWS!**

Ochsner Main Campus -palliative care Medical Director who completed a pediatric HPM fellowship at the world-renowned Children's Minnesota

CHNOLA - HPM pediatrician Dr. Ashley Kiefer who completed a pediatric HPM fellowship at St. Jude – interest is outpatient palliative care, parental bereavement and hospice

CHNOLA - full-time nurse practitioner, Catherine Buckingham, NP who completed NP school at UAB. Her interest are education and program development.





## GOALS TO CONSIDER

- Expand infrastructure – every hospital who admits high number of pediatrics = **formal IDT**
- We have dynamite trained folks – spread the love! **EDUCATION OVERHAUL**
  - Including our elected representation
- **Burnout** and concern of burnout is real and we need to take care of one another and ourselves – selfcare
- Improve **transitions** from hospital to home with hospice support
- **Home Based Pediatric Palliative Care**
- Protect **concurrent care**

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# CONCURRENT CARE

What is Concurrent Care?

How is it going in LA?

Are there any concerns?

WE CAN HELP!

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# WHAT IS “CONCURRENT CARE FOR CHILDREN REQUIREMENT?”

- March 2010 Affordable Care Act:
  - *Makes hospice services available without forgoing any curative or life-prolonging services for which the child is eligible.*
- Infants, children, adolescents and young adults who are **<21 years of age**
- Prognosis of **<6 months**
- Entitled to **curative/life-prolonging treatments AND hospice benefit**
- For any child who is supported by Medicaid (private insurances – case by case basis, very helpful)
- States would continue to pay providers of curative services **AND** hospices for services within the hospice benefit.

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# HOW IS CONCURRENT CARE GOING IN LA & MS?

Excellent! Barrett Leonhard

No hospices or hospitals have reported any challenges with reimbursement for concurrent care

Individuals who are under age 21 and who are approved for hospice may continue to receive curative treatments for their terminal illness; however, the hospice provider is responsible to coordinate all curative treatments related to the terminal illness, including:

1. Curative treatment shall be defined as medical treatment and therapies provided to a patient with the intent to improve symptoms and cure the patient's medical problem.
2. Curative care has its focus on the curing of an underlying disease and the provisions of medical treatments to prolong or sustain life.
3. The hospice provider is responsible to provide durable medical equipment or contract for the provision of durable medical equipment. Personal care services, extended home health, and pediatric day health care must be coordinated with hospice services.
4. Individuals who elect hospice services may also receive EPSDT personal care services concurrently. The hospice provider and the PCS provider must coordinate services and develop the patient's plan of care.

CHAPTER 24: HOSPICE

SECTION 24.2: ELECTION OF HOSPICE CARE

rendering services to a PACE participant. PACE must prior authorize all services. Unauthorized services provided will result in non-payment for services rendered.

**Recipients under Age 21 Receiving Hospice and Concurrent Care**

Recipients under 21 years of age may continue to receive curative treatments for their terminal illness. However, the hospice provider is responsible for and must coordinate ALL curative treatments related to the terminal illness and related conditions. No additional payment may be made regardless of cost of service for curative care treatment.

The hospice provider is responsible for making a daily visit to ALL recipients under 21 years of age and to coordinate care to ensure there is no duplication of services. The daily visit is not required if the person is not in the home due to hospitalization or inpatient respice stays.

All questionable services and/or treatments will be sent for medical review. All treatments and therapies must be included in the POC. Documentation of therapies and treatment as well as progress notes are required upon each request for a continuation of hospice care and upon the initial request for hospice care if the recipient is already receiving curative treatment(s).

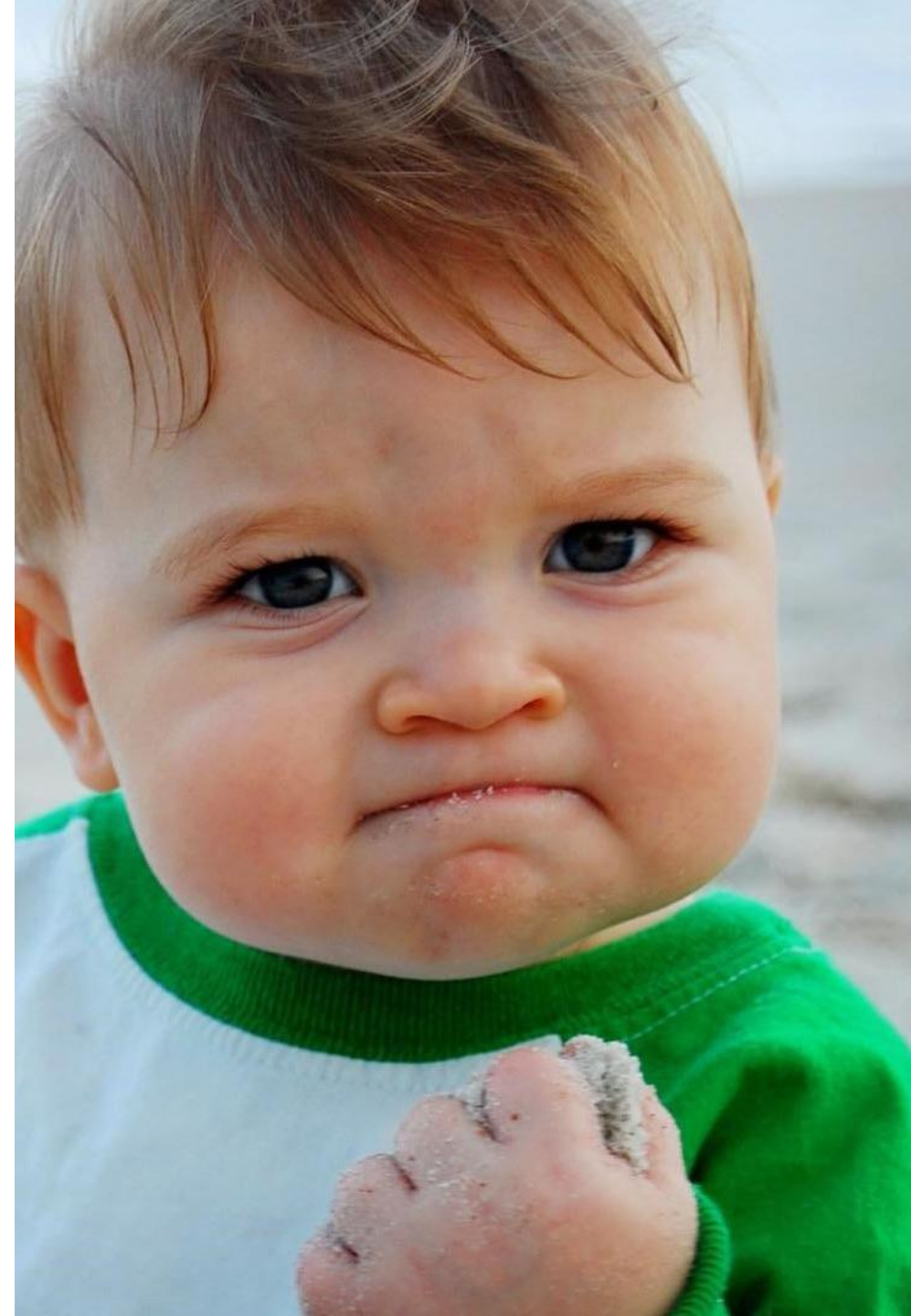
ARE THERE ANY CONCERNS WITH LA CONCURRENT CARE BENEFIT?

- LMHPCO and AAP are working with LA Medicaid to ensure that concurrent care language is adequate in providing the best care possible.

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## HOW WILL WE KNOW IF WE ARE SUCCESSFUL?

- **Community Based Palliative Care** funded by LA in all areas of LA & MS within **10-12 years**
- Formal pediatric hospice and palliative care **education** offered quarterly throughout LA & MS regions within **5 years**
  - Goal- improve hospice comfort with pediatrics and improve primary palliative care skills with community pediatricians
- Hospice checklist for hospitals to utilize as kids **transition** home to have clear communication within **5 years**
- **Website** with State specific and national pediatric resources and accessible **networking** ability within **3 years**
- Yearly **pediatric palliative care conference** within **7 years**
  - Utilize our EPEC-PEDS and ELNEC trainers in LA



A dramatic sunset over a body of water. The sky is filled with vibrant orange, red, and purple clouds. In the foreground, the silhouettes of four people are visible in a canoe on the water. The background shows a dark silhouette of a forested shoreline and distant mountains. The overall mood is serene and contemplative.

**WE GET ONLY ONE CHANCE...**



## SUMMARY

- LEAN IN and Join our consortium!
- Pediatric palliative care is rockin` and rollin` in LA & MS!
- Pediatric palliative care and hospice is going to be utilized more and more because kiddos are living longer with chronic illnesses.
  - And as our palliative care programs grow, hospice will be utilized more.
- Concurrent Care is working well for our patients – please continue to educate us on your experiences
- Let's do this!



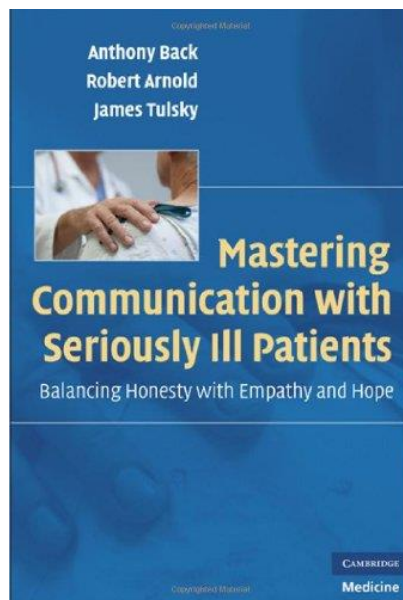


**THE  
BEGINNING!!!!**

# SKILLS DEVELOPMENT SCAFFOLDING

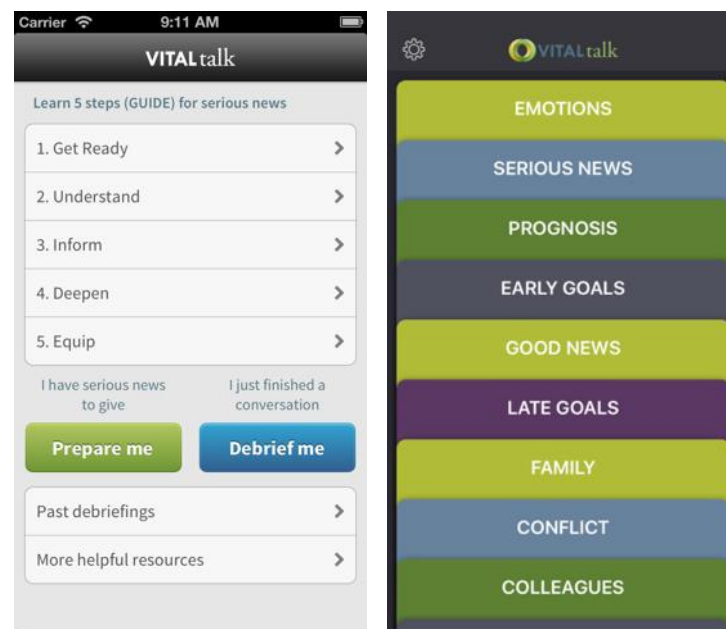


the conversation project



COURAGEOUS PARENTS NETWORK

Empowering parents caring for children with life-limiting illness.



**EPEC<sup>®</sup>**  
Education in Palliative and End-of-life Care

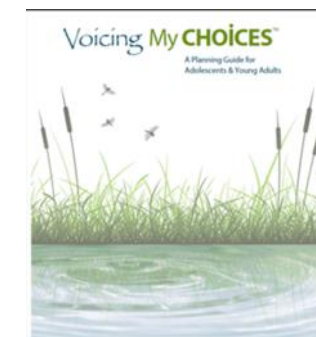
**Pediatrics Online  
Communication & Planning**

Access at:  
[epec.net/epec\\_pediatrics.php](http://epec.net/epec_pediatrics.php)



**Pediatric Module 3 Online:  
Communication in Pediatric  
Palliative Care**

Access at:  
[www.reliaslearning.com/courses/elne-pediatric-module-3-communication-in-pediatric-palliative-care](http://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](http://www.vitaltalk.org)

**PCEP**