

Parenteral Nutrition during End-of-life Care in Children: Balancing the Benefits, Burdens, and Goals

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Children's



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Disclosures

- No financial disclosures

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Learning objectives

1. Summarize how home parenteral nutrition (PN) management can be individualized, including decisions about continuation, withdrawal, and sequelae management based on a family's goals of care and priorities.
2. Collaborate with subspecialty teams, such as a palliative care team when managing children on home PN.
3. Describe the challenges of initiating and managing home PN in children who develop intractable feeding intolerance, and who are unlikely to undergo intestinal rehabilitation.

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Maggie

- 13-year-old girl
- Cerebral Palsy, Spastic Quadriplegia
- Scoliosis and contractures
- Nonverbal, nonambulatory
- Gastrostomy tube (GT)
- Oral tastes and small volume purees
- Seizures (weekly, increase in frequency when ill)
- Constipation
- PT, OT, SLP
- Lives with Mom, Dad, 3 younger, healthy siblings
 - Honorary member of the high school girls' basketball team



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Maggie

History

- Born full term
- Difficulty eating after birth
- 2 months old NG placed
- 6 months old GT placed
- Not meeting developmental milestones
- 11 months
 - Genetic testing – negative (other than variants of unknown significance)



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Maggie 13-14 years

Hospitalizations & illnesses

1. Pneumonia and other respiratory illnesses
 - Worsening seizures – medication changes, keto
2. Vomiting, abdominal bloating, due to ?GI illness?
 - GT converted to a GJ
 - Transitioned off ketogenic diet (efficacy?)
3. Pain symptoms, abdominal distension, loose stools, increased frequency of seizures, weight loss (4% in 2 months)



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Maggie

Hospitalization 3

Detailed Home History

- Diarrhea (laxatives held, lamotrigine given)
- Abdominal distension (worsened with feeds)
- Pain symptoms (moaning, wincing, crying)
- Worsening seizures (last 4 months)
- Weight loss
 - Feeds held intermittently due to pain symptoms

Evaluation

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Upper GI contrast study
- Xray
- CT abdomen

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Maggie

Hospitalization 3

History

- Diarrhea (at home-laxatives held, lamotrigine given x2)
- Abdominal distension (worsened with feeds)
- Pain symptoms (moaning with feeds)
- Worsening seizures (last 6 months)
- Weight loss
 - Feeds held intermittently due to pain symptoms

Eval: Normal/ Unremarkable

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Upper GI contrast study
- Xray
- CT abdomen

- Ongoing stooling pattern
 - Xray reviewed, and compared
 - Physical Exam
- = **Constipation, with overflow**

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Maggie

Hospitalization 3

Treatment and Course

- Bowel clean-out
 - Pain symptoms improved (not resolved)
 - Bloating improved (not resolved)
- Discharged home
 - J-feeds
 - Bowel regimen

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Upper GI contrast study
- Xray
- CT abdomen

- Xray reviewed, and compared
 - Physical Exam
- = Constipation, with overflow

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Maggie

2 months later, Hospitalization 4

History: Pain with feeds, vomiting, weight-loss 4%

- → **Acute Pancreatitis**
- Total Parenteral Nutrition with bowel rest for 24 hours
- EN restarted, and advanced
 - Intermittent discomfort (pain, vital sign changes)
 - EN increased so slowly, and intermittently
 - PN weaned down so slowly (over 3 weeks)
- “Can she discharge home on PN?”
- Discharged home on EN, after 4 weeks

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Upper GI contrast study
- Xray

- **Lipase & Amylase: HIGH**
- **CT Abdomen: Pancreatitis**

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Maggie

1 month later, **Hospitalization 5**

- History
 - Pain, moaning, wincing (? with enteral feeds)
 - Vomited x 3 in the last 2 weeks
 - Much more somnolent
 - Tachycardia, at times
- Weight loss
 - Total 8% in 9 months
 - With height increases (BMI 50% -> 5%)
- Parenteral Nutrition started

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Maggie 15 years old

Hospitalization 5

- History
 - Pain, moaning, wincing (? with enteral feeds)
 - Vomited x 3 in the last 2 weeks
 - Much more somnolent
 - Tachycardia, at times
- Weight loss
 - Total 8% in 9 months
 - With height increases (BMI 50% -> 5%)
- Parenteral Nutrition started

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Xray – no constipation
- Head imaging
- Lipase, Amylase *
- EGD – unremarkable

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Maggie

Hospitalization 5

- History
 - Pain, moaning, wincing (? with enteral feeds)
 - Vomited x 3 in the last 2 weeks
 - Much more somnolent
- Weight loss
 - Total 8% in 9 months
 - With height increases (BMI 50% □ 5%)
- Parenteral Nutrition started
- --> **Nephrolithiasis**

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Xray – no constipation
- Head imaging
- Lipase, Amylase *
- EGD – unremarkable

- CT Abdomen
 - Nephrolithiasis (?pain)

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Maggie

Hospitalization 5

- History
 - Pain, moaning, wincing (? with enteral feeds)
 - Vomited x 3 in the last 2 weeks
 - Much more somnolent
- Weight loss
 - Total 8% in 9 months
 - With height increases (BMI 50% □ 5%)
- Parenteral Nutrition started
- --> **Nephrolithiasis --> Lithotripsy**

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Xray – no constipation
- Head imaging
- Lipase, Amylase *
- EGD – unremarkable

- CT Abdomen
 - Nephrolithiasis (?pain)

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Maggie

Hospitalization 5

- Lithotripsy for nephrolithiasis
 - Initial symptom improvement, but not resolution
- Pain, moaning, wincing
- Vital sign changes (HR, RR, BP)
- **Feed Trial:**
 - 5 hours (day-time) feeds ON
 - 5 hours (day-time) feeds OFF
 - -->More symptoms when feeds were ON

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Xray – no constipation
- Head imaging
- Lipase, Amylase
- EGD – unremarkable
- + Flexible sigmoidoscopy

- CT Abdomen
 - Nephrolithiasis (?Pain)

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Maggie

Hospitalization 5

- Pain, moaning, wincing, vital sign changes (HR, RR, BP)
 - -->**More symptoms when feeds were ON**
- **Enteral Nutrition changes...**
 - Formula type & trialing oral rehydration solutions
 - Feeding schedule
 - GT venting and drainage
- **“Can she discharge home on PN?”**

Normal/ Unremarkable Eval

- GI Pathogen panel
- Fecal calprotectin
- CRP, ESR, CMP, CBC
- Xray – no constipation
- Head imaging
- Lipase, Amylase
- EGD – unremarkable
- + Flexible sigmoidoscopy

- CT Abdomen
 - Nephrolithiasis (?Pain)

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Maggie

Hospitalization 5

- Have we ruled out all causes of pain?
 - Joint imaging
 - no dislocations
 - Odd swelling, possible bruising
 - skeletal survey normal
 - Repeat CT Abdomen with enteral contrast
 - normal
 - EEG
 - Abnormal & no correlation with symptoms



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Should we send this patient home on PN?

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Should we send this patient home on PN?

When does an “enteral feeding problem” become a goals-of-care discussion?

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Maggie

Hospitalization 5 Additional Signs & Symptoms

- Waves of pain symptoms
- Frequent somnolence; sleeping 20-22 hours per day
- Vital sign irregularity
 - Intermittent tachycardia
 - RR fluctuations
 - Hypotensive and hypertensive episodes
 - 1 fever of unknown etiology
- 2 episodes of unilateral swelling (hand and upper chest)
 - Diuretic x1



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Intractable Feeding Intolerance (IFI)

Severe, persistent inability to tolerate oral or tube feeding, with sustained clinical improvement with minimal to no EN

- Severe Neurologic Impairment (SNI)
- Without obvious GI pathology
- Without any obvious pathology

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Intractable Feeding Intolerance (IFI)

- Etiology
 - Altered central nervous system – enteric nervous system communication
- Additional signs of central nervous system changes
 - Vital sign irregularity / neuro-storming / dysautonomia
 - Somnolence
 - Episodic, unexplained edema
- Diagnosis is challenging

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IFI is a Diagnosis of Exclusion

Must consider other etiologies for feeding intolerance

- Infections (UTI, joints, ear, throat)
- Mechanical obstruction, partial obstruction, constipation
- Pancreatitis
- Peptic ulcer disease, gastritis
- Nephrolithiasis
- Musculoskeletal / joint pathology
- Cholecystitis, choledocholithiasis
- Medical child abuse

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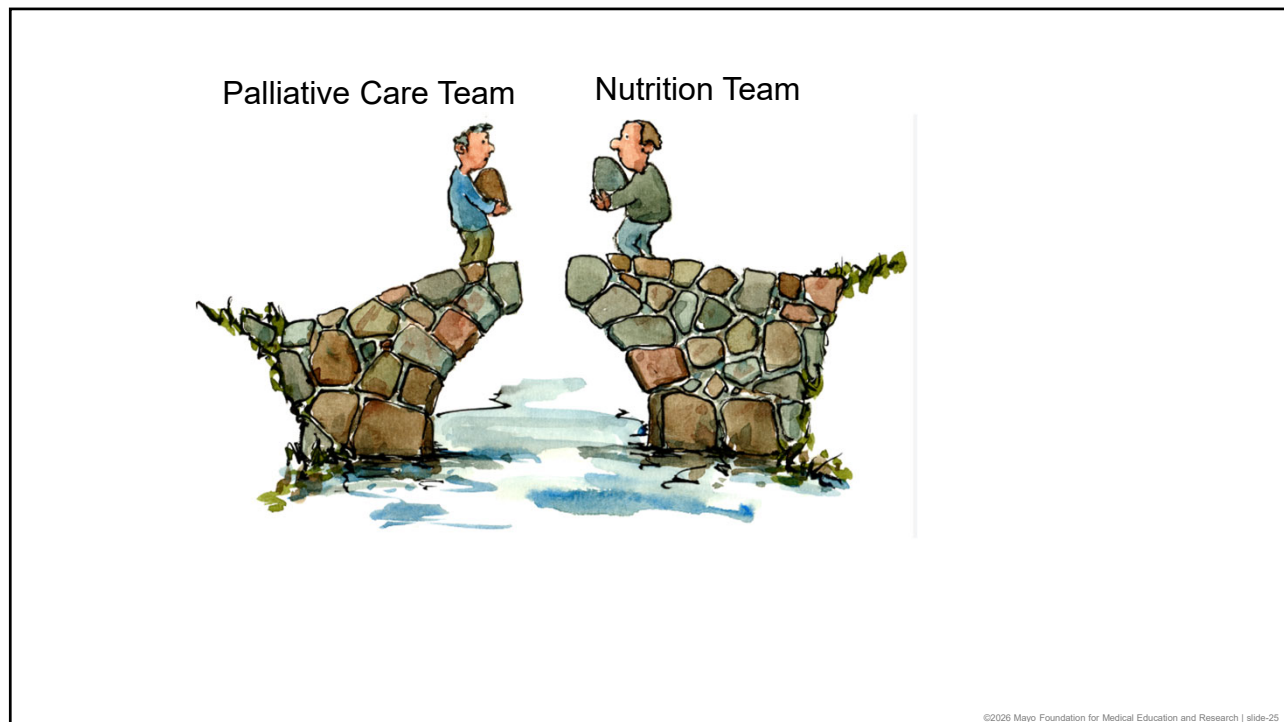
Maggie (15 years old)

Hospitalization 5

- Can she go home on PN?
- Should she go home on PN?
- Who decides?



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1. Feeding a Child is Primordial and Instinctive

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 - parental food provisioning is a core form of parental care that evolved because it promotes offspring survival and development.
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 - because offspring depend on parental care for survival
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 - maternal behavior in mammals is highly conserved evolutionarily
- Zippel MN, Reeve HK, Peniston OJ. (2024). *Maternal care leads to the evolution of long, slow lives*. PNAS.
 - the mother-offspring dependency relationship as a defining feature of mammalian life history

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***“What are we trying to accomplish with Home PN?”
Where are we going?”***

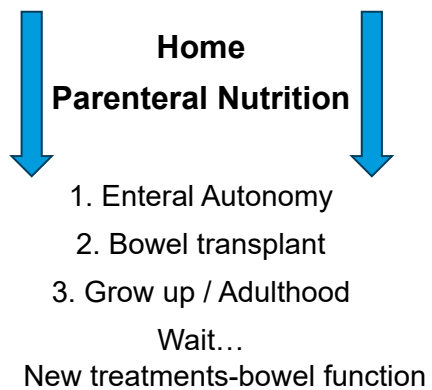


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Intestinal Rehabilitation

-----Intestinal Failure-----



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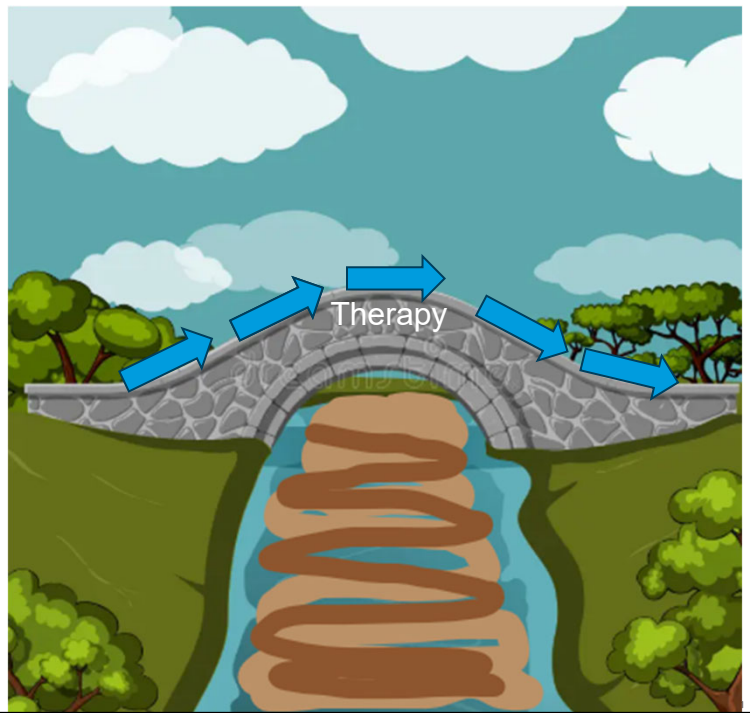
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Therapies

- Chemotherapy
- Radiation therapy
- Physical therapy
- Psychotherapy
- ***Home Parenteral Nutrition***



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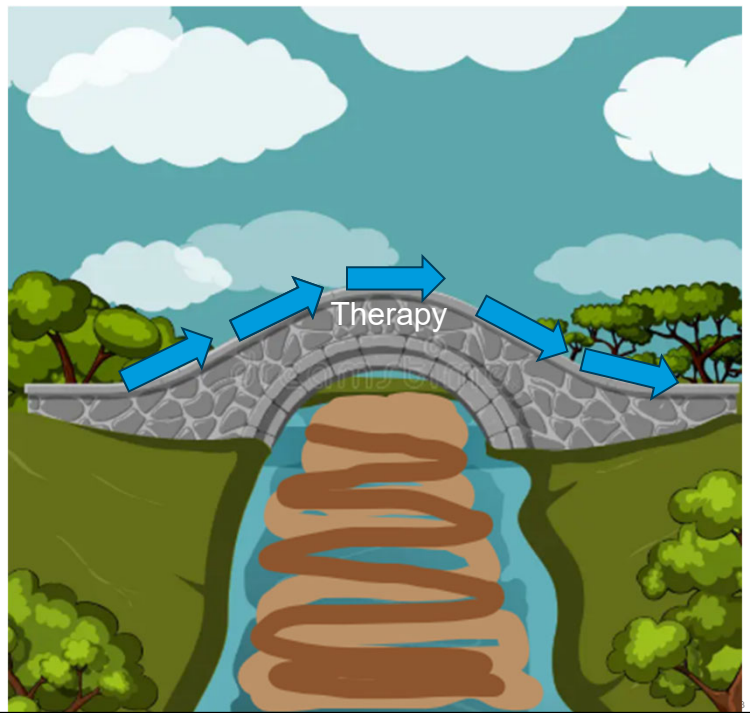
Therapies require Therapy Plans

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Therapies

- Chemotherapy
- Radiation therapy
- Psychotherapy
- Physical therapy
- **Nutrition @ Home**



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Palliative Care Team

Nutrition Team



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Pediatric Palliative Care Team

- **Doctors**
 - Specialize in palliative medicine
- **Nurses and advanced practice providers**
 - Provide direct patient care and symptom management
- **Social Workers**
 - Offer emotional support and assistance with practical needs
- **Chaplains**
 - Address spiritual concerns and providing support regardless of faith
- **+/- Therapists**
 - Occupational and Physical

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Pediatric Palliative Care Team

- Establish and adapt goals of care
- Shared decision making
- Advance Care Planning
 - Assist in making informed decisions including where care is received care, how they want to manage their treatment options
- Coordination of care
- Symptom management and treatment
- Holistic support: addresses physical, emotional, social and spiritual needs
- End-of-Life care

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Therapy Plan *for Home Parenteral Nutrition*

- Rehabilitation
- Maintenance (trajectory of growth and development)

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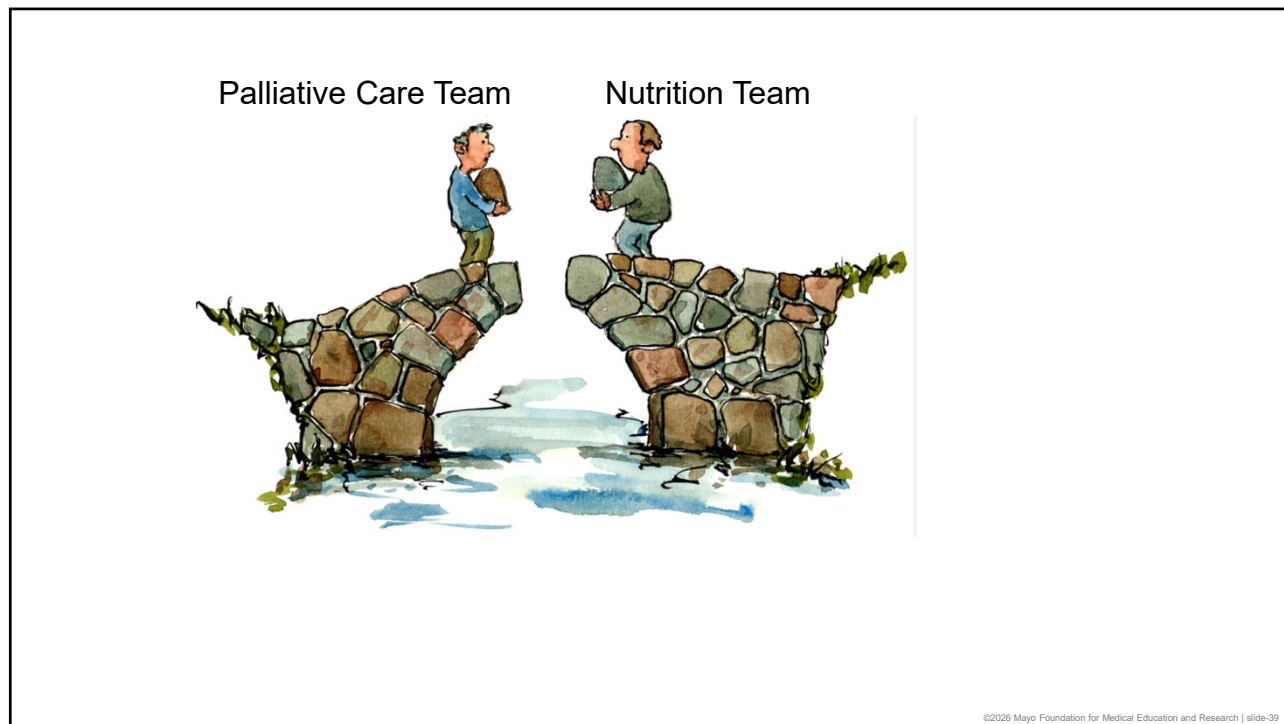
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Therapy Plan ? *For Home Parenteral Nutrition*

- Rehabilitation
- Maintenance (trajectory of growth and development)
- **Palliative / End-of-Life**

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Tailoring the Therapy Plan

Standard plans

- Home-care company / DME
- Central Line
- Central line training and trouble shooting
- Home PN storage and administration education
- Pump training and troubleshooting
- Antimicrobial locks
- Stable PN prescription
- Equipment education
- Preparation Time

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Tailoring the Therapy Plan

Standard plans & Alternative plans

- Fever
- Electrolyte imbalance
- Central line complications
 - Occlusions
 - Break
 - Dislodgement
- Clinic appointments
- Laboratory studies and timing
- Advancement of EN

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TABLE 2 Home parenteral nutrition pre-discharge plans will depend on a family's goals-of-care.

	Standard plans	Alternative Plan 1	Alternative Plan 2
HPN labs: electrolytes, CBC, iron studies, etc.	Weekly (initially); routinely scheduled thereafter	Scheduled, but infrequent; only if hospitalized or as needed if symptoms or risks for electrolyte imbalance	Never
Fever	Requires evaluation for CLABSI and other causes of fever, regardless of symptoms or potential sources of fever: emergency visit, labs, blood cultures, IV antimicrobials, hospitalization	Plans depend on other symptoms or sources of fever; emergency visit versus remain at home with hospice nurse evaluation	Remain at home and accept risks; may stop HPN
Electrolyte imbalance (severe)	Emergency visit or hospitalization; correct electrolyte imbalance, establish and prescribe new HPN order	Remain at home; stop HPN and change to standard IV fluids	Stop HPN
Central line occlusion	TPA (at home, infusion center, emergency room); replace CVL if occlusion persists	TPA (at home, infusion center, or emergency room) but, if unsuccessful, leave CVL in place	Stop using CVL (stop HPN) and remain at home
Central line break or dislodgement	Emergency visit; attempt repair, and/or replace CVL	Emergency department for attempted repair; no replacements	Stop using CVL, (stop HPN) and accept risks at home
Nutrition support clinic appointments	In person within 4 weeks	Video or phone visits scheduled	None scheduled; only as needed

Abbreviations: CLABSI, central line associated blood stream infection; CVL, central venous line; HPN, home parenteral nutrition; TPA, tissue plasminogen activator.

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Fever

Standard Plan

Requires evaluation for CLABSI and other causes of fever, regardless of symptoms or potential sources of fever: emergency visit, labs, blood cultures, IV antimicrobials, hospitalization

Alternative plan #1

Plans depend on other symptoms or sources of fever; emergency visit versus remain at home with hospice nurse evaluation

#2

Remain at home and accept risks; may stop HPN

Central Line Occlusion

Standard Plan

TPA (at home, infusion center, emergency room); replace CVL if occlusion persists

Alternative plan #1

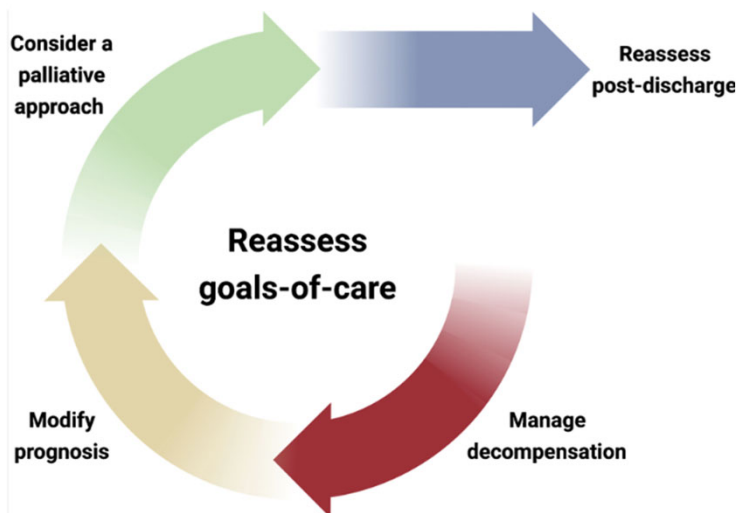
TPA (at home, infusion center, or emergency room) but, if unsuccessful, leave CVL in place

#2

Stop using CVL (stop HPN) and remain at home

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Dividing and Conquering

Pediatric Nutrition Team	Pediatric Palliative Care Team
PN prescription	Understand Goals of Care
Central venous access	Changes in goals, and therapy plan
Antimicrobial locks	Symptom Management
Laboratory monitoring	Values
Growth, weight gain, weight loss	Navigating Benefit vs Burden
Providing expertise in standard plans	Evolving End-of-Life decisions
Communicating with the Palliative Care Team	Communicating with the Nutrition Team

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Megan Thorvilson, MD, Palliative Care

“The same nutrition prescription can have very different meanings and outcomes, depending on the family’s goals of care, and the Therapy Plan prescribed.”

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It takes a village



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It takes a village



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Palliative Care Team

- Begin early
- Support symptom management along the way
- Understand family's goals of care and clarify over time
- Facilitate shared decision-making
- Help families navigate uncertainty
- Support caregivers through complex decisions

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Clinic Home Enteral Nutrition Team

- Understand feeding history
- Aware of feeding intolerances
- Know what feeding changes have been used
- Understand growth patterns
- Knowledge of GI symptoms and management
 - Reflux and vomiting
 - Gastroparesis
 - Constipation

Hospital Nutrition Service

- Hospital RDs (continuity) for EN
- Hospital Nutrition Team / Consult Service
 - GI providers, PharmD, RD, RN
- Assess evaluation for IFI

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CLINICAL OBSERVATIONS

Where comfort and nutrition meet: A case series of children with severe neurologic impairment receiving home parenteral nutrition at the end of life

Dana Steien MD  | Erin Alexander DO  | Molissa Hager MS |
Andrea Armellino RD | Megan Thorvilson MD 

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Ethical Principles in Medical-Nutrition Decisions

- Autonomy
 - Promotes the consideration of an individual's, or caregiver's preferences during medical decision-making processes
- Beneficence
 - A medical treatment is based on a medical condition, and the medical treatment will benefit the patient
- Nonmaleficence
 - Not harming the patient by administering a medical treatment, OR by forgoing a medical treatment that could have been provided
- Justice
 - Treating all individuals fairly

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TABLE 1 Case Details of children with severe neurologic impairment who developed intractable feeding intolerance and used home parenteral nutrition concomitantly with hospice during their end-of-life care.

	Patient 1	Patient 2	Patient 3	Patient 4
Initiation of HPN	12 years old	8 years old	1 year old	12 years old
Time to enroll in hospice after HPN start	Same time	4 months	1 month	Same time
Duration receiving HPN	26 months	9 months	16 months	1 month
Number of CLABSIs	2	1	3	0
CVL replacements	1	1	12	0
Primary central intravenous line type	Hickman	Hickman	Hickman	PICC
Outpatient appointments	8	7	1	1
In-person	5	0	1	0
Virtual	3	7	0	1
Diverting ileostomy	No	Yes	No	No
Feeding tube type	GT (previous GJT)	GT (previous GJT)	GT (previous GJT)	GJT
Hospitalizations while receiving HPN	4	7	17	0
Routine laboratory studies (at HPN start)	Yes	Yes	Yes	No

Abbreviations: CLABSIs, central line associated blood stream infections; CVL, central venous line; GJT, gastro-jejunostomy tube; GT, gastrostomy tube; HPN, home parenteral nutrition; PICC, peripherally inserted central catheter.

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Take Aways

- Nutrition is a Therapy
- Nutrition and its administration requires a Therapy Plan
- Working together for our patients can be rewarding
- Time is precious

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**Thank you
For your Precious Time**



Courtesy of HGA. Photo credit John Magnoski.

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References

- Steien D, Alexander E, Hager M, Armellino A, Thorvilson M. Where comfort and nutrition meet: A case series of children with severe neurologic impairment receiving home parenteral nutrition at the end of life. *Nutr Clin Pract.* 2026 Apr;41(2):680-687.

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Questions & answers



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