

THE PATIENT:

Rebecca, Aged 10



THE HEALTHCARE PROFESSIONAL:

Specialist Paediatric Dietitian in Gastroenterology and Intestinal Failure at Royal Manchester Children's Hospital



PATIENT OVERVIEW:

Rebecca is a 10-year-old female with a diagnosis of short bowel syndrome and has navigated a complex medical history since birth. Born via elective caesarean section at 39 weeks due to breach presentation, Rebecca's first day of life marked the onset of health complications, with bilious vomiting progressing to faeculent vomiting and abdominal distension.

She was admitted to the neonatal intensive care unit and subsequently transferred to the paediatric intensive care unit for surgical review. Rebecca had a laparotomy which confirmed she had a volvulus and large section of necrotic bowel which was subsequently resected. Post-surgery, Rebecca's small bowel length measured 12 cm (10cm proximal bowel and 2 cm to ileocaecal valve), with a total colonic length of 65.5 cm.

NUTRITIONAL INTERVENTION:

Post-resection, Rebecca was initiated on a parenteral nutrition regime to meet 100% of her nutritional needs. At three months, Rebecca's weight increased from 3 kg to 3.4 kg resulting in a downward shift from the 16th centile to below the 0.4th centile.

In response to this, trophic enteral feeding trials were initiated via an nasogastric (NG) tube, introducing an extensively hydrolysed infant formula (eHF) alongside varied amounts of eHF offered orally.

Rebecca had experienced challenges with feed tolerance, so, only small portions of milk, egg, wheat and soya-free solids were introduced when she was ready for weaning to commence.

This cautious introduction allowed for careful monitoring of her response to solid foods which was initially a high stool output.

Rebecca's growth trajectory remained gradual, tracking up to the 2nd centile, with her weight reaching 6 kg at the age of seven months. The phased introduction of solids persisted, along with continued parenteral nutrition over the subsequent years. It wasn't until the age of five that Rebecca was successfully weaned down night by night to four nights' parenteral nutrition with a dairy-free diet, increasing her weight to 16.2 kg, at the 6th centile.

However, when Rebecca reached six years of age, mealtimes became more challenging, with prolonged feeding times and the onset of behavioural issues related to food avoidance. This not only adversely affected Rebecca's ability to meet her nutritional requirements but also took a toll on her parents' mental wellbeing.

Consequently, a gastrostomy tube was inserted to reduce elevating pressure at mealtimes and with the aim of supporting a further reduction of parenteral nutrition. Rebecca was also referred to a psychologist to support behavioural concerns associated with food intake.





PROGRESS WITH PAEDIASURE PEPTIDE

At seven years old, Rebecca's weight gain plateaued, dropping to the 4th centile, and as challenges with oral intake persisted, her prescribed regimen at this point included 3 x 200 mls feeds of PaediaSure Peptide daily, accompanied by a reduction in parenteral nutrition to three nights a week.

The decision to prescribe a peptide-based feed for Rebecca was based on her history of compromised GI tolerance due to short bowel syndrome. This introduction of PaediaSure Peptide proved pivotal, leading to a significant improvement within three months as Rebecca tracked up to the 9th centile. This regimen was sustained, with a gradual decrease in parenteral nutrition and adjustments to the volume of PaediaSure Peptide based on the amount of solids consumed during the day.

By the age of 10, Rebecca successfully weaned off parenteral nutrition entirely. She embraced a diet comprising 200 ml of PaediaSure Peptide via her gastrostomy button three times daily and 1000 ml overnight as a continuous feed. Her dietary preferences expanded to include an all-inclusive solid food diet, and she developed tolerance for dairy consumption, including cow's milk proteins.

REBECCA'S TYPICAL DIET, AGE 10

<p>BREAKFAST</p>  <p>Nil.</p>	<p>LUNCH</p>  <p>½ adult portion of pizza, chicken nuggets, sausages or cheeseburger.</p>	<p>DRINKS</p>  <p>1000ml flavoured water at school. 1000ml flavoured water at home.</p>
<p>AFTERNOON SNACKS</p>  <p>Chocolate, crisps, popcorn or sweets.</p>	<p>EVENING MEAL</p>  <p>Pasta and meatballs, chicken dinner with Yorkshire puddings.</p>	<p>ENTERAL FEEDING REGIME</p>  <p>Daytime: PaediaSure Peptide 200 mls x 3 times daily via gastrostomy. Night time: PaediaSure Peptide 1000mls overnight as a continuous feed.</p>

NUTRITIONAL GOALS

Rebecca's nutritional strategy has been tailored to meet the specific nutritional requirements dictated by her short bowel condition. In adhering to nutritional guidelines, the multi-disciplinary team caring for Rebecca have been working to align with ESPGHAN guidelines and the SACN requirements per kilogram, with extra nutrition integrated into the plan to combat the unique challenges posed by her short bowel in tracking up to the 50th centile for weight.

Throughout the course of her management, there has been a commitment to striking a balance between fulfilling Rebecca's nutritional requirements and enhancing her quality of life. The emphasis extends beyond clinical aspects to ensure the active involvement of Rebecca's parents in planning her nutritional interventions, empowering and supporting them to address both Rebecca's needs and their own wellbeing.

MEDICAL MANAGEMENT & STRATEGIC INTERVENTIONS

A significant positive outcome of the transition away from parenteral nutrition was the stabilisation of blood parameters, particularly the correction of previously elevated alanine transaminase (ALT) levels.

However, the management of Rebecca's health journey has also involved careful consideration of less favourable implications such as responding to a decrease in bicarbonate levels upon weaning off parenteral nutrition. In this instance, a comprehensive approach was taken, incorporating both intravenous (IV) fluid administration and oral bicarbonate supplementation to rectify the metabolic imbalance.

Sodium bicarbonate and loperamide are integral components to mitigate losses, addressing her unique gastrointestinal needs. Additionally, the inclusion of cyclical antibiotics, namely metronidazole and tobramycin, serves to combat bacterial overgrowth—a common concern in cases of short bowel syndrome.

Looking ahead, there is a contemplation of introducing a robust probiotic regimen once the central line is removed, presenting a forward-looking approach to further enhance her gastrointestinal health.

KEY LEARNINGS

- + Nutritional intervention goals are often multifaceted to optimise overall health and wellbeing. Whilst the primary focus may be achieving growth improvement, efforts also need to be directed towards enhancing quality of life and reducing risk where possible.
- + Collaborating closely with families and their wider support network not only alleviates the strain on all stakeholders but also fosters a supportive environment conducive to better patient outcomes. It allows for a shared understanding of the challenges, making it easier to navigate the complexities of the medical journey.
- + Continuous reassessment and adjustment of nutritional intervention strategies are crucial. The gastrointestinal system, particularly in cases of short bowel syndrome, exhibits significant adaptability. Challenging the nutritional plan becomes a means of acknowledging the dynamic nature of the patient's condition – recognising that the bowel's growth and development necessitate a flexible and responsive approach to nutritional interventions.

HOW IS THIS INFORMATION RELEVANT TO YOUR ROLE?

WHAT DID YOU LEARN & HOW WILL THIS IMPACT ON YOUR FUTURE PRACTICE?



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