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Dietetic management of a child with cerebral palsy

Clinical history and diagnosis

Amelia moved into our area and started at a local school for children with disabilities. Amelia has bilateral spastic dystonic cerebral palsy (CP) with a Gross Motor Function Classification System (GMFCS) Level 4. She was born premature and has a severe learning disability. Amelia can sit unsupported and move by commando crawling. She often bounces in her chair and loves swimming. Amelia has had long standing growth concerns and her weight has always been on or below the 0.4th centile. She can feed herself some finger foods, but she is mostly spoon-fed.

Initial assessment

I met Amelia when she was 6.5 years old alongside her Speech and Language Therapist (SLT). She weighed 16.3kg (0.4th centile) and her supine length was 103.4cm (0.4th centile). It can be challenging to accurately measure length in children with neurological impairment (NI) due to hypertonia and scoliosis. ESPGHAN advise not to use height and weight measurements alone to assess nutritional status in children with a NI.[1] When seeing Amelia, she appeared underweight; therefore, I felt her length was an underestimation.

Amelia had a good appetite and enjoyed mealtimes. She would eat three meals and snacks per day. Mealtimes often took a long time, and it could be difficult to identify the volume of food eaten due to the amount of food spilled. Amelia would consistently drink less than her fluid requirements.

She suffered with constipation and was using an osmotic laxative to support regular bowel movements. She would become dysregulated if she was hungry and during transitions – food and nursery rhymes helped to regulate her.

Dietetic and SLT plan

SLT advised that Amelia was able to manage majority of textures providing she had support to eat. Her diet recommendations are the International Dysphagia Diet Standardisation Initiative (IDDSI) Level 0 fluids (thin fluids) and Level 7 foods (regular easy to chew) – see Figure 1.[2] We aimed to achieve catch up growth, so I advised food fortification including an oral nutritional supplement (ONS); in this case, neutral Fortini Compact Multi Fibre* (MF). Her family would add this to her breakfast and mix through suitable meals, for example pasta, mash potato and curry. The aim was to increase energy intake but not increase food volume.

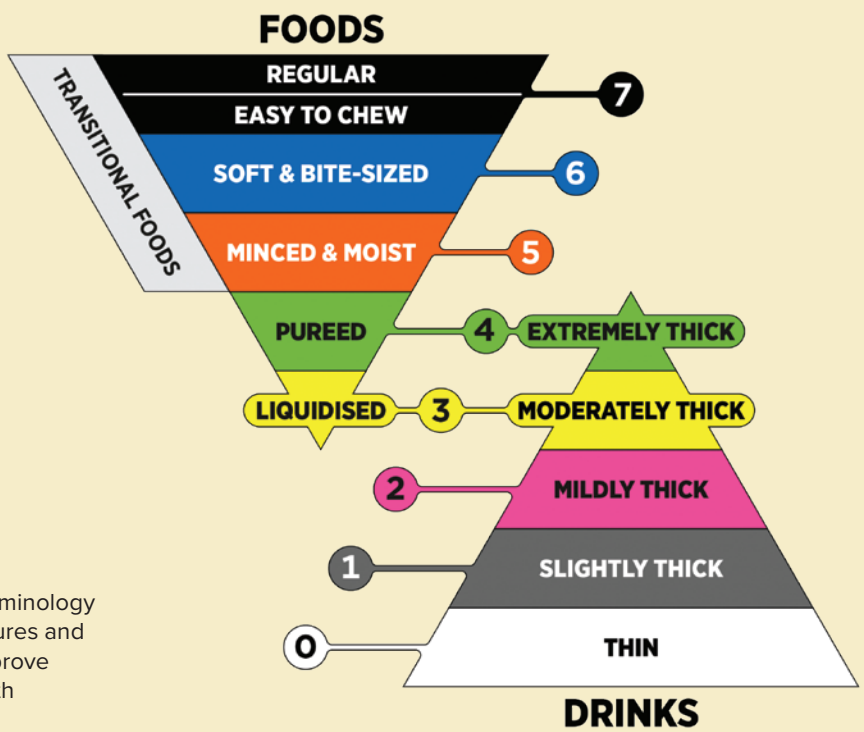
Initial follow up

6 months later (7 years old) Amelia weighed 17.1kg (0.4th centile), meaning her growth continued to track. Her length was 119cm (25-50th centile); this appeared more accurate compared to her initial length.

Third review

Amelia's family moved home and she became fussier with her foods. She began to refuse meals unless they were her favourites and she would only eat snacks in school. She started to struggle with some sickness, particularly in the evenings. Her food intake was meeting approximately 60% of her estimated energy requirements for catch up growth. I recommended two bottles of Fortini Compact MF* to meet her energy deficit. This helped to improve her weight. At 7 years 3 months she weighed 19.3kg (>2nd centile).

Figure 1: The IDDSI Framework



Providing a common terminology for describing food textures and drink thicknesses to improve safety for individuals with swallowing difficulties.

Unexpected change

Amelia became unwell and subsequently developed an aversion to drinking. This resulted in a nasogastric tube (NGT) being passed. She was only eating snacks – therefore her feeding regime aimed to meet her fluid requirements and 80% of energy requirements via four bolus feeds throughout the day.

Initially, Amelia struggled with sickness and nausea and was commenced on domperidone and omeprazole which helped significantly.

With time and encouragement, Amelia started to eat and her feeding plan became much more flexible. She would still have a top-up feed before bed and extra depending on her food intake during the day. Amelia's feeding plan continued to meet her fluid requirements.

Ongoing management

Amelia continues to be weighed in school monthly. She has a NGT for fluid top-up only. She continues to have three-monthly dietetic appointments, and her family contact us if they have any concerns.

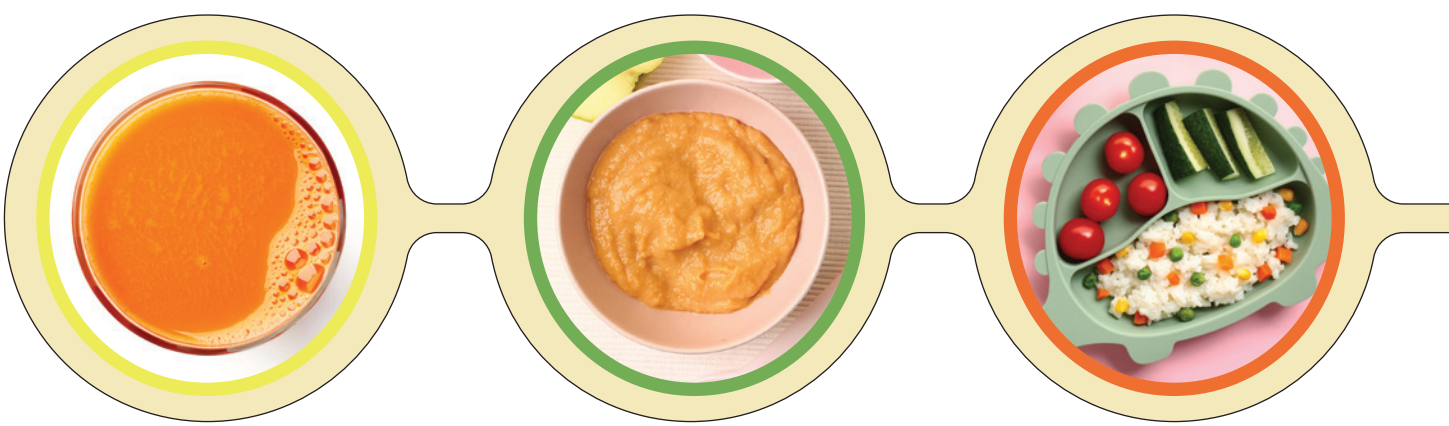
She is not having any ONS currently as she is eating well at home and school. Amelia's family have a small supply to use when she attends a different setting, as this can reduce her food intake.

Children with CP are at greater risk of malnutrition[3] and there are many factors that contribute to this – Table 1 highlights the factors that affect Amelia.

Table 1: Factors affecting Amelia's growth and oral intake

Factor	Description related to Amelia
Physical Activity Level	Has hypertonia which can lead to involuntary movements. She cannot walk but does enjoy bouncing and commando crawling. These factors can make it difficult to quantify energy expenditure.
Dysphagia	Foods need to be a safe consistency for her to swallow efficiently.
Food preferences	Will sometimes refuse foods if they are not her favourite foods.
Gastrointestinal symptoms	Constipation Reflux
Changes in routine/ environment	Her appetite and food acceptance can reduce with uncertain changes.
Dysregulation	Foods, such as chocolate buttons, can help calm situations.

> It is important to choose an ONS that is suitable for the child and that can be flexible in how it is used.



Discussion and practice points

92% of children with CP have significant gastrointestinal symptoms and constipation is common in children with NI.[1] ESPGHAN advise to increase a child's fluid and fibre intake to support regular bowel movements.[1] Abnormal muscle tone can increase a child's energy expenditure up to 10%[1], which impacts a child growth if energy requirements are not met orally. Compact ONS, and those containing fibre, can benefit children suffering with these symptoms. For Amelia, Fortini Compact MF* helped increase the energy density of her food to meet her energy demands and provided some fibre to support regular bowel movements.

Amelia significantly enjoys mealtimes and loves her favourite foods (chocolate buttons). It is crucial to support enjoyment of food and quality of life alongside meeting nutritional needs.

It is important to choose an ONS that is suitable for the child and that can be flexible in how it is used. Think outside of the box:

- What can it be added to?
- Can it be given in small, frequent doses?
- Would the individual prefer it frozen or warm?

ONS must meet the child's modified diet recommendations from SLT. This is to ensure eating is safe but also efficient.[1]

Finally, working alongside key professionals is essential to support a child holistically. In Amelia's case, I work alongside her school nurse, SLT and a paediatrician. Children often follow different routines in different settings; therefore, a plan needs to factor these differences in.

Conclusion

In conclusion, there are many factors that contribute to nutritional status for a child with CP. ONS can be beneficial in meeting energy demands when a child struggles to meet them with diet alone.[1,3] A child-centred plan that can adapt and evolve throughout a child's journey is the key to success.

References

1. *Romano, et al. J Pediatr Gastroenterol Nutr. 2017;65(2):242-64.*
2. *International Dysphagia Diet Standardisation Initiative (IDDSI) [Online]. 2019. www.iddsi.org/standards/framework [Accessed Jan 2026].*
3. *Silva, et al. Rev Paul Pediatr. 2023;42:e2022107.*

***IMPORTANT NOTICE**
Fortini Compact Multi Fibre is a Food for Special Medical Purposes for the dietary management of disease-related malnutrition and growth failure in children from one year onwards and must be used under medical supervision.

> It is crucial to support enjoyment of food and quality of life alongside meeting nutritional needs.