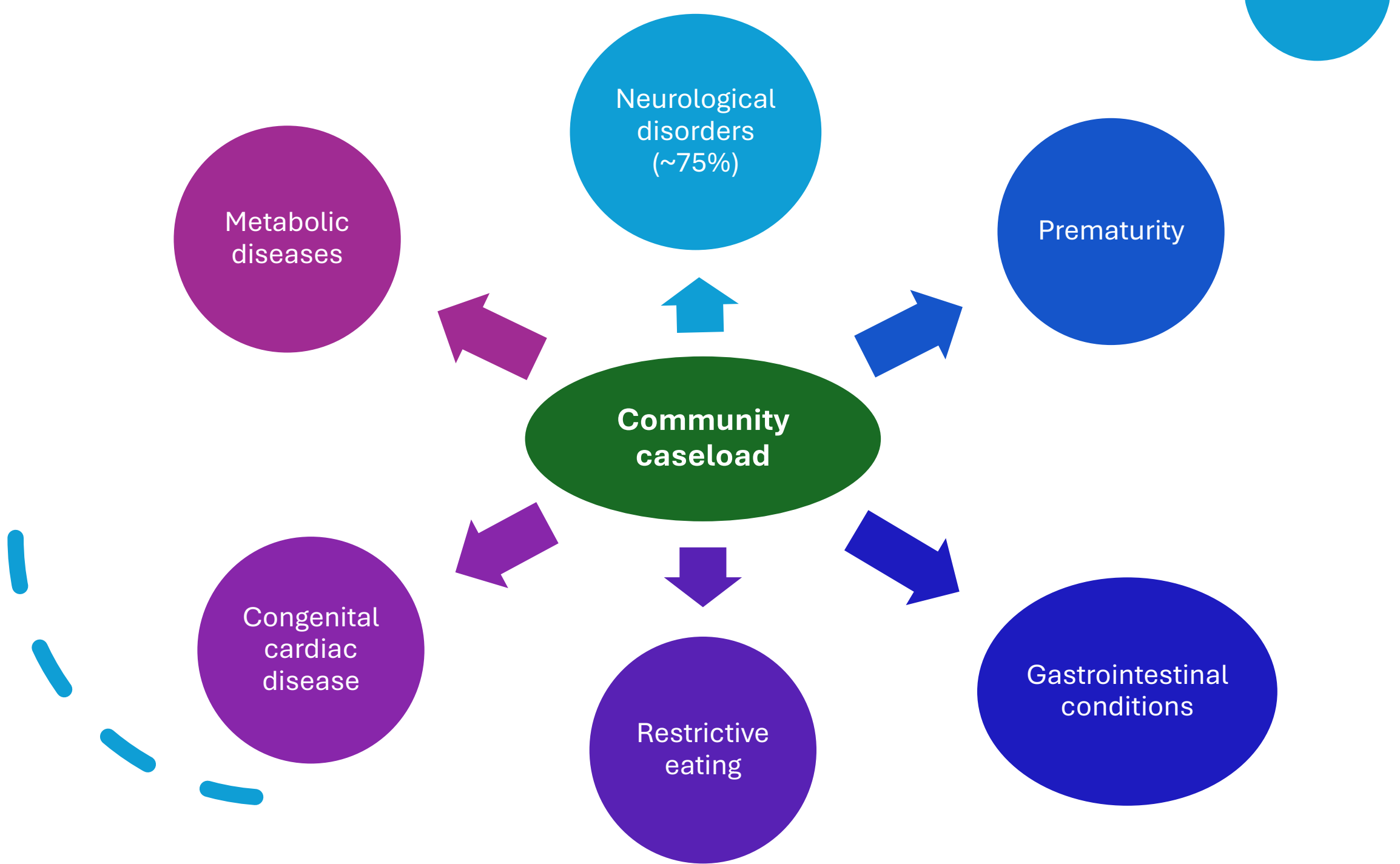


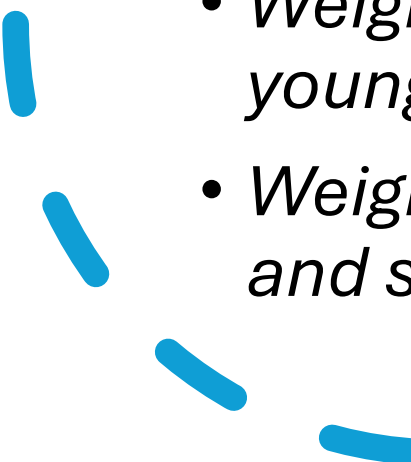


Complex Management of Enteral Feeding – tube weaning strategies

**Kinga Dojnikowska
Specialist Paediatric Dietitian**



Tube feeding should be considered in the following situations:

- 
- *Unsafe swallowing and risk of aspiration*
 - *Inability to consume at least 60% of energy needs by mouth*
 - *Total feeding time of more than 4 hours per day*
 - *Weight loss or no weight gain for a period of 3 months (less for younger children and infants)*
 - *Weight for height (or length) less than 2nd percentile for age and sex*

The decision to tube feed



SHARED DECISION
MAKING

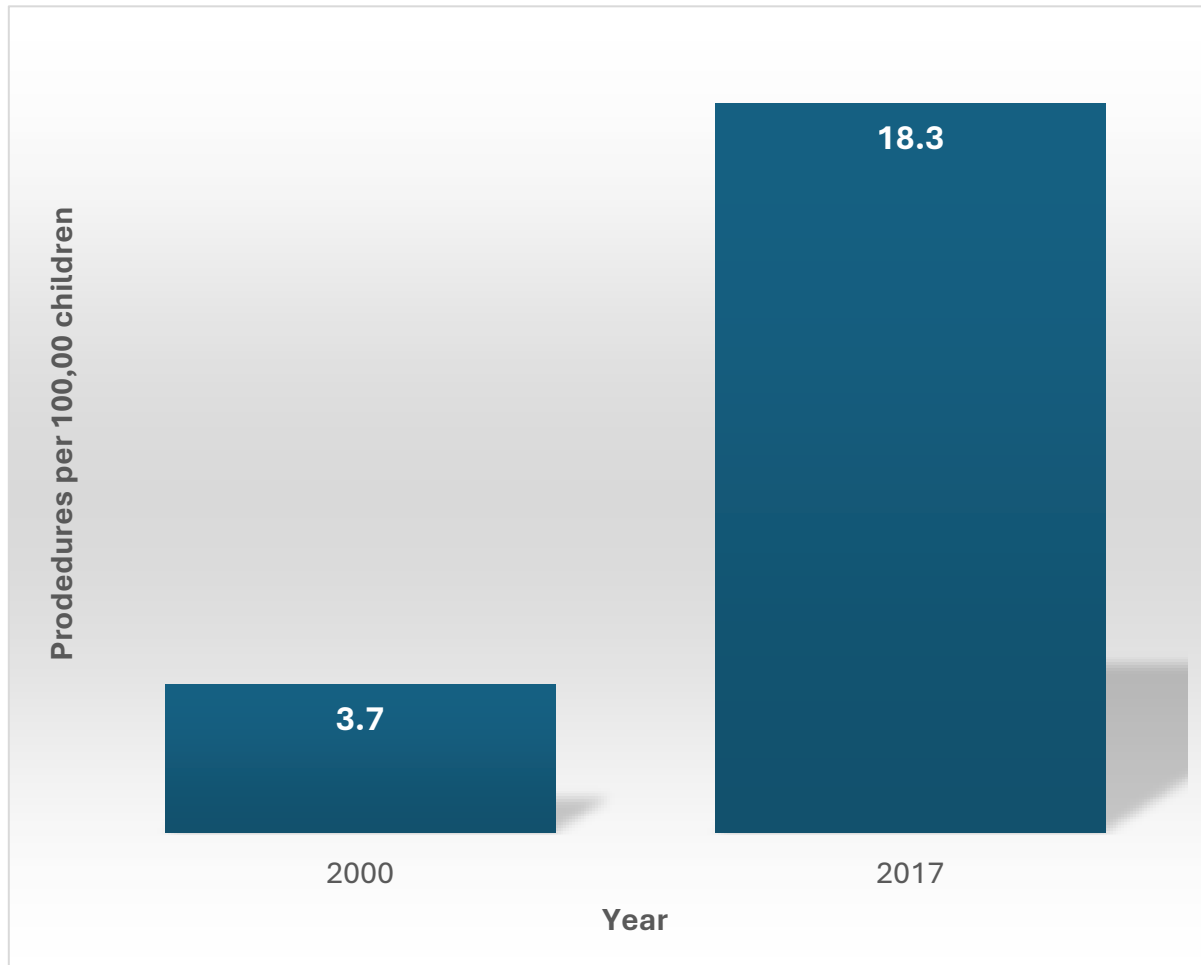


ETHICAL
CONSIDERATIONS



LONG TERM GOALS

Increasing reliance on enteral feeding: are we challenging long-term goals?



Figures suggest diseases contributing to need for enteral nutrition has remained stable e.g. prevalence of cerebral palsy remained stable (1.5-3.3 per 1000 birth) since 1985.

(Popescu & Mutalib, 2023)

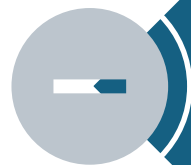
'Tube feeding dependency'



Poorly developed oral motor skills/ reduced positive oral stimulation



Disrupted hunger-satiation



Food aversion from unpleasant feeding experience (i.e., coughing, gagging, reflux, and vomiting)



Impaired child-caregiver interaction

(Goldstein et al. 2025; Krom et al., 2017)

Impact of tube feeding

Increase risk of
medical
complications

Limited
opportunities for
socialising

Cost

Quality of life

Family burden

Increased
parental anxiety
and stress

Tube weaning

“All the processes and interventions required to transition an individual from a nasogastric/gastrostomy tube dependency to oral feeding of solid or functionally appropriate food that would be considered age-appropriate in a typically developing cohort and meet all his or her nutritional needs without disproportionately affecting development, social environment, and family”

(Dipasquale et al., 2022; Dovey et al., 2018)

Table 4. Eligibility criteria for tube weaning [15].

Eligibility Criteria for Tube Weaning ¹
Stable underlying chronic disease
Absence of short- or medium-term scheduled procedures that could cause or raise the risk of malnutrition (i.e., surgery and organ transplantation)
Satisfactory or at least stable nutritional status according to standard or disease-specific growth charts
Safe and functional swallowing
Family willingness and availability

¹ Children must fulfill all the conditions.



Strategies of tube weaning

- Hunger provocation
- Behavioural and sensorimotor interventions
- MDT approach with parent education and training
- The 'Graz model'
- Pharmacological approaches
- In patient
- Outpatient
- NHS – community based

(Clouzeau et al.; 2022; Goldstein et al. 2025;
Wright et al., 2022)

REVIEW ARTICLE



Weaning children from prolonged enteral nutrition: A position paper

Haude Clouzeau^{1,10}, Valeria Dipasquale ^{2,10}✉, Laila Rivard³, Katia Lecoeur², Audrey Lecoufle², Valérie Le Ru-Raguénès⁴, Dominique Guimber², Véronique Leblanc⁵, Gaelle Malécot-Le Meur⁶, Sophie Baeckeroot⁷, Audrey Van Malleghem², Irène Loras-Duclaux⁸, Amandine Rubio⁹, Aline Genevois-Peres⁷, Sophie Dubedout⁷, Mélanie Bué-Chevalier⁴, Marc Bellaïche⁵, Véronique Abadie⁶ and Frédéric Gottrand ²

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Core Recommendations & Strategies

- ✓ The Multidisciplinary Approach
 - ✓ Multimodal Programs
 - ✓ Outpatient clinic as first-choice setting for weaning
 - ✓ Progressive Volume Reduction
 - ✓ Safety & Abort Triggers
 - ✓ Post-Weaning Surveillance
 - ✓ Tube Removal Timeline
-

Factors associated with failure and success of tube weaning



Age



Duration of
enteral feeding



Oral feeding
skills



Medical
complexity



Parental
motivation

(Dipasquale et al., 2021)



Case studies...



Consideration

- Prolonged nasogastric feeding is common and can be associated with increased food refusal/ oral aversion.

(Ricciuto et al., 2015)

Case Study 1 - Noah

- Age 2 months
- Background: Neonatal stroke, Transposition of the great arteries, Ventricular Septal Defect, Coarctation of the aorta
- Nasogastric tube in situ. Difficulty feeding with history of vomiting, pump feeding (as bolus) due to not tolerating gravity feeding– slow feeding rate gradually increased over time
- Seen in joint feeding clinic with Dietitian and SLT Dysphagia



7 months

Accepting 5-10ml of milk orally 3-4 times a day. Bottle offered before NG feed.

Minimal interest in oral tasters

10 months

Putting biscuits in his mouth but not swallowing. Discussion re PEG referral with parents, SLT and Paediatrician

9 months

Refusing milk from bottle, no interest in puree. Happy to touch and play with food but would not taste. Would put empty spoon into his mouth, but wouldn't touch it if it was covered in puree

Oral aversion likely due to negative oral experience

13 months

Starting accepting sips of water and 1-2 spoons of fruit puree

16 months

Gastrostomy inserted
Significant improvement in oral intake
More interest in food, but fluid intake remained poor

24 months

Started accepting feeds orally,
gastrostomy feeding discontinued

Age of 31 months

Gastrostomy removed

22 months

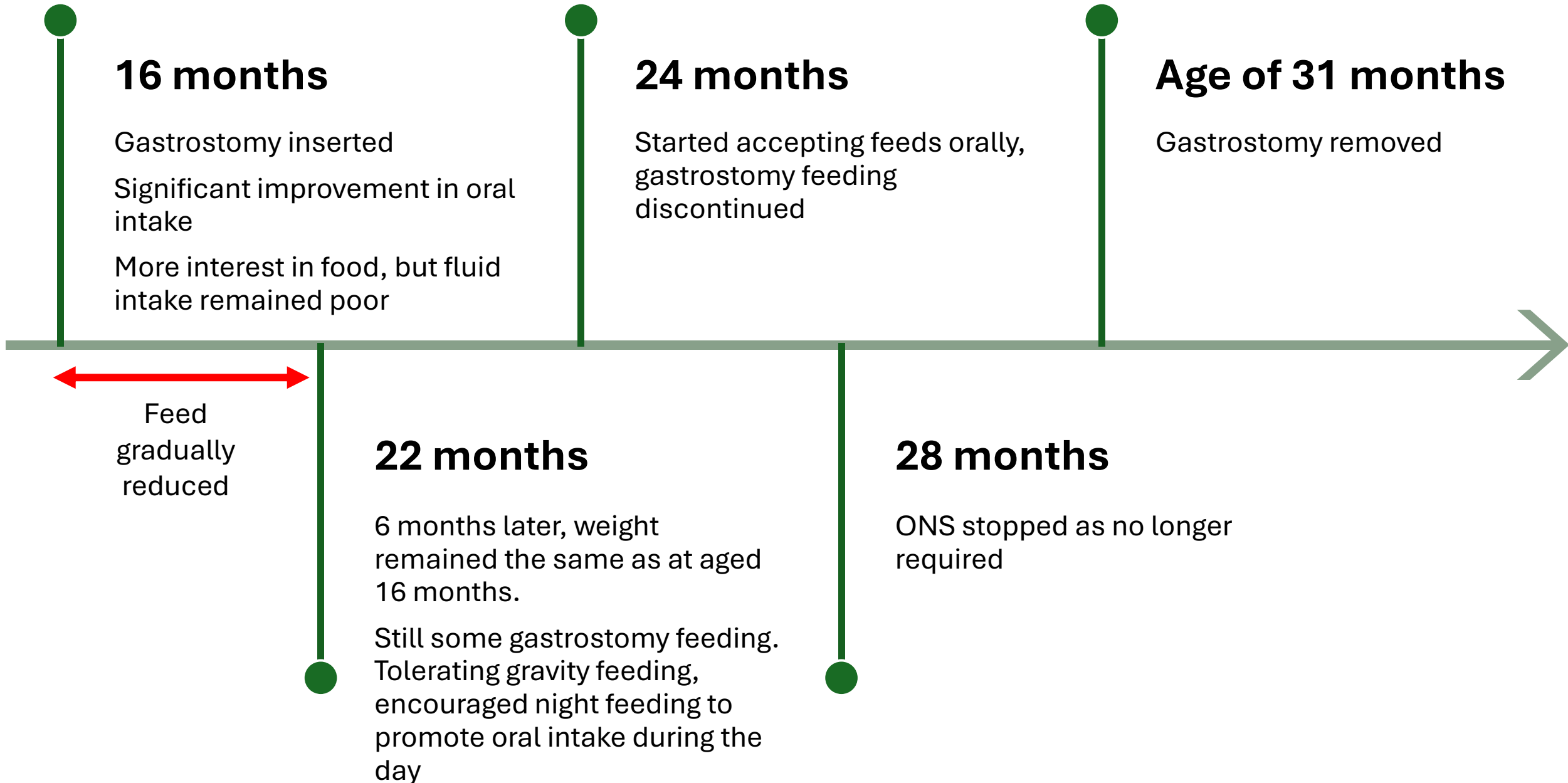
6 months later, weight remained the same as at aged 16 months.

Still some gastrostomy feeding. Tolerating gravity feeding, encouraged night feeding to promote oral intake during the day

28 months

ONS stopped as no longer required

Feed gradually reduced





consideration

- **Practicality of intervention - the reality of a community perspective**

Case Study 2 - Luca

Term baby referred to the Community Dietetic Service at aged 2 months old following hospital discharge.

Background:

- Gastro-oesophageal reflux confirmed on barium swallow, with reflux reaching the distal oesophagus.
- 2 x episodes of hypoventilation and desaturations requiring CPAP in the neonatal period.
- Sleep study demonstrated no further desaturations following commencement of NJ feeding.

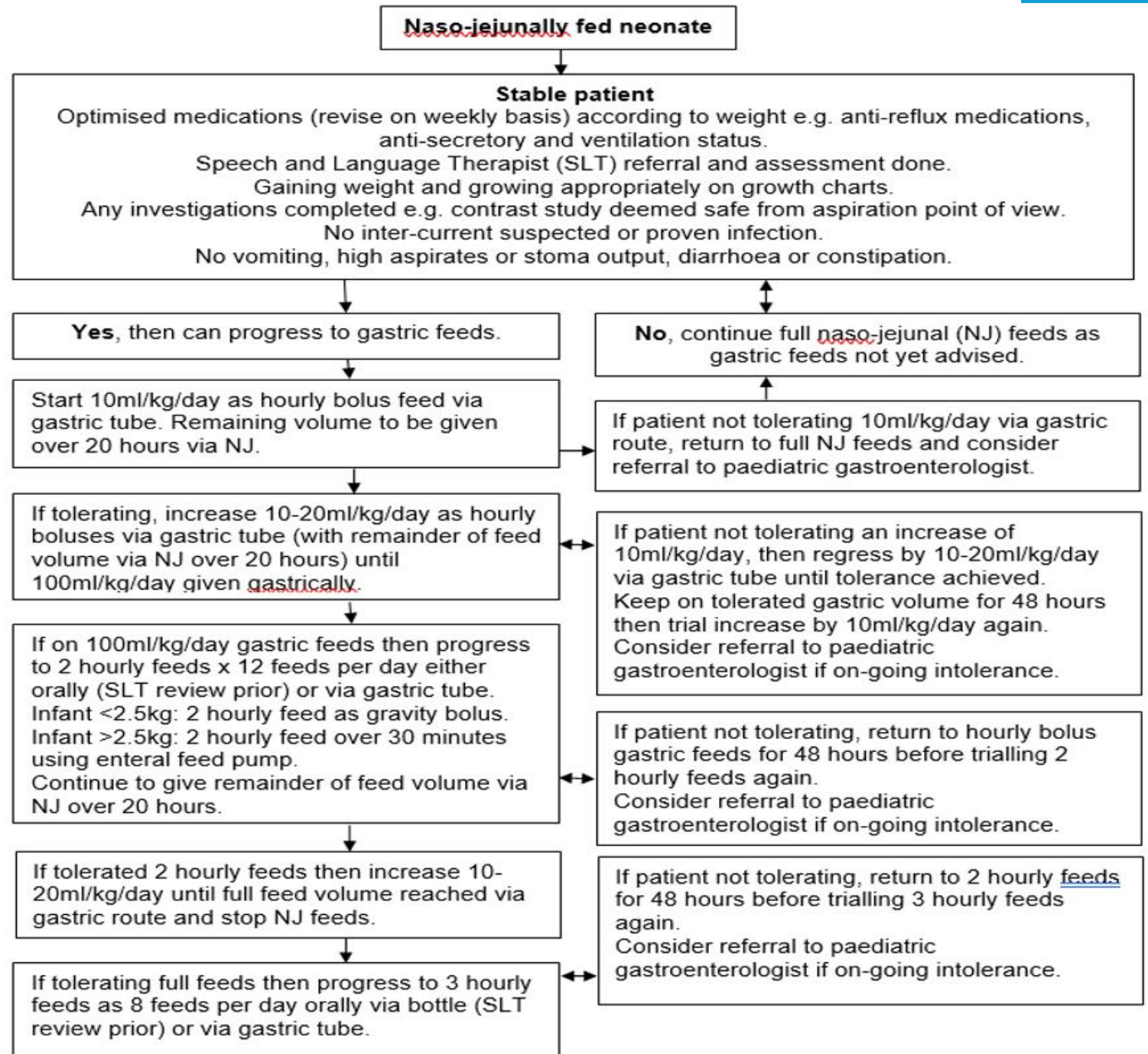
Feeding History at Referral

- NJ tube in situ for feeding since 2 x episodes of desaturation during feeding in hospital due to ?GOR
- Receiving expressed breast milk (75%) and amino acid (AA) formula (25%) via continuous NJ feeding.
- Oral stimulation only, with 1ml expressed breast milk via blocked teat when awake and alert.

Initial dietetics assessment

- Has been tracking the 25-50th centile for weight, length and head since birth.
- Increasing interest in breastfeeding. Breastfeeds were being used to settle baby.
- Unclear plan for NJ removal or feeding progression.
- No concerns with stoma output.
- Reviewed by SLT: Breastfeeding increased to approximately 5 minutes, three times daily. No concerns regarding feed safety. Ongoing caution due to previous desaturation history.

Inpatient weaning guidance



Initial community NJ to NG weaning plan



Day	NJ Feeding Regimen (42ml/hr throughout)	NG Feeding Regimen	Total Enteral Feed
1	760ml over 18 hours at 42ml/hr Total: 760ml	5ml hourly × 18 feeds Total: 90ml	850ml
2	670ml over 16 hours at 42ml/hr Total: 670ml	10ml hourly × 18 feeds Total: 180ml	850ml
3	580ml over 14 hours at 42ml/hr Total: 580ml	15ml hourly × 18 feeds Total: 270ml	850ml
4	490ml over 12 hours at 42ml/hr Total: 490ml	20ml hourly × 18 feeds Total: 360ml	850ml
5	400ml over 10 hours at 42ml/hr Total: 400ml	25ml hourly × 18 feeds Total: 450ml	850ml
6	310ml over 7.5 hours at 42ml/hr Total: 310ml	30ml hourly × 18 feeds Total: 540ml	850ml
7-10	250ml over 6 hours at 42ml/hr Total: 250ml	50ml every 2 hours over 30 minutes at 100ml/hr Total: 600ml	850ml

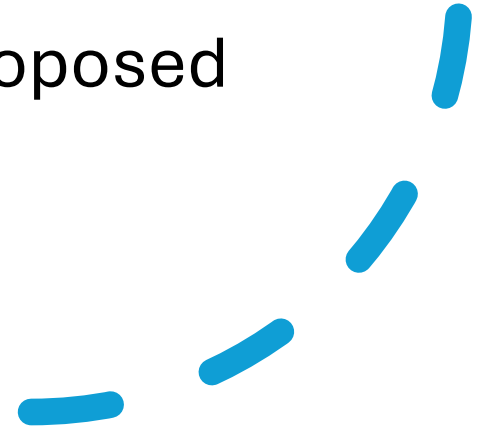
Family Response

Mother became distressed after receiving the plan.

Main concerns:

- Extremely intensive regimen.
- Requirement for frequent feeds throughout the day.
- Caring for two toddlers alongside Luca.
- Father working full-time.
- Practicality of implementing the plan at home.

Mother declined to follow the proposed regimen.



New community feeding plan

- NJ Feeding: 400ml/day administered at 40ml/hr whenever Luca is not receiving an NG feed or breastfeeding (~10 hours)
- Community nurses to measure oxygen saturation levels during feeds in clinic prior to starting NG and Breastfeeds using a pulse oximeter.

Time	Feed
10pm-10am	Responsive breastfeeding as directed by Luca
12:00	NG feed 50ml over 30 minutes @ 100ml/hr
14:00	NG feed 50ml over 30 minutes @ 100ml/hr
16:00	Breastfeed
18:00	NG feed 50ml over 30 minutes @ 100ml/hr
20:00	NG feed 50ml over 30 minutes @ 100ml/hr

MDT Monitoring (community version!)

- **MDT Feeding Assessment**
- Decision made to observe direct breastfeeding in clinic.
- Present: SLT, Community Nurse, Community Dietitian
- **Assessment**
- Continuous oxygen saturation monitoring during oral feed.
- **Outcome**
- No desaturations observed.
- No signs of respiratory compromise.
- Breastfeeding well tolerated with no visible signs of aspiration.
- Agreed to continue weaning from NJ to oral with NG top ups

The next week...

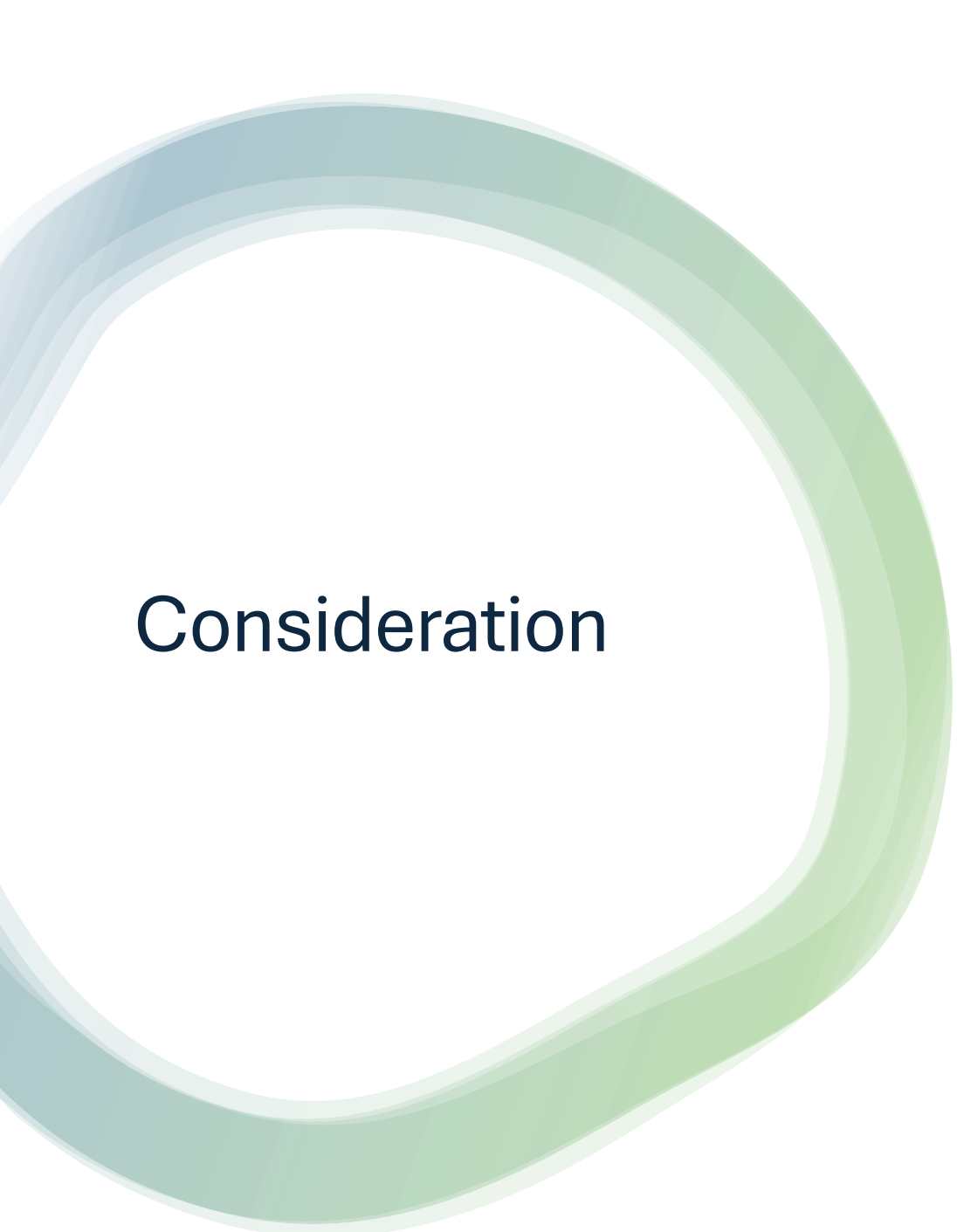
- Mother's expressed breast milk supply stopped. Only able to feed directly from the breast. AA formula put through NG tube increased stoma output.
- Luca accidentally removed NJ tube. NG only in situ. Mother declined use of AA formula via NG due to poor tolerance. Continued breastfeeding only.
- Following discussion with Community Paediatrician: Due to no concerns following feeding assessment with nursing, SLT and DT agreed Luca could continue exclusively breastfeeding

Outcome

-  Growing appropriately and no signs of dehydration
-  Feeding exclusively at the breast
-  No recurrence of respiratory concerns
-  No replacement NJ tube required and NG tube removed.

Key learnings

- 1. Have an Exit Plan**
- 2. Hospital Plans Are Not Always Community Plans**
- 3. MDT Assessment Can Facilitate Positive Risk-Taking**
- 4. Families Are Experts in Their Child**
- 5. Avoid Tube Dependency Where Appropriate**

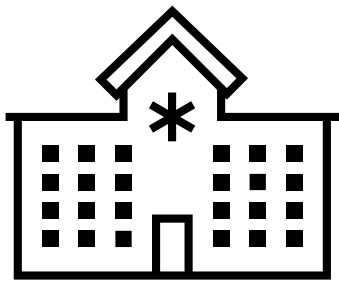


Consideration

- **Is it only parental anxiety?**

Case Study 3 - Lily

- Referred to Community Dietetics aged 2 years when family moved into the area
- Background: Ex-prem (30w), GOR, Nissen's fundoplication, presumed dumping syndrome, recurrent episodes of hypoglycaemia, gastrostomy in situ – mini button, history of oral aversion – reported by mum
- Referred by another dietetic team – previously managed on fully oral intake and required gastrostomy for fluid top ups and medications, however at the initial assessment mum requested to commence pump feeding as Lily stopped eating
- Liaison with CCNT and Dietitian who previously supported Lily and her family – high level of concerns regarding poor compliance with clinical/ medical advice and changes to feeding plan



Frequent A&E attendance but poor attendance to other medical appointments. Mum typically cancelled shortly before the appointment



Changes to feeding plan made regularly by mum without discussion with dietitian. Reducing/ stopping feed due to 'improved oral intake', recommencing feed due to 'weight loss'



Several referrals to social care by numerous professionals but none followed up



?Perplexing presentation/
Fabricated or induced illness
or mother advocating for her child – difficult to prove



Liaison with school regarding oral intake.
Significant improvement in weight
Another attempt to reduce feed

Parental resistance to feed reduction
MDT meeting



Agreed elective hospital admission for diagnostic workup
Reassuring results, overnight feeding not indicated
More intensive tube weaning commenced

PEG removed after 6 months of fully oral intake



Key Takeaways

Clinical strategy

- **Revisit Goals:** Always consider weaning if safe
- **Early intervention:** Don't wait too long to start
- **Adaptive plan:** Expect and make plan amendments

Collaboration and Support

- **Multidisciplinary Team:** Use a shared approach
- **Family Involvement:** Keep caregivers at the centre
- **Continues Care:** Monitor closely even after success



Join the ASCEND movement

If you provide paediatric home enteral tube feeding (HETF) dietetic care to children and young people, we would value your contribution to ASCEND. Help us build the evidence needed to shape the future of this specialist field. Together, we are developing the first evidence-based safer-staffing and workload recommendations for paediatric home enteral feeding services.

You may work in a community, acute or mixed health service. If you provide or support the provision of dietetic care to children and young people receiving long-term HETF in the community, we want to hear from you.

What is ASCEND?

ASCEND - **A**ssessing paediatric **C**aseload complexity and **E**nteral **N**utrition **D**emand - is a UK-wide collaborative project commissioned by the BDA Paediatric Specialist Group (PSG) and Dietitians Interested in Special Children (DISC), and funded by the British Dietetic Association's Paediatric Specialist Group.

ASCEND is launching across the United Kingdom. We very much hope that our colleagues in the Republic of Ireland will be able to join us shortly, subject to final confirmation that all applicable Irish requirements have been met.

By bringing together information from community paediatric dietetic services across the UK, ASCEND will build the first UK-wide evidence base to inform safer staffing, sustainable workloads and workforce planning for services supporting children and young people receiving home enteral tube feeding.



<https://hef.bda.uk.com/>



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Thank you



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