



Nutritional Implications and Management of GI Dystonia in Children and Young People with Severe Neurodisabling Conditions

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Disclaimer

- Received honorariums and sponsorship from the following:
 - Nutricia
 - Abbott
 - Reckitt Benckiser

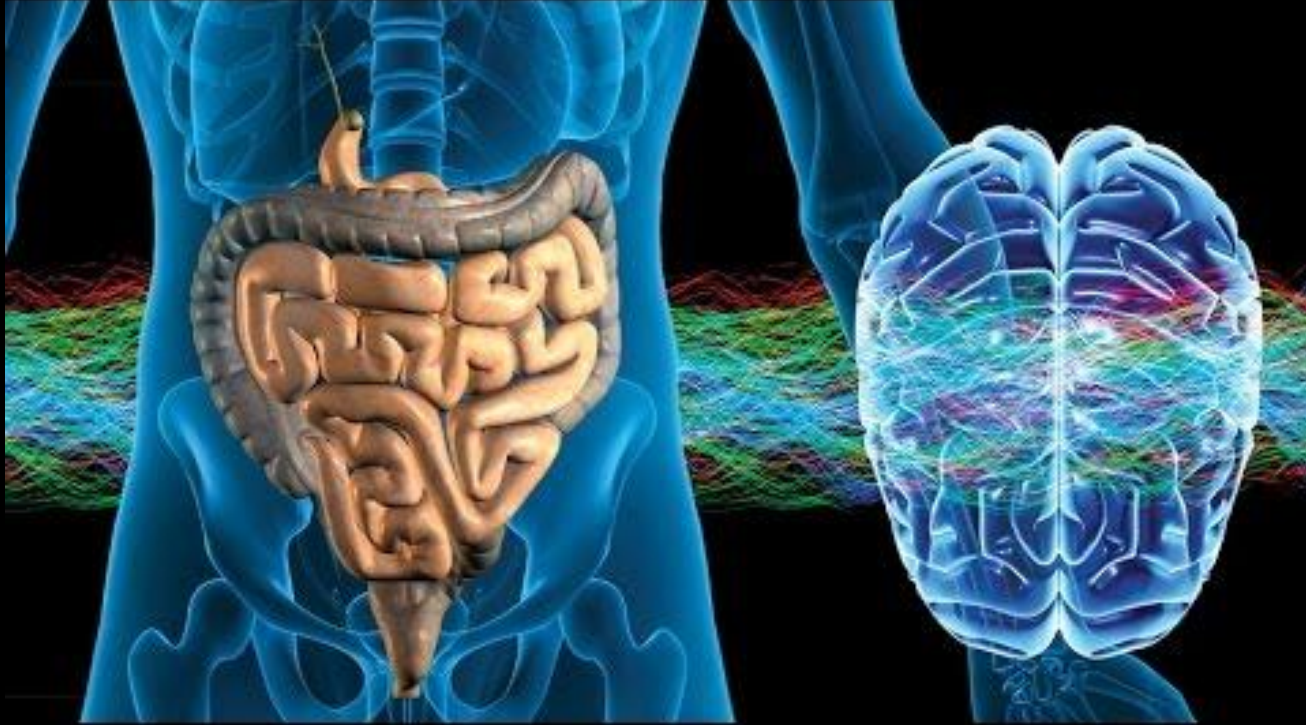
Learning Objectives

- Understand the enteric nervous system in relation to GI symptoms
- Define Gastrointestinal Dystonia (GID)
- Recognise nutritional implications in children and young people with severe neurodisabling conditions (CYPSND) / neurological impairment (NI)
- Explore management strategies and feeding options

Neurological Impairment (NI) - Definition

- Any disorder affecting the brain, spinal cord and/or nerves
- Caused by structural, chemical or electrical abnormalities with the nervous system
- Can affect speech, movement (motor skills) and /or cognitive function
- Over 400 classified neurological conditions
- Cerebral palsy – affects motor function – most common group
- Any NI affecting motor function and motility can cause gastrointestinal (GI) disturbances

The Enteric Nervous System



The 'brain of the gut'

Enteric Nervous System (ENS)

- Communicates with the central nervous system (CNS)
- Part of the autonomic nervous system (ANS) - can work independently of the CNS
- Governs the function of the GI tract - oesophagus to anus
- Termed the “second brain” - is embedded in the lining of GI tract
- ENS is essential for controlling digestive function: motor, secretory, blood flow, hormone release and motility

Problems affecting GI function in NI

- **Oral:** Problems with teeth, jaw, bruxism (grinding), sialorrhoea (drooling)
- **Orophangeal Dysfunction:** dysphagia, risk of aspiration
- **GORD:** risk of aspiration
- **Orthopaedic:** Scoliosis, trunk hypotonia
- **Vomiting**
- **Constipation**
- **Pharmacological:** Medication interactions and side-effects on GI function
- **GI Dystonia:** can related to 1 or more of the above

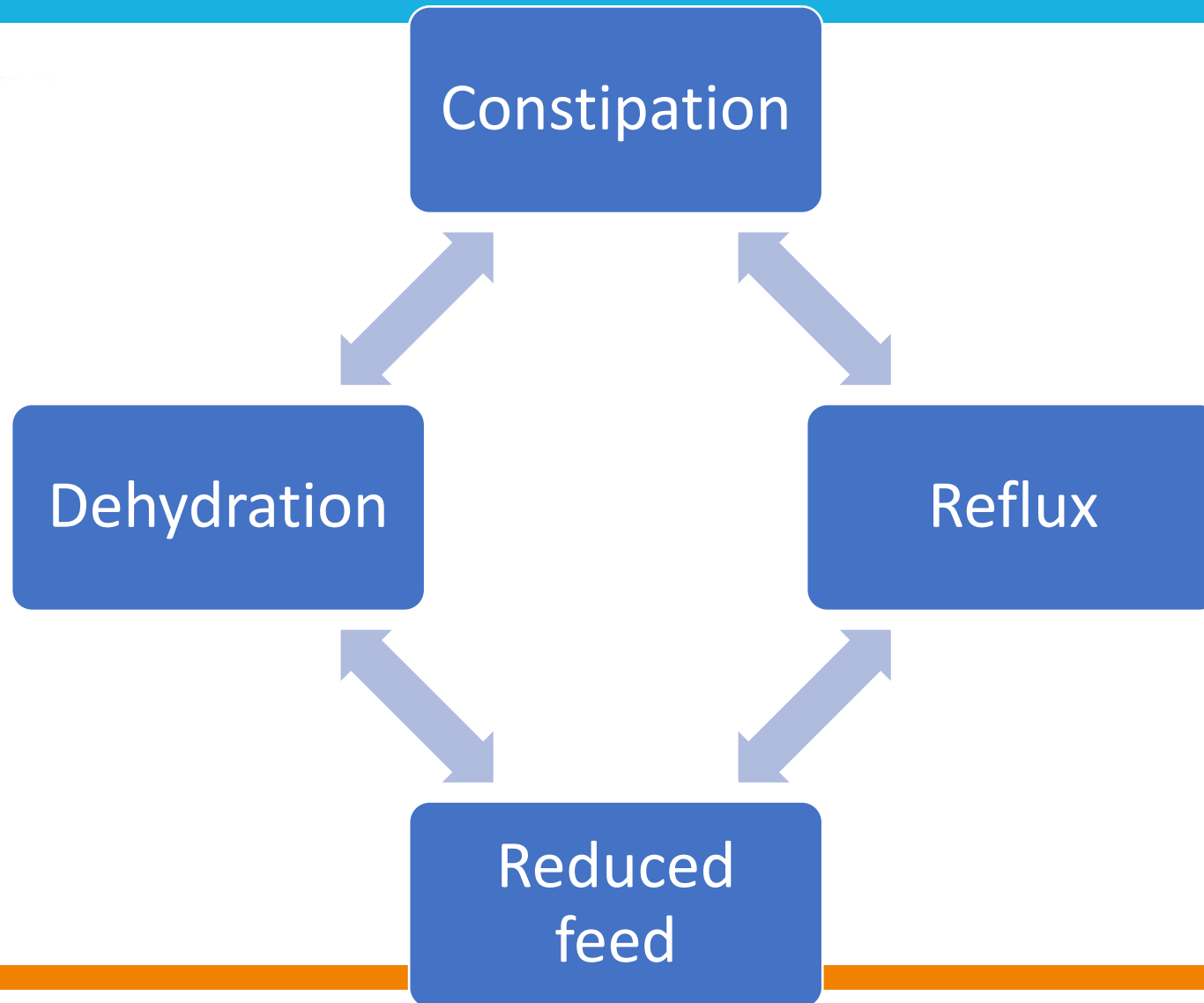
Potential cause of GI symptoms:

- Delayed gastric emptying
- Decreased intestinal motility
- Decreased abdominal muscle strength
- Posture/positioning
- Autonomic nerve dysfunction
- Side-effects of medications

Potential cause of GI symptoms:

- Inadequate nutrition: Feeding plans that fail to meet nutritional requirements leading to malnutrition
 - Undernutrition
 - Overfeeding – common in children with NI
- Inappropriate feeding plans may exacerbate symptoms, resulting in pausing or incomplete feeds being given

Interplay of GI Symptoms



Definition, investigation and management of gastrointestinal dystonia in children and young people with neurodisability

Barclay AR, et al. Arch Dis Child 2025;110:742–750.

- Panel of 27 experts from 13 UK specialist centres across the British Isles¹
- Stakeholder groups:
 - Gastroenterology
 - Neurology/neurodisability
 - Surgery
 - Palliative care
 - Allied health professionals

- Clinical manifestations of distress attributable to the gastrointestinal tract, directly and indirectly related to feeding and bowel habit, where confounding systems of distress have been addressed or excluded
 - Pain behaviour
 - Hypertonicity
 - Retching
 - Vomiting
 - Autonomic activation
 - Abdominal distension

Diagnostic features ¹	
Mandatory	GMFCS 4–5 or equivalent Temporal relationship between feeding and symptoms Positive clinical diagnosis made by MDT with expertise in feeding in severe neurodisability
Common	Temporal hypertonicity Distress Retching Malnutrition due to feed cessation Feed-related symptoms most significant reduction of quality of life
Rarer	Autonomic activation Inadequate evacuation effecting feed tolerance

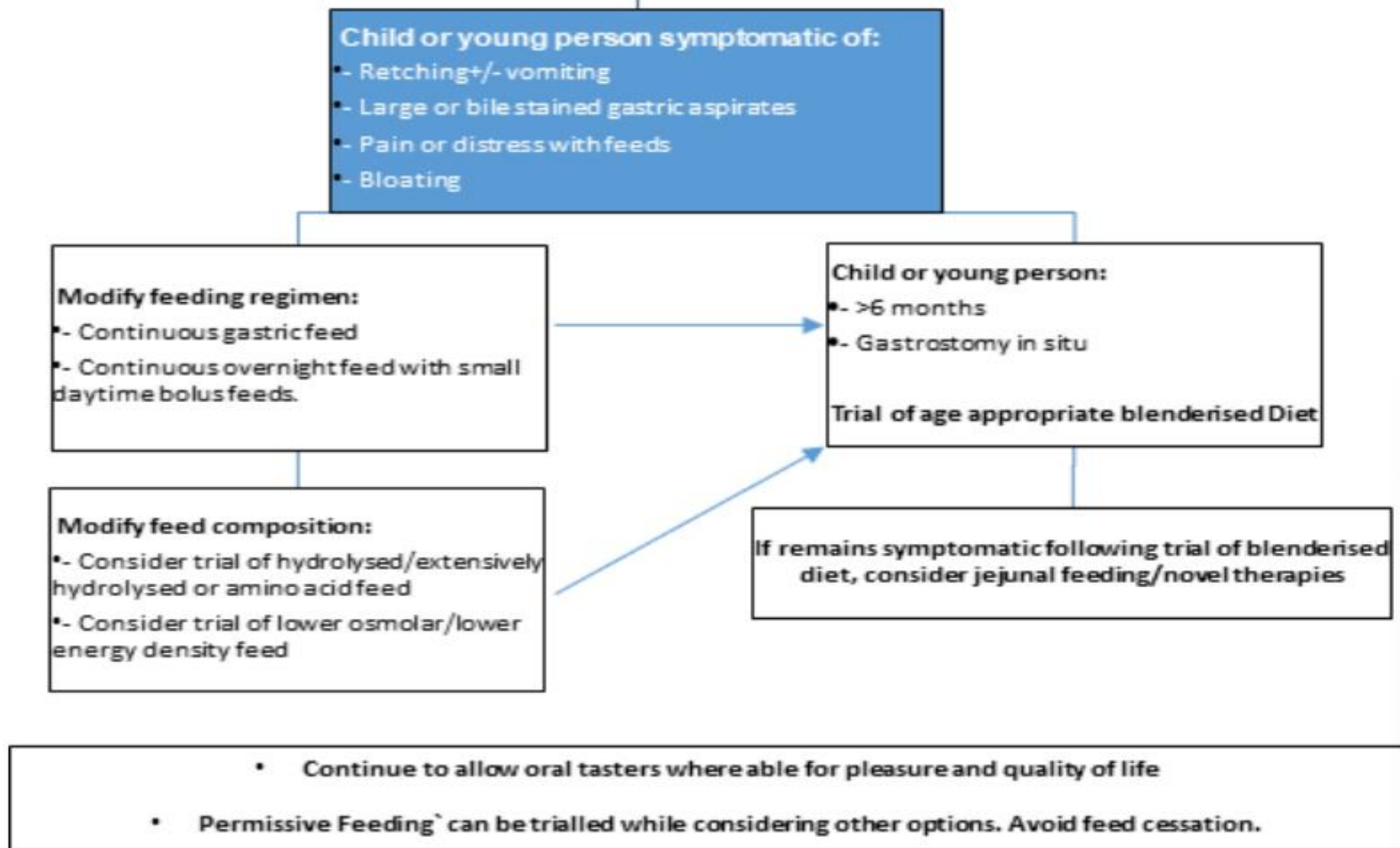
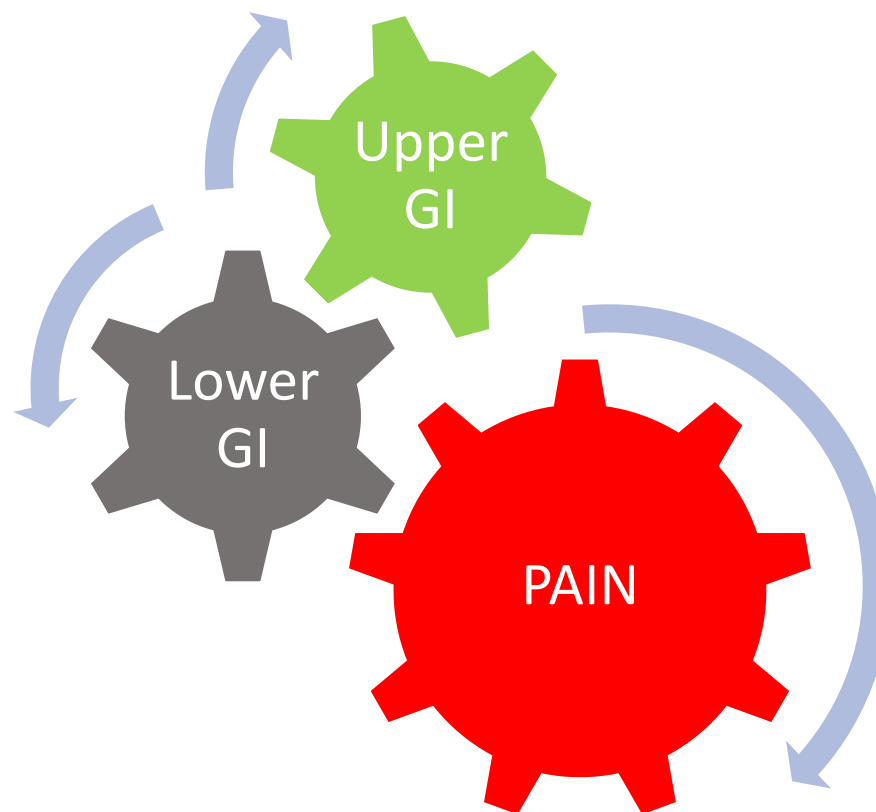


Figure 2 Nutritional interventions for GID. GID, gastrointestinal dystonia; MDT, multidisciplinary team.

Consider:

- Feed type
- Feed volume
- Route of feeding
- Medications
- Environment
- Carer support



Adapted from: APPM guideline
Gastrointestinal Dystonia in children and young people with
severe neurological impairment in the palliative care setting²



Route of feeding – Oral, gastric, jejunal, PN?



Feeding regime – bolus, continuous, combination?



Feed choice – polymeric, hydrolysed, amino acid, osmolality, energy density



BLENDED DIET – if gastrically fed and appropriate tube in situ

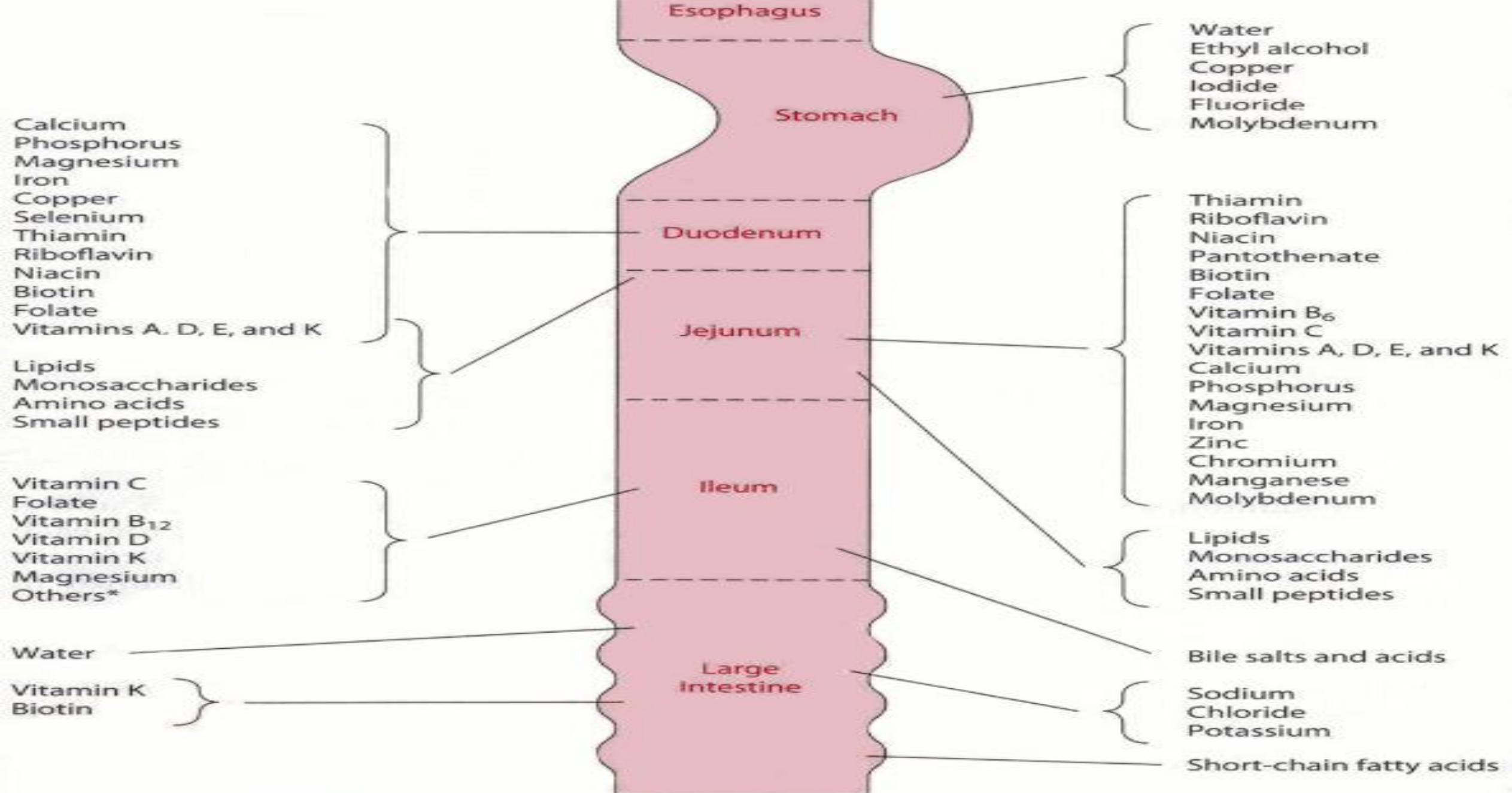


Medications - adding for symptom management, consider medication 'holidays' for drugs that are known to cause GI disturbance



Is deterioration in feed tolerance part of disease progression?

Nutritional goals may change from target of optimal nutrition to improving symptoms – palliative care pathway?



*Many additional nutrients may be absorbed from the ileum depending on transit time.

Courtesy: *Advanced Nutrition and Human Metabolism*, fifth edition.

SOCIETY PAPER

European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment

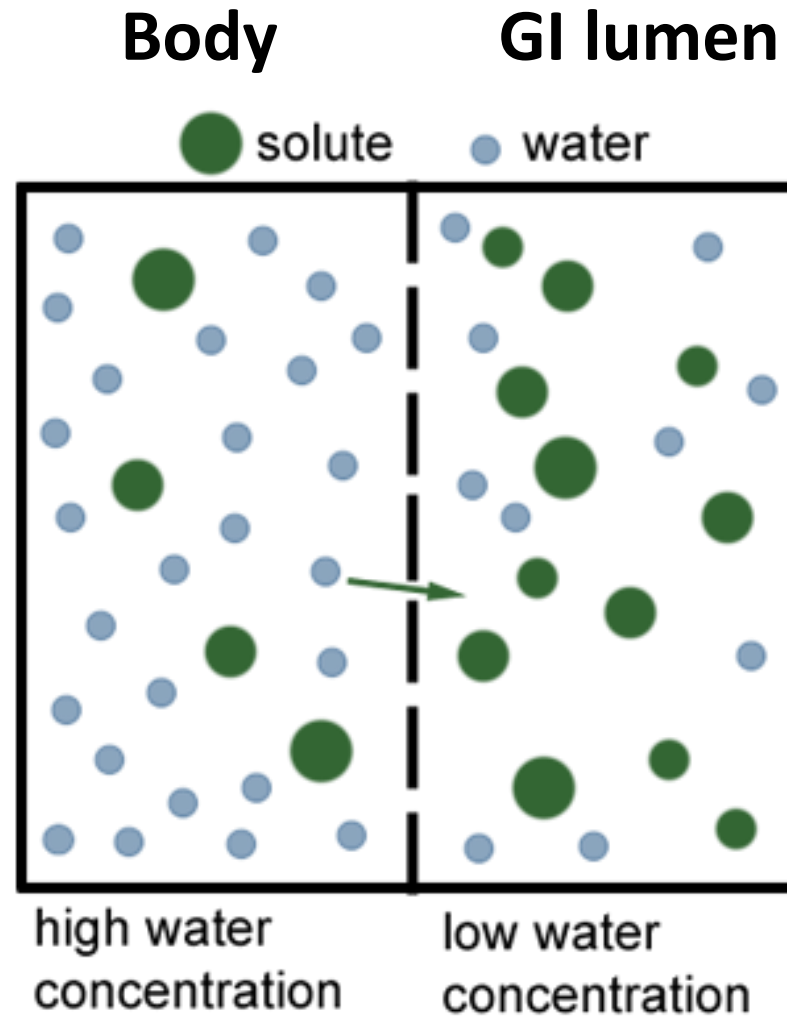
**Claudio Romano, †Myriam van Wynckel, ‡Jessie Hulst, §Ilse Broekaert, ||Jiri Bronsky,
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ABSTRACT

- ESPGHAN WG recommend:
- using a standard **1.0 kcal/mL polymeric** age-appropriate formula including **fibre** for children with NI older than 1 year
- using 1.5 kcal/mL containing fibre in cases of poor tolerance...., providing **hydration is carefully monitored**
- using a **low fat, low-calorie, high-fibre** and micronutrient-replete formula....after **nutritional rehabilitation** in immobile children with NI

- Pros and cons for each
- Bolus = more physiological
 - Gravity or pump-assisted intermittent feeding
 - Not suitable for jejunal feeding
- ESPGHAN WG recommendation:
 - using a combination of nocturnal continuous feeds with daytime bolus feeds in children with high calorie needs or poor tolerance to volume

- The osmolality of body fluid is around 300 mOsm/l
- Isotonic feeds have an osmolality similar to body fluid
- Hypertonic feeds draw water into the lumen of the gut, which can lead to:
 - Nausea
 - Vomiting
 - Diarrhoea
 - Cramping



Is high energy, low volume REALLY easier to tolerate?



**30 g clotted cream
= 175 kcal**



**265 ml whole milk
= 175 kcal**



- Supported by the BDA⁵
- Improves GI symptoms: Reflux, vomiting and constipation
- Improves microbiome
- Enhances QOL for patient and carers – normalises feeding

- Poole *et al*: Positive benefits of blended diet: weighing in on gastrointestinal dystonia⁶
 - Reduces need for invasive treatment of GID
 - Maintained nutritional status or improved growth compared to formula feeds
 - Improved symptoms and QOL
 - Reduced medications







Cycling feed types, novel enteral feed products



Improvements in medications to reduce GI side effects



Improved awareness and understanding of the need to focus on symptoms, QOL and not just growth



Improved MDT working, diagnosis and treatment of GI symptoms in children with NI



Increased use of blended diet - ?? Progress to jejunal blended diet with appropriate feeding pump



1. Barclay AR, Meade S, Richards C, *et al*. Definition, investigation and management of gastrointestinal dystonia in children and young people with neurodisability. *Arch Dis Child* 2025;110:742–750.
2. APPM Guidelines supported by Cochrane Response Gastrointestinal Dystonia in children and young people with severe neurological impairment in the palliative care setting. Authors: Warlow T *et al*
3. Smith J, Carr T, & Gropper, S. (2016). *Advanced nutrition and human metabolism* (5th ed.)
4. ESPGHAN: 2019 Recommendations for Nutritional Management of Children with Neurological Impairment (NI)
5. BDA Practice Toolkit The Use of Blended Diet with Enteral Feeding Tubes November. 2021
6. Poole R, Brooks M, Hay J, *et al*. P41 Positive benefits of blended diet: weighing in on gastrointestinal dystonia. *Frontline Gastroenterology* 2021;12:A36.

