Case Study:
The successful transition of a paediatric patient reliant on nasogastric tube feeding to oral feeding

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Patient:	E (Female)
DOB:	5/2/10
Diagnosis:	• Right-sided aortic arch with aberrant left subclavian artery • Vascular ring division (5/7/10) • Bronchomalacia • Nocturnal BiPAP • Nasogastric tube feeding/behavioural feeding

Introduction

Behavioural feeding difficulties are a common problem in all children, with 20 per cent of children with normal development exhibiting feeding difficulties, and 90 per cent of children with special needs.[1] Children who have been tube fed are felt to be at the more severe end of the spectrum behavioural feeding difficulties. This may be due to a variety of reasons, including:

- Missing the critical period of introduction of oral feeds[1]
- An inability to experience hunger and appetite regulatio[1]
- A fear of food and oral aversiveness[1]
- A lack of exposure to normal eating behaviour
- Using food refusal as a means of exerting control[1]

Re-establishing oral feeding is a possibility. One study demonstrated that after nine nasogastric (NG) fed patients followed a 14-week protocol, eight achieved full oral intake and one 50 per cent oral intake.[2]

In this case study we demonstrate that with careful multidisciplinary work, a supportive environment for parents and a clear plan of action, a child who had been tube fed for seven months, and was demonstrating orally aversive behaviour, can be successfully moved onto full oral intake and maintain her own nutritional status.

> A comprehensive feeding plan for home was made to ensure patient E met her nutritional requirements orally.

Summary of care

With over 20 episodes of intervention by both dietetic and speech and language therapy (SLT) disciplines to date, patient E achieved the aim of meeting her requirements orally. See **Table One**.

We initially met Patient E in July 2010, following surgery for division of her vascular ring. Following this surgery the patient developed bronchomalacia and required overnight BiPAP (bi-level positive airway pressure). She was orally fed at this point but demonstrated some aversive behaviour. In order to meet calorie requirements of 110-120kcals/kg/day a fortification plan was commenced fortifying 100mls of a 1kcal/ml formula with 2g Duocal and encouraging solids.

At this point, the SLT team became involved and a mealtime observation was made. The SLT identified a possible reduction in oral sensation and a tendency to use her fists to simulate oro-motor movements. Further advice was given on the management of feeding behaviour, e.g. creating a positive atmosphere, limiting meal times to 30 minutes, and offering solids regularly.

Initially, Patient E showed positive progress and was able to meet her requirements orally. However, she failed to gain weight on a calculated intake of 112kcals/kg and the need for nasogastric tube (NGT) feed top up's were therefore agreed. An NGT feeding regime was designed to provide 130kcals/kg.

Over the next two months, Patient E was reviewed over the telephone. She showed a steady decline in her feeding behaviour and became increasingly reliant on the NGT. Her mum verbally expressed her frustration on a number of occasions. The issue of gastrostomy feeding was raised with mum who, although found this a distressing subject, was open to having the discussion.

In November 2010, she was reviewed by the paediatric respiratory consultant, the dietitian and the SLT as an outpatient. Her weight gain on her NGT feeds was excellent. However, her ongoing behavioural feeding difficulties and refusal to drink milk orally was causing her parents a great deal of stress. At this time, Patient E was managing half a pot Petits Filous orally and no liquids from a beaker. Mum was seen to be visibly upset by the lack of progress with feeding. A plan was made to admit Patient E to the ward for a five-day intensive programme to remove her NGT and re-establish oral feeding. Mum's attitude towards feeding appeared to be quite negative and she did not feel the situation would ever change. She agreed to a psychology referral to give her support for this admission.

The admission – 10.1.11-14.1.11

Prior to this admission, the SLT and dietitian had met to arrange a plan of action for when Patient E was admitted. This involved removing the NGT and giving Mum and Patient E regular support at meal times. Mum had also been offered a psychologist appointment.

Table One: Episodes of Intervention

Date	Weight (kg)	Centile
12/7/10	5.38	2nd
22/7/10	5.29	2nd
5/8/10	5.75	0.4th – 2nd
28/8/10	6.16	2nd – 9th
9/9/10	6.35	2nd – 9th
20/9/10	6.8	9th -25th
2/11/10	7.35	9th – 25th
10/1/11 (NGT removed)	8.205	> 25th
13/1/10	8.12 - negligible weight loss	25th
1/2/11	7.8	<25th

Day 1 – 10/1/11

In view of concerns about hydration status the NGT remained in situ on the first day of the admission but was not used for milk feeds. A clearly structured plan of when to offer milk and solids was put in place.

Intake = 133kcals/day.

Day 2 – 11/1/11

Patient E's appetite for solids increased after stopping NGT feeds. The NGT was removed. Mum was upset but much reassurance was given that support would be provided if there were concerns regarding hydration. A feeding session was held in the coffee shop focusing on maintaining a relaxed environment away from the hospital bedside. The introduction of a beaker with water was tried.

Intake = 337kcals/day.

Day 3 – 12/1/11

Intake of solids continued to improve but no improvement in taking fluids from beaker. Mum met with the psychologist.

Intake = 620kcals/day, 76kcals/kg.

Day 4 – 13/1/11

Patient E showed excellent progress, increasing her oral intake from 133kcals per day to 670kcals/day (76kcals/kg). Mum was praised for her efforts and we discussed meeting requirements orally with high calorie foods and food fortification. During lunch positive behaviour was noted, such as opening her mouth to receive food and smiling. Mum appeared more relaxed. Patient E continued to refuse the beaker of fluids but appeared to be maintaining her hydration status.

Day 5 – 14/1/11

A comprehensive feeding plan for home was made to ensure patient E met her nutritional requirements orally. Bloods were taken to check hydration status. Mum was given plenty of positive encouragement and praise. Patient E was allowed home without her NGT and a plan for psychology/dietetic/SLT follow-up was made for the following week.

Table Two: Advantages and Disadvantages of an Inpatient Admission to Manage Feeding Difficulties

Advantages	Disadvantages
Weight and hydration status can be monitored	Artificial hospital setting can cause parental stress
A high frequency of encounters with feeding specialists can be achieved, e.g. the patient can be seen at every mealtime	The patient may be less likely to eat well when out of their own home
Medical access when required	Significant time investment required by professionals
Parents are free from other responsibilities to focus on the feeding plan and they can receive support during this stressful time	Exposure to hospital acquired infections
Careful monitoring of nutritional intake can be made	Disruption to normal life, including the care of siblings
IP admissions may result in more rapid behavioural change	

> "...evidenced-based practice and intense support, including an inpatient stay, can achieve a positive result."

In the period following her discharge, Patient E was unfortunately admitted to her district general hospital with respiratory syncytial virus (RSV) bronchiolitis. She continued to manage three portions of solids per day. Her fluid intake had improved to 50mls from a beaker. Following her discharge from her local hospital, Patient E attended a follow-up appointment with the feeding team at the Royal Brompton Hospital. She was maintaining her nutritional intake and hydration status orally. Her mum appeared relaxed and happy. She was handed over to her local therapists for further monitoring.

Discussion

There were various strategies which contributed to the success of our feeding plan:

- **Multidisciplinary Team (MDT) working**
  Puntis (2008), when writing about the role of multidisciplinary feeding clinics in management of feeding difficulties, states that: *'Multidisciplinary team working allows parents more rapid access to appropriate expertise.'*[3] Whilst Patient E was not managed within a clinic setting, the role of the MDT was clearly essential in ensuring the success of the feeding programme.
- **Employing evidence-based behavioural feeding strategies**
  Strategies for manipulating behaviour to enhance oral intake and dietary variety have been studied. Wardle and Cooke (2008)[4] summarised various means of improving intake. They suggest that regular, repeated exposure to new tastes and textures enhances acceptance of new foods. Parental modelling of eating behaviour and trying new foods also appears to be one way of increasing the likelihood that a child will accept a new food. Throughout our input with Patient E we encouraged persistence in offering new foods and fluid from a beaker and we supported her mother to provide a positive model of eating behaviour. A regular routine of offering meals and snacks was established and reviewed at regular intervals. The creation of a positive feeding environment was also encouraged so that Patient E would learn to enjoy mealtimes.[1]
- **Training parents**[1]
  Parents provide a link between the therapists advising on the feeding plan and the child's natural environment where the plan is to be executed. The parents of Patient E received extensive and regular input and follow-up from the team. Meeting parents on neutral ground created a more relaxed atmosphere. This built up trust and communication, and allowed the parents to observe strategies employed by therapists to improve the patient's intake. Additionally, parents were listened to and the pace at which they wanted change to occur was respected.
- **Swift removal of the NGT**
  Frequently, a slow reduction in enteral feeds is appropriate in trying to manipulate appetite.[5] Our approach may, therefore, be considered by some to be controversial. In this case we were working within a limited time period of five days and we were keen to quickly assess the patient's ability to regulate her own appetite and respond to hunger. Having regular contact with Patient E, and knowing her well, enabled the MDT to make the decision that this was the best course of action for this individual.
- **The necessity of an inpatient admission**
  Many children are successfully treated for their feeding difficulties within an outpatient setting. However, for some children, the extent of their feeding difficulties means that treatment within these settings is not always successful. For these children, a more intensive regime with multidisciplinary input may be required. See **Table Two** for advantages and disadvantages of inpatient admission.

The overriding factor when deciding to admit this patient was the observation that the parents did not seem to be able to progress on to oral feeding in the community setting. During a medical review, mum became emotional and upset about the possibility of the patient requiring long-term nutritional intervention. At that time it was decided by the dietitian, SLT and consultant paediatrician that more intensive intervention was required. This would meet the emotional needs of the parents and provide the therapeutic intervention required.

It is fair to observe that perhaps admitting this patient to a tertiary centre for children with cardiothoracic issues was not the most practical solution. Certainly, engaging with the community therapists and approaching the issue in a community setting is considered the preferred approach. In this instance, due to the level of input our team had with this family and the obvious need for an intense feeding programme, the admission was considered the best course of action for this individual.

Conclusion

This case study demonstrates that oral feeding can be achieved in a patient reliant on NGT feeding. It should not be considered a model for every child who is NGT fed as the feeding plan followed was particular to this patient. The success of the project does raise the question of whether a protocol for successful reestablishment of oral feeding might be useful. However, as outlined by this case study, each case is highly individual. Additionally, a blanket protocol would be challenging given the complexity of the medical history of many of the children who are reliant on NGT feeding.

We provided regular input with this child over a seven-month period with a successful outcome. The success of this patient's journey is an example of the fact that evidenced-based practice and intense support, including an inpatient stay, can achieve a positive result. We now look forward to hearing how Patient E progressed with her enjoyment of eating.

References: **1.** Southall A, Martin C (2011). Feeding Problems in Children: a practical guide. Second Edition. Radcliffe Publishing. **2.** Davis AM, et al (2009). Moving from tube to oral feeding in medically fragile nonverbal toddlers. J Pediatr Gastroenterol Nutr.; 49(2). **3.** Puntis J (2008). Specialist feeding clinics. Arch Dis Child.; 93: 164–167. **4.** Wardle J, Cooke L (2008). Genetic and environmental determinants of childrens food preferences. British Journal of Nutrition; 99, Suppl. 1: S15–S21. **5.** Dunitz-Scheer M, et al (2009). Prevention and treatment of tube dependency in infancy and early childhood. ICAN.; 1-73.