Non-Specific Poor Tolerance to a Whole Protein Nutrient Dense Formula in Congenital Heart Disease

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Dottie* was born at term by emergency caesarean section secondary to foetal distress. She had undergone normal ultrasound imaging at 20 weeks with no abnormality detected. Her birth weight was 3.48 kg (50th centile) and there were no immediate concerns. She was discharged home having established exclusive breastfeeding. Dottie was admitted to hospital age three weeks with concerns related to feeding, including tiredness with feeds, poor volumes taken and noticeable tachypnoea. She struggled with breastfeeding and weight gain had been poor (3.49 kg, 25th centile). She underwent investigation which identified a large inlet muscular ventricular septal defect, posterior deviation of the outlet septum and a small aortic valve (5 mm). The ventricles were balanced but there was increased pulmonary blood flow with dilated main and branch pulmonary arteries. Dottie remained in hospital for a week of observation and once daily diuretics. A breastfeeding specialist confirmed an uncoordinated and weak suck. Advice was given to the mother to optimise feeding, particularly surrounding positioning. Infatrini was introduced as a top up via nasogastric tube (NGT) to supplement breastfeeding. She was discharged with a small weight gain but weight overall had fallen to the 9th centile.

Age two months

Since starting Infatrini, Dottie's mum had noticed a slightly increased stool frequency (additional 1-2 stools/day) and the stools were noticeably looser. Volumes of feed taken were inconsistent but on average were <110 mls/kg/day. Feeding times were prolonged (in excess of 60 mins) and breastfeeding had ceased. Mild reflux symptoms were reported, with inconsistent frequency. Dottie's weight had continued to drop and she was now on the 2nd centile. The decision was made to swap to Infatrini Peptisorb in view of lower than expected weight gain for volume, changes in stool pattern and parental concerns of non-specific 'poor tolerance'. In the following weeks her weight gain pattern stabilised on the 2nd centile but did not significantly improve. However, the family reported more successful feeding times and her stools were firmer. Her surgery was planned for one month later.

Age three months

Surgery was undertaken at three months. Her weight was now tracking the 2nd centile but she remained underweight in proportion to her head circumference and length (50th centile). Surgery was unremarkable and successful. Discharge weight was 200g below admission weight and Dottie was discharged with her NGT in place as she had failed to re-establish oral feeds.

Age four months

On review the family reported good re-establishment of regular feeding pattern but some feed avoidance behaviours remained. Weight had increased to pre-surgery admission weight and centile position (2nd centile). The NGT was repeatedly dislodging but replacement was becoming distressing for Dottie and despite alternating nostrils the skin around her nose was breaking down. The decision was made to trial oral feeds only. At this stage the volume of Infatrini Peptisorb tolerated was 90-120 mls/kg/day.

Age five months

Weaning began around five months. This was the family's first child so care was taken to go through the general principles and practicalities of weaning specific to the context of a cardiac infant. In view of her history of bottle aversive behaviours (feeds were still taking over an hour) a joint dietetic and speech and language therapist appointment was arranged. Feeding strategies to promote oral progress were recommended, including messy play and education for the family on positive mealtime outcomes.

The Infatrini Peptisorb Case Study Series

A series of case studies sharing experiences and best practice surrounding the management of faltering growth and malabsorption in paediatrics. For further information on the infatrini range visit: www.nutriciaproducts.com/paediatrics/



Dottie was also seen for routine cardiac review. Echocardiography confirmed a stable VSD patch with no residual shunt, no outflow tract obstruction, normal left ventricular size and function, and a patent aortic arch. The cardiology conclusion was that she had done very well following her surgery and now had a functionally normal circulation. Diuretics were stopped and follow up cardiology review was arranged for 6 months' time.

Age six months

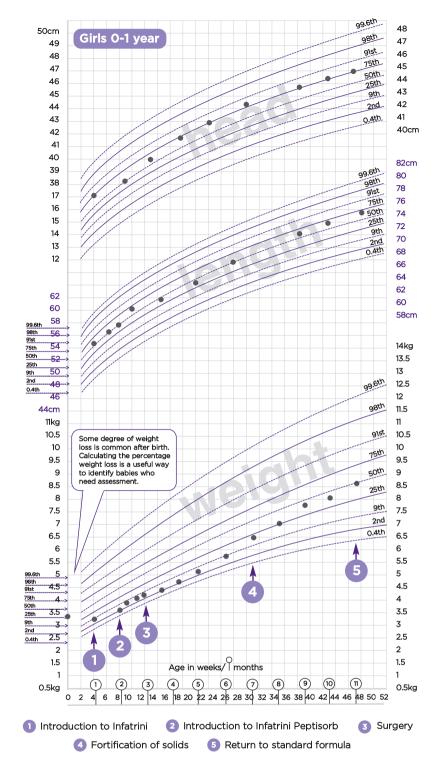
Weaning was slow to progress. However, it was identified that mum's expectation of a portion of food was quite unrealistic. Further education for the family on weaning foods and expectations was provided. Feed intake was stable and feeding times, reflux symptoms and stool output were all acceptable. These factors combined successfully contributed to an improved weight, now on the 9th centile.

Age nine months

Dottie had made some progress and was more accepting of bottle feeds and textures. She remained behind with some feeding skills for age (however this was consistent with a child with early medical intervention) but positive steps with growth were evident. The family's anxiety levels were settling coinciding with her weight pattern improvements. Fortification of weaning foods (advised around 7 months) appeared to be associated with a slight further increase in weight gain velocity and weight was now >25th centile. This was close to other anthropometric markers on the 50th centile.

Age 11 months

Review showed Dottie's weight gain was very good and she had caught up to her proportional centile (50th). She remained in the early stages of texture acceptance but variety of foods within her range was very good. The decision was made to discontinue Infatrini Peptisorb and introduce standard infant formula. A telephone review and community weight check were organised for six weeks later to ensure her growth pattern was maintained.



Learning points

- 1. Non-specific poor tolerance of nutrient dense formula in very young infants can present an issue in conditions where promotion of weight gain and growth is a priority. Using specialised formulas with characteristics that may have some theoretical tolerance benefits (i.e. hydrolysed proteins, high medium-chain triglyceride [MCT] content) represent another option for dietitians to support vulnerable groups.
- 2. Weaning can be a stressful time for new parents and supporting families of cardiac infants is necessary especially since these infants are widely recognised to have a high prevalence of feeding difficulties. To minimise such difficulties, effective communication with families on topics such as expected rates of growth, normal feeding behaviours and normal age appropriate solid intakes can provide valuable reassurance to families and support more successful progress.
- 3. Catch-up growth following early undernutrition and subsequently evolving feeding difficulties can be challenging to manage and it can take significant time before weight and growth goals are achieved. When using nutrient dense formulas regular monitoring is a key responsibility for dietitians. Care is required to neither cease their use to soon nor to continue their use too long where the provision of excess calories and protein are no longer required.