PaediaSure® Peptide

Case Study

CEREBRAL PALSY

THE PATIENT:

Lucas, Aged 3

THE HEALTHCARE PROFESSIONAL:

Elizabeth Loring, Specialist Dietitian,
Central and North West London NHS
Foundation Trust (CNWL)

PATIENT OVERVIEW:

Born prematurely at 24 weeks, Lucas is one of a twin that has faced significant health challenges from birth, including a Level 5 Cerebral Palsy diagnosis, chronic lung disease, hydrocephalus, visual impairment, hearing loss, and epilepsy. Additionally, he underwent surgical management for small bowel necrosis, an event that, despite intervention, resulted in lasting tolerance implications.

FEEDING CHALLENGES AND NUTRITIONAL INTERVENTION:

With early growth and developmental concerns plus feeding difficulties including vomiting and reflux adding to the complexity of his medical journey, Lucas spent the first seven months of his life in hospital. A comprehensive nutrition plan was implemented from birth involving a 20-hour enteral feeding regime, interchanging breast milk* with an amino acid-based (AAF) formula. Oral intake was limited due to Lucas displaying symptoms of dysphagia, with an immature co-ordination of the suck, swallow and breathe pattern.

Once this feeding regime had been established, Lucas was discharged with a nasogastric (NG) tube for medications and a naso-jejunal (NJ) tube in place to continue meeting his nutritional requirements at home without the worry of gastro-oesophageal reflux and vomiting.

Before discharge, an Abbott Nurse Advisor visited Lucas's parents in hospital to demonstrate how to use the enteral feeding pump and make sure they felt comfortable with the equipment.

The NJ tube was subsequently removed during an admission to hospital at eight months of age as Lucas was tolerating NG feeds well. At this point, the hospital team also transitioned Lucas from a continuous pump regime to 4-hourly bolus pump feeds with 130ml of extensively hydrolysed formula (eHF) over 1 hour.

OPTIMISING LUCAS' FEEDING REGIME - A JOURNEY TO FIND THE RIGHT BALANCE:

Persistent worries about Lucas' weight prompted a concerted effort to increase his nutritional intake. However, given his length-related concerns and limited mobility, there was a careful consideration to strike a balance between meeting his nutritional requirements and preventing excessive weight gain relative to his length.

Elizabeth continually optimised the feeding regime to meet Lucas' nutritional needs whilst considering the potential burden of each change on the parents.

Examples of changes included:

+ Enhancing daytime feed volume from 130 ml to 155 ml per bolus in an effort to minimise night feeds and in turn, alleviate the need for parental supervision during night feeding. Despite these efforts, Lucas encountered difficulties in tolerating a volume sufficient to entirely eliminate the requirement for night feeds.
+ Working with Lucas' Speech and Language Therapist (SLT) to safely introduce solid oral intake, preceding some bolus feeds with purees to enhance oral motor skills, coordination, and the overall swallowing process.
+ Adapting to different quantities of supplements as his oral intake developed, recognising that vomiting tended to occur in the morning while clearing secretions, so he coped with higher volumes in the evening.

Despite ongoing attempts to enhance Lucas's feeding regime and a prescription of anti-reflux medication, he continued to experience episodes of vomiting and his weight gain remained slow. The next few months were spent trying to further stabilise the feeding regime; moving to concentrated feeds when unwell to reduce vomiting episodes and continuing with the introduction of different purees to improve oral intake.

When Lucas reached 18 months old, Elizabeth considered steps towards more typical dietary patterns by moving away from infant formula and reducing the volume of feeds to create periods of hunger, facilitating the introduction of IDDSI level 4 purees into his diet, as recommended by the SLT.

The decision to transition to a peptide-based enteral feed was made with a view to increasing calorie density, reducing feed volume, pump time, and alleviating vomiting symptoms. Elizabeth proceeded by ordering samples of PaediaSure Peptide through Abbott's sample service.

Abbott
life. to the fullest.

---

* Breastfeeding is best for infants and is recommended for as long as possible during infancy.

At the point of transition, 180 ml x 5 of eHF, provided 585 kcal. Through a gradual titration process, incorporating a combination of eHF and PaediaSure Peptide in varying ratios initially at 50:50, then transitioning to 25:75, Lucas eventually shifted to consuming 4 x 150 mls of PaediaSure Peptide, totaling 600 kcal. His fluid requirements were met with an additional 200-300 mls / day of water flushes.

To encourage palatability, PaediaSure Peptide was primarily administered orally with volume limited to no more than 20 ml per feed due to ongoing challenges with oral co-ordination. The remainder was given via the NG tube as tolerated. Additionally, the volume of purees remained modest, with Lucas consuming no more than 6-7 small baby spoons three times a day.

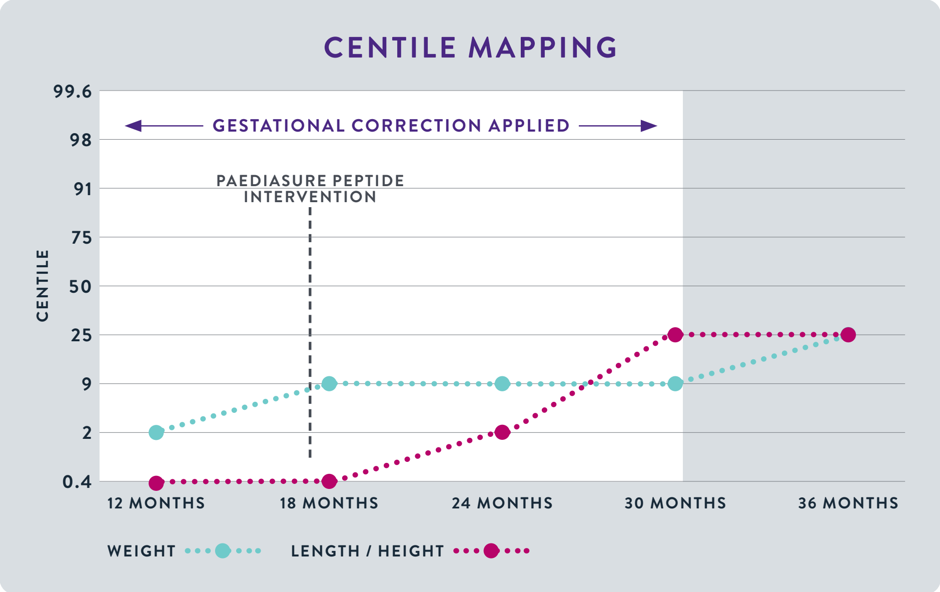
PROGRESS WITH PAEDIASURE PEPTIDE:

Once established, PaediaSure Peptide marked a turning point in Lucas' feeding regimen, with reduced vomiting and support of a feeding pattern that suited the family so purees could be given at mealtimes alongside his sibling.

While PaediaSure Peptide remained predominantly administered enterally, there were instances of increased oral intake, ranging from 10 to 60 ml per day.

Slow and steady progress was observed, with Lucas achieving the 9th centile in weight and wet nappies and regular bowel movements indicating improved overall health.

Lucas's parents also reported a noticeable enhancement in their quality of life (QoL) as both the preparation and feeding processes took less time.



GASTROSTOMY AND CONTINUED NUTRITIONAL SUPPORT:

At two years old, Lucas underwent a gastrostomy procedure at Great Ormond Street Hospital (GOSH) and he continued to tolerate PaediaSure Peptide. At this stage, any gradual increments in intake were primarily oral rather than via his gastrostomy tube.

ONGOING SUCCESS AND CURRENT STATUS:

At three years' old, Lucas has demonstrated remarkable progress. Weighing 14 kg, and above the 25th centile, he continues to receive 170 ml of PaediaSure Peptide four times a day, supplemented by purees, yoghurts and bite-and-dissolve textured foods.

His preschool provides special needs support and administer the feeds on-site to provide his parents with the respite they need. Despite the challenges posed by his medical conditions, PaediaSure Peptide has played a pivotal role in supporting his growth and overall wellbeing.

KEY LEARNINGS

- Lucas' symptoms of vomiting and gastro-oesophageal reflux, which were worsened during periods of illness highlight the importance of maintaining a consistent nutritional regime with products that are well tolerated.
- There is no 'one size fits all' approach to feeding regimes, particularly for patients with complex health needs. Progress is achieved through close monitoring of adherence and tolerance along with continuous optimisation to meet the unique needs of each patient.
- The optimisation of feeding regimes for paediatric patients is a collaborative effort of the healthcare team and parents to ensure there is a good level of knowledge and support.
- Consideration of the parents' health and wellbeing to be able to support their child's feeding regime is essential.

HOW IS THIS INFORMATION RELEVANT TO YOUR ROLE?

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

Abbott

life. to the fullest.