

**"We Just Wish She Could Tell Us What She Wants": A  
Special Child, A Special Family and A Special Calling**  
Pediatric Palliative Care Case  
Webinar for the Supportive Care Coalition  
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## Disclosures

Each author has no disclosures.

## Objectives

1. Review the unique challenges presented by a non-verbal patient, and ways to support the surrogate decision makers to ensure the patient's best interest remains the central focus for all care.
2. Identify ways that a holistic, interdisciplinary approach and collaboration across disciplines can optimize the care of complex pediatric patients and their families.
3. Demonstrate effective communication strategies to utilize when a patient's clinical condition quickly changes from chronic to acute to critical, and ways to respond to, and support the patient, family and care team.

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## Case Introduction: "B"

"B" is a 15yo with history of prematurity, cerebral palsy, blindness, contractures, seizures, constipation, feeding failure s/p g-tube, hydrocephalus s/p ventriculo-peritoneal shunt, w/ global developmental delay, and behavior problems.

Had 24-48 hours of emesis, not tolerating feeds.

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## Case Introduction: "B"

Objective 1:

- GI issues begin
- Surgery
- Failed extubation

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## Objective 1: Unique challenges with non-verbal patients

- Non-verbal versus non-understanding
- Bringing the patient's "voice" to the conversation
- Empowering surrogate decision makers

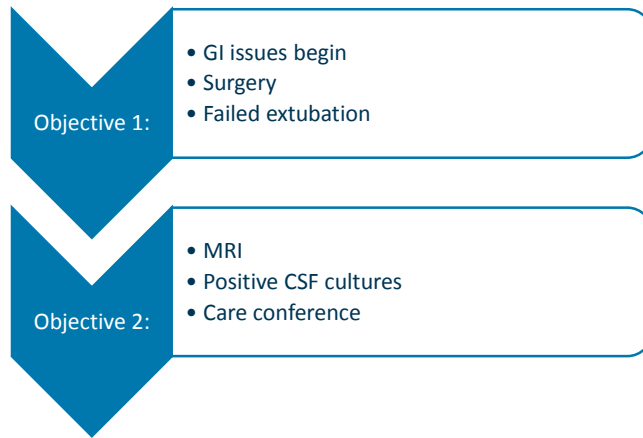
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## Objective 1: Unique challenges with non-verbal patients

- Establishing achievable goals without affirmation from patient
- Support family in their grief

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## Case: "B"



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## Objective 2: Wholistic, interdisciplinary approach

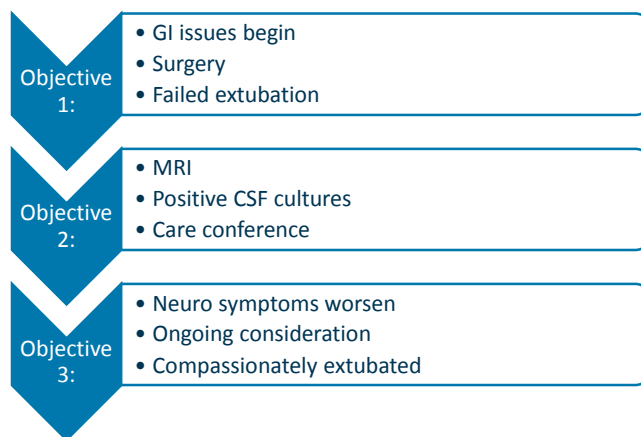
- Colleagues providing honest assessments
- Narrow window for clinical success given multi-system complications
- Trusting our trusted colleagues
- Spiritual tensions about God's will for B

### Consulting Teams:

- Critical Care
- Neurosurgery
- General Surgery
- Neurology
- Infectious Disease
- Supportive Care
- Chaplain
- Social Work
- Occupational Therapy
- Physical Therapy
- Child-life Specialist
- Music Therapist

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## Case: "B"



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## Objective 3: Effective communication strategies

- Assessing the space and pace
- Engaging a trusted person to communicate with family
  - Provider, family member, spiritual leader, associate
- Coaching family along the processing journey
- Recognizing and supporting distressed team members

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## Questions, Contact Us

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