



Feeding the Neurodisabled child

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Overview of presentation

- Historical considerations and oral feeding
- Recent guidance / references
- Setting the scene and “New natural history”
- Terminology
- Recognising symptoms and pattern of deterioration
- When to consider with parents that GI dysfunction may be life limiting
- Exploring role of changes to feed type, mode of delivery or drugs - creating an MDT approach
- Considering the parent voice: supporting parents’ decision making

Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study

Table II: Feeding and nutritional problem responses in relationship to the degree of motor deficit for those in Group A

<i>Feeding/nutritional problem</i>	<i>Total nr of participants</i>	<i>%</i>	<i>Severity of motor impairment</i>			<i>Pearson r</i>	<i>p value</i>
			<i>Mild</i>	<i>Moderate</i>	<i>Severe</i>		
Help with feeding needed	238/268	89	27	85	126	188.9	<0.001
Choking with food	142/257	56	12	38	90	62.68	<0.001
Feeding reported as stressful or unenjoyable by parent	51/262	20	5	11	35	10.74	< 0.005
Prolonged (≥ 3 h/d) feeding times	71/258	28	3	8	60	53.2	<0.001
Parents considered child underweight	93/240	38	6	25	62	26.87	<0.001
Child received caloric supplements	23/271	8	1	2	20	15.64	<0.001
Gastrostomy feeding	20/265	8	1	0	19	19.63	<0.001
Never had feeding and nutritional status assessed	169/264	64	32	77	60	28.15	<0.001
Frequent vomiting	55/249	22	1	12	42	33.3	<0.001
Bowels opened > every 3 days	68/267	26	5	16	47	17.2	>0.002

Oral feeding challenges in the neurodisabled child

Posture and motor control	Poor head, trunk or pelvic stability; abnormal tone; fatigue
Oral-motor skills	Reduced lip closure; tongue-thrust or persistent extrusion reflex; poor jaw grading; weak chewing; inefficient bolus formation and propulsion; drooling
Swallowing safety	Delayed swallow; unsafe swallow
Sensory and behavioural factors	Oral hypersensitivity or aversion; reduced communication of hunger or satiety
Mealtime efficiency	Very slow feeding; prolonged meals; frequent pauses; fatigue; dependence on a specific carer and / or specialised utensils

Homemade blended diet

Social and Psychological factors	Gives a sense of normalcy and nurturing for the family. Convenience +/-
Food allergies	Allow for careful control over known food allergens
Gastrointestinal tolerance	Significant reduction in symptoms such as gagging, retching, diarrhoea, nausea and vomiting
Gastrointestinal Microbiota	Blenderised diets are associated with increased intestinal bacterial diversity and improved gut microbial composition
Financial cost	Generally, cheaper compared with commercial formulas
Obstruction of the tube	Have higher viscosity than commercial feeds and this can raise the possibility of tube blockage
Nutrient supply	Can have an inconsistent and unpredictable micronutrient and macronutrient profile
Microbial contamination	The microbial content of blenderised feeds may be higher due to improper food handling, preparation and storage

Commercial food-based formula



Commercial food-based formula (CFBF)

- Better GI tolerance, reduced medical burden, and improved caregiver-reported quality of life
- CFBF vs plant-based standard tube feeds → significantly fewer inpatient admissions, ED/urgent care visits, and lower overall healthcare costs

Microbiome, Immunity and Neurological Outcomes

Microbiome mechanisms (plausible, increasingly supported)

- Children on liquid/low-fibre tube feeds show:
 - Lower microbial diversity and fewer SCFA-producing taxa (*Faecalibacterium*, *Ruminococcus*, *Lachnospirillum*). Enrichment of taxa linked to barrier dysfunction and inflammation.
- Fibre-rich, whole-food blended diets are associated with higher SCFA producers and improved GI symptom profiles, consistent with enhanced barrier function, reduced inflammation, and better motility.

Microbiome–immunity link (general paediatric evidence)

- Antibiotic-perturbation studies: disrupted gut microbiota → weaker vaccine antibody responses (influenza, rabies, SARS-CoV-2).
- Probiotic/bacterial lysate trials: modest reductions in respiratory infection frequency/severity in children.

Neurological/developmental outcomes: current gap

- No robust evidence yet that blended diets improve core neurological outcomes (motor function, cognition, seizure control) via microbiome changes.

Setting the scene:

Blair *et al.* *BMC Neurology* (2019) 19:111
<https://doi.org/10.1186/s12883-019-1343-1>

BMC Neurology

RESEARCH ARTICLE

Open Access

Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and National Death Index

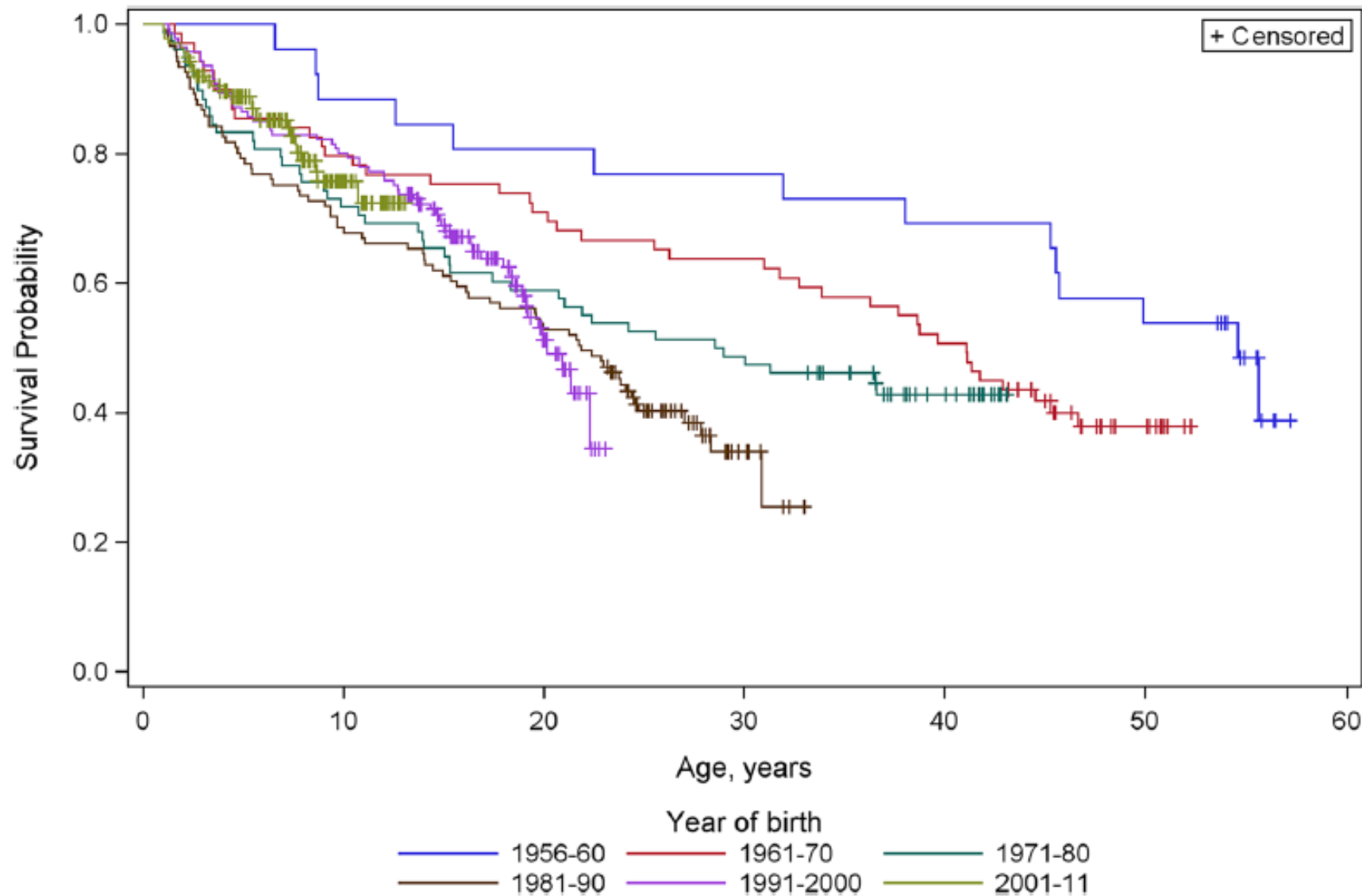


Eve Blair^{1,2*} , Katherine Langdon³, Sarah McIntyre^{1,4,5}, David Lawrence⁶ and Linda Watson⁷

Western Australia CP register born between 1956 and 2011.

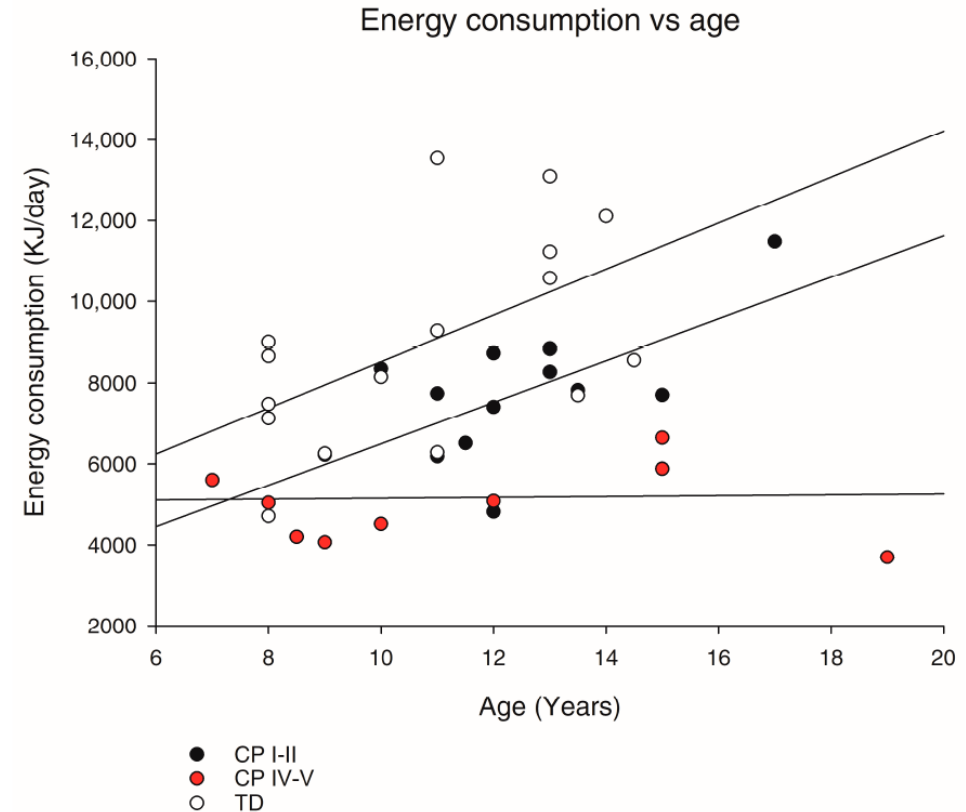
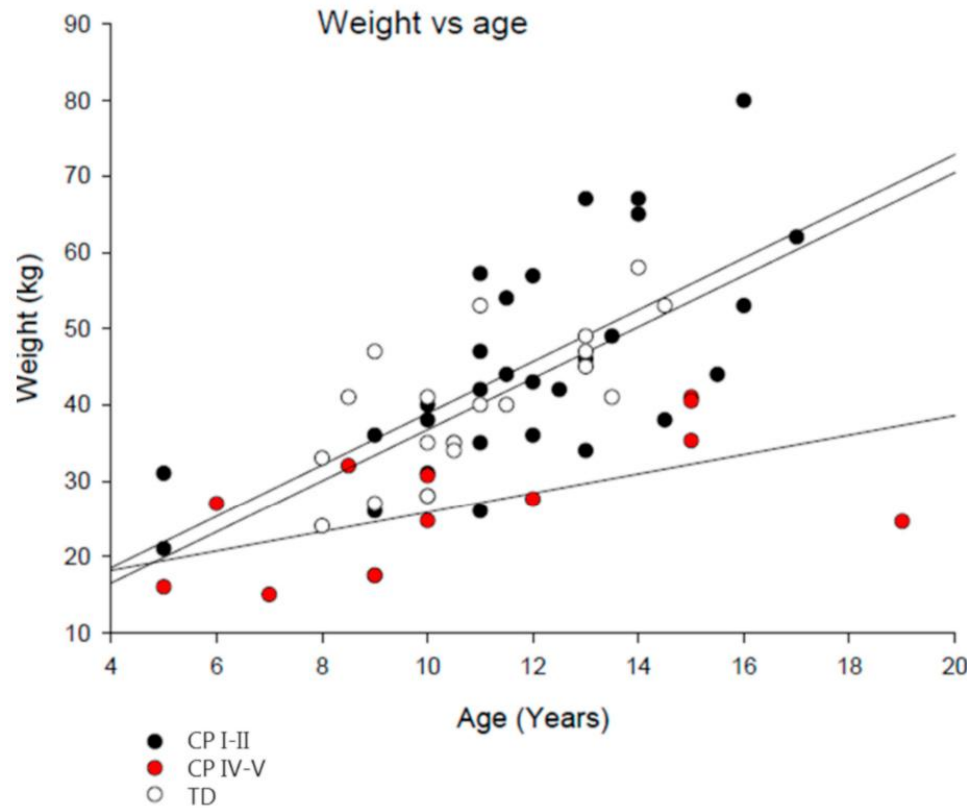
3185 CP registrants surviving at least 1 year, of whom 436 (13.7%) had died as of December 2014 and 2749 had not.

“New natural history” :



Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and National Death Index Blair et al. BMC Neurology (2019) 19:111

Weight and energy intake by age in children with cerebral palsy



Suboptimal Nutrition and Low Physical Activity Are Observed Together with Reduced Plasma Brain-Derived Neurotrophic Factor (BDNF) Concentration in Children with Severe Cerebral Palsy (CP) *Nutrients* 2019, 11(3), 620;

Gastrointestinal dysfunction in the significantly neurologically impaired (SNI) child - terminology

- **Gastrointestinal Dysfunction** - A spectrum ranging from poor oro-motor coordination, gastro-oesophageal reflux (GOR) and constipation at the mild end to more severe GI dysfunction associated with GI dysmotility and feed-induced GI dystonia.
- **Gastrointestinal Dystonia (GID)** - *“Clinical manifestations of distress (pain behaviour, hypertonicity, retching, vomiting, vagal phenomenon, abdominal distension) attributable to the gastro-intestinal tract, directly and indirectly related to feeding and bowel habit, where confounding systems distress have been addressed or excluded.”*
 - Child has Severe Neurological Impairment (SNI) (GMFCS 4-5 or equivalent)
 - A temporal relationship with feeding and symptoms must be present (although this may lessen or cease in progressive disease)
 - Feed intolerance that has reached the threshold for GID would include malnutrition primarily due to periods of feed cessation or reduction, or gastrointestinal symptoms being the greatest burden on quality of life (QoL) for the child and family.

Gross Motor Function Classification System



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Gastrointestinal dysfunction in the significantly neurologically impaired (SNI) child - terminology

- **Intestinal failure**

Reduction of functional gastrointestinal mass below that needed for digestion and absorption of fluid and nutrients for maintenance in adults and growth in children.

A child requiring greater than 50% of calories by the parenteral route for greater than or equal to 28 days post-term corrected gestational age

- **Intractable Feeding Intolerance** - Intractable symptoms and suffering from enteral feeding which may lead to an inability to sustain life via the enteral route.

“New natural history” :

- “The enteric nervous system, a semiautonomous part of the nervous system responsible for regulating the gastrointestinal (GI) function, is invariably affected with neurodisabilities and can drive some GI complaints. With increasing longevity of children on the extreme end of neurodisability, a new chapter of complex GI symptoms begins to unravel, and novel terminologies, such as GI dystonia, although poorly understood, are fast becoming embedded in medical jargons”.

Mutalib M. Arch Dis Child 2021;106:736–738

- Improved survival is likely related to medical advances and access to medical technologies and supports, including non-invasive mechanical ventilation for children with chronic respiratory failure. Therefore, we are witnessing a “new natural, or perhaps ‘unnatural’ history” for children with SNI whose lives are being extended by medical advances.

Katz NT et al. American Journal of Hospice and Palliative Medicine. 2023;0(0).

Association for
Paediatric
Palliative
Medicine

APPM Guidelines
supported by
Cochrane Response

Gastrointestinal
Dystonia in children
and young people
with severe
neurological
impairment in the
palliative care setting

Authors: Timothy Warlow, Jill Yates,
Naomi Taylor, Gemma Villanueva, Bindu
Koodiyedath, Lizzie Griffiths, Pat Sartori,
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Guidance / references:

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Intractable Feeding Intolerance in Children With Severe Neurological Impairment: A Retrospective Case Review of Nine Children Known to a Pediatric Palliative Care Service

Paediatric Palliative Care Program
Royal Children's Hospital
Melbourne
Australia.

*American Journal of Hospice
& Palliative Medicine®*
2023, Vol. 0(0) 1–10

Review

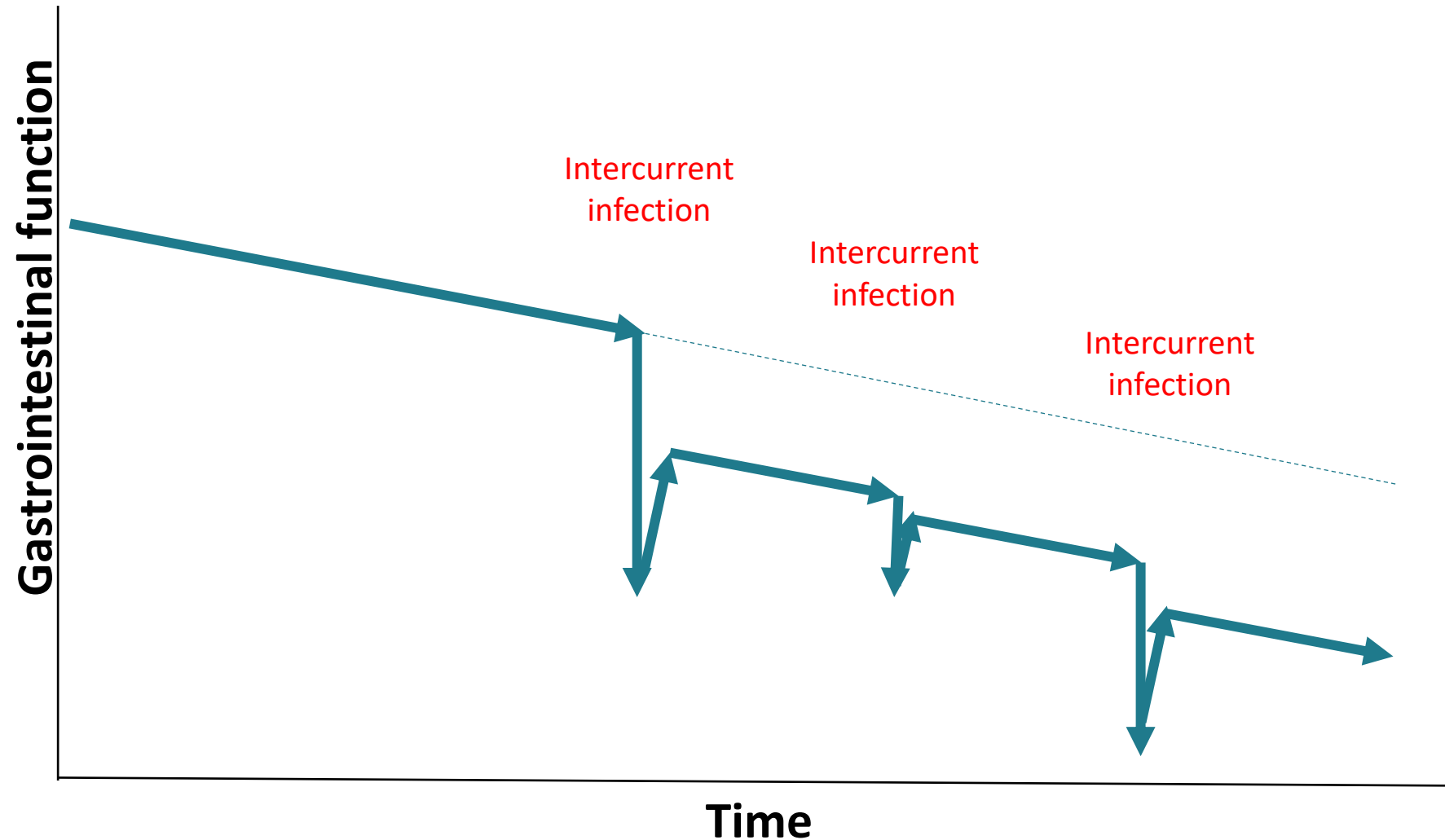
Feeding Intolerance in Children with Severe Impairment of the Central Nervous System: Strategies for Treatment and Prevention

Children 2018, 5, 1; doi:10.3390

Parenteral Nutrition in Pediatric Patients with Neurodisability: Current Perspectives

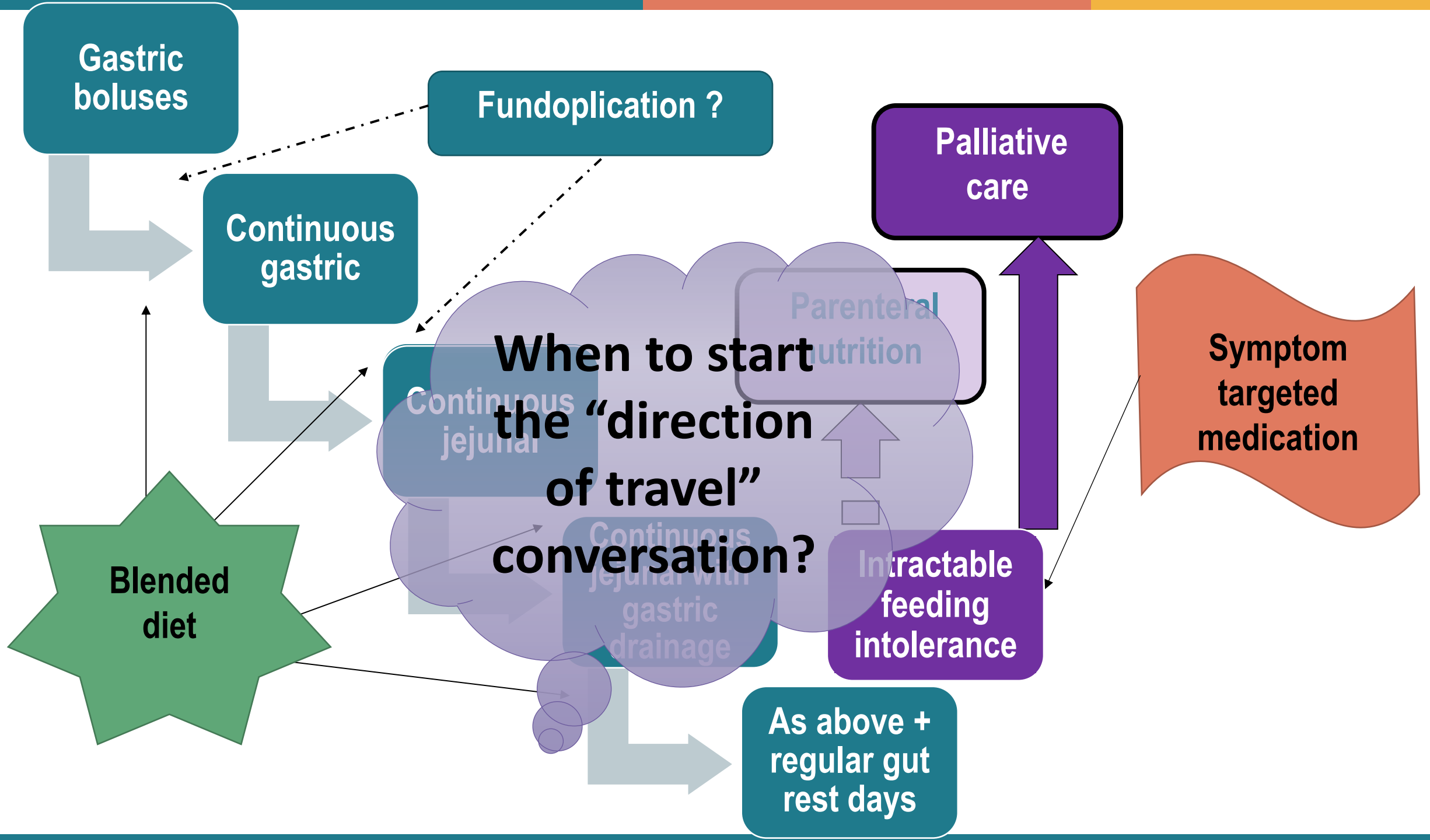
*Pediatric Health, Medicine and
Therapeutics* 2023;14 11–17

Natural history of feeding intolerance in children with severe neurological impairment



Managing acute deterioration at times of intercurrent illnesses

- May be un-feedable gastrically +/- jejunally
- Period of gut-rest with enteral Dioralyte
- May not be able to tolerate even Dioralyte or enteral drugs
- Admission for intravenous fluid and drugs (+/- PN)
- **REMEMBER** – status dystonicus if enteral Baclofen stopped

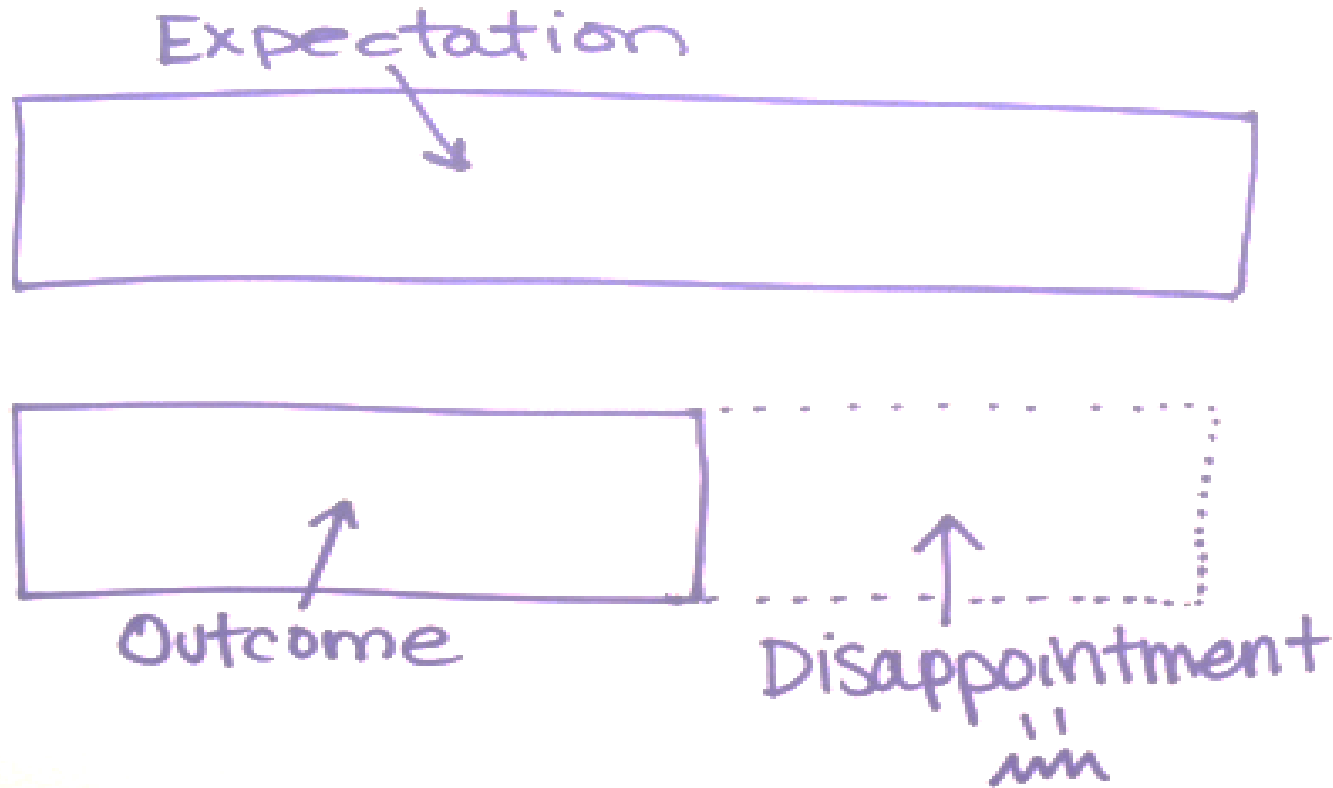


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2023, Vol. 0(0) 1–10*

- “The first mention of GI dysfunction or failure occurred within 2 months of death in 4 patients and 13 months in all children, possibly suggesting that recognition or articulation of the potentially life-limiting extent of GI problems occurs late”.
- “Intractable feed-related suffering and the inability to tolerate enteral feeding despite escalating feeding support (medications, tube feeding) are not typically seen as potentially irrecoverable organ dysfunction in the same way that escalating respiratory support is understood to represent deterioration in respiratory function”.
- “We suggest that recurrent or progressive difficulty in sustaining life via the enteral route is a sentinel moment in the life of, and crossroads in care for, a child with SNI, and warrants careful consideration of the clinical presentation and appropriateness of interventions”.

Start the “direction of travel” discussions early



bringing focus from
nutrition to quality of
life

Investigation and drug therapy

A Framework

Children with SNI and recurrent retching, emesis, and feeding intolerance often have multiple sources that contribute to these symptoms.

1. Problems with tests that are “fixable”: urinary tract infection (UTI), acute pancreatitis, cholecystitis, nephrolithiasis, volvulus, helicobacter pylori.
2. Problems with tests that can be modified and empirically managed: GERD, dysmotility.
3. Problems without tests due to the altered nervous system that can be modified, require empirical trials, and can remain intractable: autonomic dysfunction, altered enteric nervous system, visceral hyperalgesia, central neuropathic pain, altered vomiting centre in the medulla.

Recognising symptoms and pattern of deterioration

Table 1. Chronic sources of retching, emesis, and visceral pain.

Cause	Management Options	Comments
Constipation		Colonic distention from constipation can trigger pain symptoms due to visceral hyperalgesia and central neuropathic pain
GERD, motility disorders		Motility disorders can be a result of impaired input from the CNS to the enteric nervous system Suggested by bloating, distension, retching, vomiting, discomfort Other problems can contribute, including constipation and pain
Vomiting reflex		Suggested by retching, forceful vomiting, and associated symptoms of sweating, pale skin, and appearing distressed Hypersalivation / mouthing / reluctance to orally feed / air swallowing
Visceral hyperalgesia, central neuropathic pain		Suggested by pain, retching, and emesis associated with feedings, intestinal gas, flatus, and bowel movements Dystonia / distress / self harm / aggression
Autonomic dysfunction		Suggested by pain and emesis associated with tachycardia, hyperthermia, diaphoresis, and skin flushing Dystonia

Ach: acetylcholine; CNS: central nervous system; D: dopamine; H: histamine; 5HT: serotonin; GERD: gastroesophageal reflux disease; PPI: proton pump inhibitor.

Recognising symptoms and pattern of deterioration

Phenotype	Presentation
Pain predominant	• Intermittent feed intolerance with pain and distress which resolves or improves on feed reduction/cessation. • Feed intolerance associated with episodes of intercurrent illness. • Increased frequency and severity of episodes over time. • Autonomic symptoms which may mimic potential infection.
Upper GI predominant	• Intermittent nausea, retching or vomiting which resolves or improves on feed reduction or cessation. • Nausea, retching and vomiting cause distress/agitation and worsen dystonia. • Symptoms often exacerbated by episodes of intercurrent illness. • Increased frequency and severity of episodes over time. • May include pain, distention and be associated with autonomic activation.
Lower GI predominant	• Intermittent abdominal distention, severe pain and distress with temporal association to bowel habit. • Symptoms worse when bowels not opened for period of time. • Symptoms worse on defecation and passing wind. • Associated with marked, intermittent abdominal distension in absence of other signs of acute abdomen.

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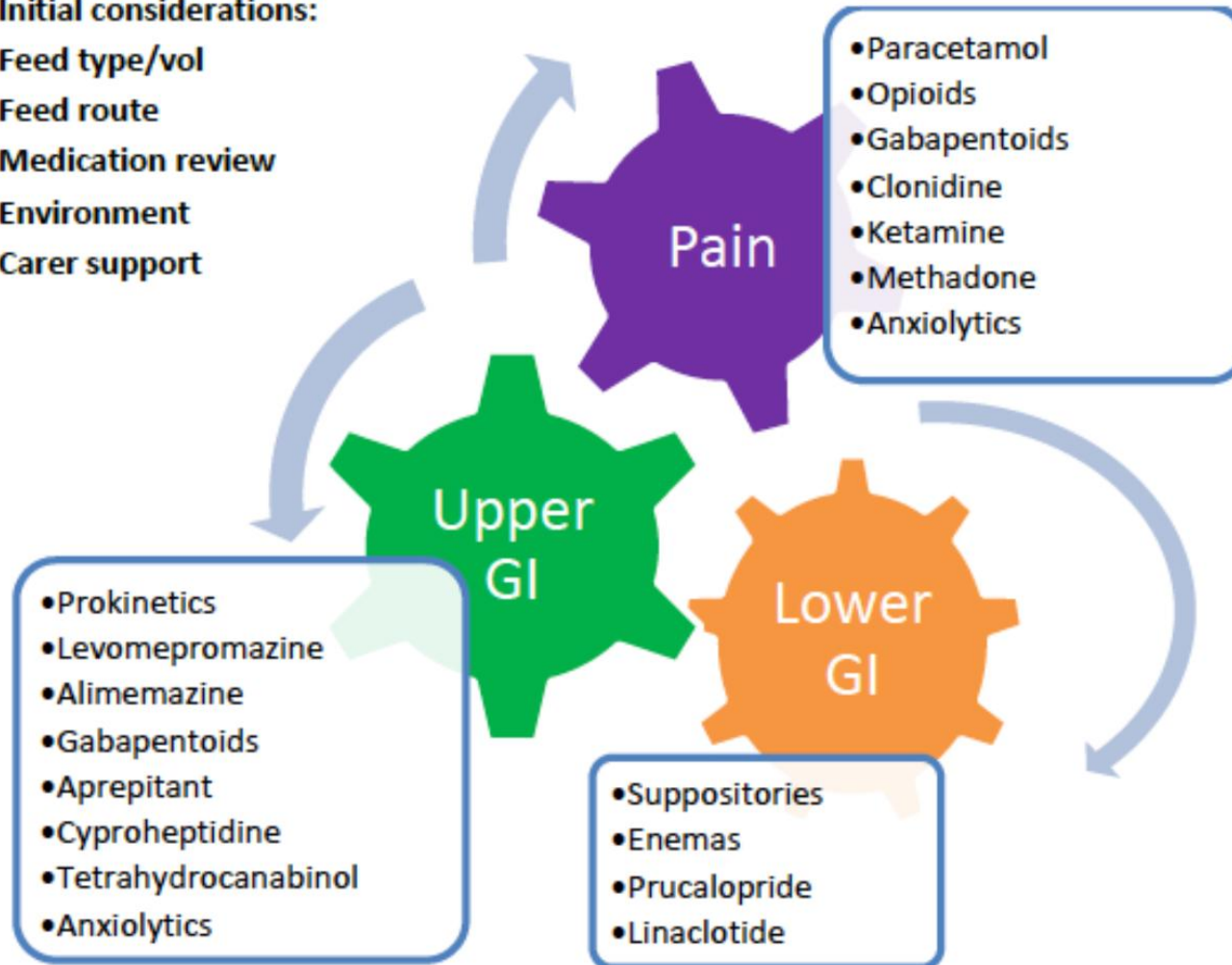
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Editor: AK Anderson

Exploring role of drugs: creating an MDT approach to manage therapy trials

Initial considerations:

Feed type/vol
Feed route
Medication review
Environment
Carer support



Expert advice for
complex
symptoms and
medication
combinations

Goal setting
monitoring and
evaluation

Psychosocial and
spiritual support

Symptom and
advance care
plans written

End of life care

Management

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Treatment – basics – my tips

1. Could the dysmotility be secondary to cow milk protein allergy?
Always trial a cow milk free diet / amino acid based feed for 4 weeks
2. Could small bowel overgrowth be contributing?
Trial metronidazole / Rifaximin enterally
3. Could constipation be contributing?
Often enteral Movicol / Laxido + rectal stimulants tolerated best
4. GORD symptoms but failure of response to anti-reflux treatment?
Complications of GID may be mis-attributed to GORD.
5. Worsening self harm / behaviour?
Trial a period of stopping feed & giving Diarolyte
6. How much of child's symptomatology is due to aerophagia?
Could gastric decompression help?

Usual first considerations

Difficult gastric feed tolerance:

- Trial feed change to a commercial food-based formula or blended diet
- Optimise PPI
- Consider whether visceral hypersensitivity or delayed gastric emptying is the most likely driver

Visceral hypersensitivity – trial Gabapentin

Delayed gastric emptying – trial treating constipation or small bowel overgrowth
– trial prokinetic

Considering the parent voice: supporting parents' decision making



My Anticipatory Care Plan

For Babies, Children and Young People

Name: _____

This Anticipatory Care Plan can help you and your family or carer start talking to your care support team about you and your condition and what matters to you. If required, your family or carer can then help you write your wishes in your plan. As your plan is kept by you and your family or carer, you can then let everyone who's caring for you know your wishes and they can make them happen.

To PN or not PN

“In most high-income countries, the advanced provision of care to children with severe neurodisabilities allowed ‘invasive’ support to become acceptable, and complex orthopaedic procedures, neurosurgical operations, intensive care and airway support are considered routine across the spectrum of neurodisabilities. Organ transplantation are increasingly offered to children with significant neurodisabilities. An argument will arise why long-term and home PN is not routinely offered to these children”.

White E, Mutalib M. Parenteral Nutrition in Pediatric Patients with Neurodisability: Current Perspectives. *Pediatric Health Med Ther*. 2023 Feb 5;14:11-17

McCallum Z, Delany C, Gillam L. Crossing the line? Ethics of parenteral nutrition in paediatric neurodisability complicated by intestinal failure. *Arch Dis Child*. 2023 Jan;108(1):11-14.

To PN or not PN – my approach

- Prepare the way – start talking about the direction of travel early
- Listen, care & develop a trusting relationship
- Gradually move the focus from nutrition to QOL
- Be proactive +++ in trying everything to improve nutrition - but only to limit of tolerance
- Be open and honest
- Bring up PN as a treatment. Explain why you don't recommend it.

Dear Dr Bunn,

We wanted to send a little note to say thank you for 'being you.'

From the first time that you met our little darling we felt that [redacted] was better understood & listened to. You always showed such compassion towards the difficulties & pain that [redacted] so often experienced.

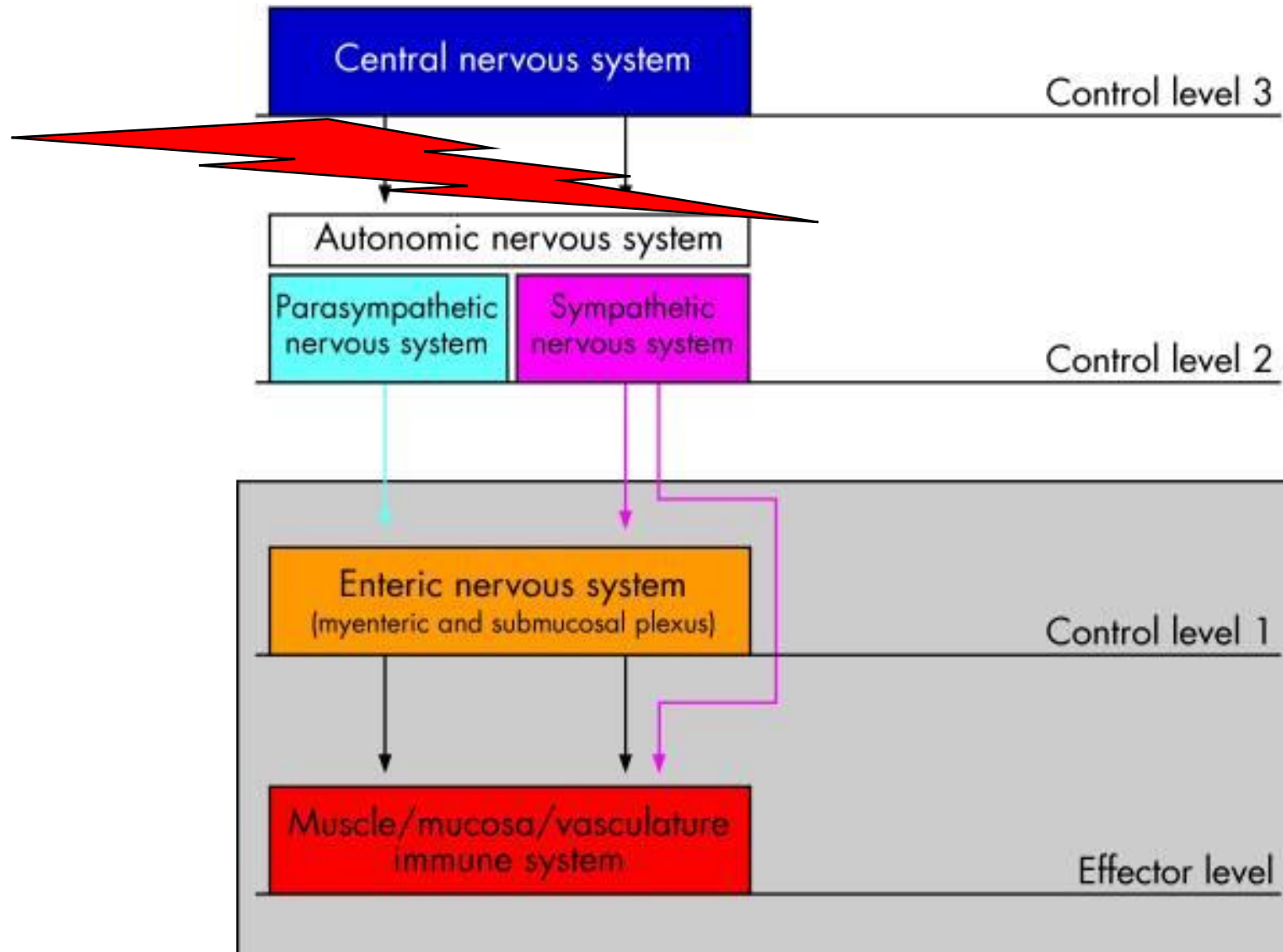
Your support in making care whenever possible at home instead of hospital was always so greatly appreciated for our little 'home-bird.' You had to share some of the hardest news for us to hear in [redacted] short life but we always appreciated your honesty & the respect you showed towards [redacted] & ourselves.

Kindest regards

Overview of presentation

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Neurological control of GI function



Foregut Dysmotility

High density of autonomic innervation

1. Oesophageal dysmotility
2. GORD
3. Antro-duodenal dysmotility
4. Retching
5. Dumping Syndrome

Foregut

