

CLINICAL INSIGHTS AND CAREGIVER VOICES: HOME-BASED MEDICALLY-COMPLEX TUBE WEANING

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DISCLOSURES

Financial Disclosures

Brianna Miluk is the owner of Pediatric Feeding Therapy, LLC. Bri also contracts as a speech-language pathologist with Earthshine Speech and Language.

Denise has none to disclose.

Non-Financial Disclosures

Brianna Miluk serves on the Feeding Matters Conference Committee.

Denise Clark has none to disclose.

LEARNER OUTCOMES

1. Describe the importance of family-driven care in supporting functional outcomes for feeding therapy.
2. Relate caregiver experiences to current clinical practices to improve tube weaning approaches.
3. Define motor learning principles and their application to feeding and oral motor skills.

MEET NASIR



WHEN WE FIRST MET

Relevant History and Current Status

- Born: 39 weeks
- Now: 1 year 7 months
- Diagnoses: congenital pulmonic valve stenosis, dextro-transposition of great arteries, hypoxic ischemic encephalopathy (HIE)
- HIE happened after cardiac arrest at 11 months old
- Hospitalized for 8 weeks after cardiac arrest
- Seizure activity & stroke post cardiac arrest, but none since discharge
- Bilateral VF paralysis at initial FEES in hospital
- Unilateral VF paresis at most recent FEES (14 months), but cleared for thin and puree
- Typical development before cardiac arrest

Current Feeding Status/Observations

- G-tube dependent for nutritional intake
- Sometimes accepts smooth puree, but gags on textures
- Refuses to bite or chew
- Orally aversive, mom trying anything to get some bites in!
- Has not attempted drinking since most recent FEES due to parental concern
- Mouths fingers/hands and toys
- Tongue protrusion with purees

CLINICAL CONSIDERATIONS

Family-Centered Care

Goal Writing
Home Programming

Responsive & Child Led

Autonomy, Competence, & Relatedness
Tube Weaning

Motor Learning

Advance Oral Motor skills
Expand Variety

CAREGIVER CONSIDERATIONS

Progress

Focus on the benefits of the G-tube

Timeline expectations

Challenges

Medical Complications

Oral Aversion

Emotional Aspects

Hopelessness
to
Hopeful

HOW WE WORKED TOGETHER

- Collaborative goal writing
- Prioritize caregiver input for home programming
- Teach-back method
- Emphasize importance of asking questions and requesting clarification
- Revisit goals, expectations, and progress

WHERE WE STARTED



- Following Nasir's lead
- Building textures
- Introducing straw
- Caregiver coaching, building competence, confidence, and advocacy!

WHERE WE FINISHED



- Weaned from g-tube
 - Kept tube through cold/flu season and upcoming surgery
- Advanced to age appropriate diet
- Mom felt confident in feeding Nasir - reduced anxiety & stress about mealtimes!

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