ABSTRACT

Background Enteral feeding is vital for sick infants, but the transition to normal diet may be difficult. The authors describe a feeding team which provides multidisciplinary management of ‘hard to wean’ children within a large children’s hospital, using reduction of feed volume to stimulate hunger, combined with psychological input to improve mealtime interactions and relieve parental anxiety.

Aims To assess the impact of feed reduction on growth and identify factors associated with successful feed cessation.

Subjects and methods Clinical and anthropometric data retrieved from case notes and clinic database for all 41 children referred for feed withdrawal over a 5-year period.

Results The children were aged median 4.0 (range 0.7–15) years when first seen; 27 (66%) were male and before reduction they received a median of 3766 (range 1987–9728) kJ daily from enteral feeds. Parents were often extremely anxious about weight loss and needed considerable support to make feed reductions. After follow-up for median (range) 1.7 (0.4–5.4) years, 32 (78%) were on solely normal diet, seven were still enterally fed and two were reliant on oral supplement drinks. Those referred after age 5 years were more likely to still be on artificial feeds (OR 7.4 (1.3–42); p=0.025) or to have taken more than a year to stop (OR 6.9 (1.1–43); p=0.04). Feed reduction was commonly followed by a decline in body mass index, but this was not associated with slow growth.

Conclusions A majority of children eventually ceased feeds successfully, but slow and failed weaning is more likely after age 5 years.

INTRODUCTION

The process of withdrawing children from enteral feeding can be challenging for parents and professionals. Enteral feeding provides vital support for sick infants, but once medically stable the transition to a normal diet may be difficult and some children then continue artificial feeding for many years. The difficulties associated with withdrawal from tube feeds to oral feeds have been well documented. Children who are tube fed may have missed out on critical periods for the development of feeding skills; they may also have undergone repeated aversive oral experiences from nasogastric tube placement, or have been force fed, leading to a learned aversion to oral stimulation. Most important, appetite is disrupted. Children regulate their energy intake quite precisely, so if enteral feeding is meeting all their energy requirements, they will not experience hunger.

What this study adds

▶ Multidisciplinary input can help anxious parents agree to feed reduction and persist in the face of short-term weight loss.

▶ Most children can be weaned off feeds within a year, but the process is slower if started after the age of 5 years.

▶ Reduction in feeds often leads to weight loss and decline in body mass index but this is not associated with slow growth.

Although there is agreement that a multidisciplinary approach is necessary to help the withdrawal process, few interventions have been formally described or include data on long-term outcomes, although one trial did show the benefit of a behavioural regime. A number of groups have described intensive inpatient withdrawal regimes where feeds are greatly reduced and then stopped over a few days in order to stimulate hunger. However, if a child still lacks feeding skills, the risk is that substantial short term weight loss will occur and this may lead to restarting of tube feeding during or after the admission. The long term safety of this approach has never been formally assessed, but in one series there was a death due to aspiration. However, most families neither have access to such regimes, nor would be willing to take such a drastic therapeutic approach, and will continue to be managed as outpatients. These longer-term ambulatory regimes have not been formally described to date, possibly because the numbers seen in any one centre tend to be small.

Yorkhill children’s hospital set up a feeding team in 2002 specifically to assist the
withdrawal of children from artificial feeding. The hospital provides tertiary care for the West of Scotland and manages a range of severe medical and surgical conditions. Most of the children referred have survived major neonatal health problems and many remain chronically ill or impaired. There had often been previous unsuccessful attempts at withdrawal. The team provides multidisciplinary management by a clinical psychologist, dietician and paediatrician, combining careful nutritional management with psychological techniques.

As weight loss was so commonly associated with feed reduction, we first set out to audit our practice to assess whether feed reduction was associated with stunted growth or significant degrees of undernutrition, but this audit also provided the opportunity to identify the prognostic factors associated with successful feed withdrawal. The aim of this study therefore was to assess the impact of feed reduction on growth and identify factors associated with successful feed cessation.

**METHOD**

Participants were all 41 children first seen in the years 2002–2007 who had been referred for withdrawal from nasogastric or gastrostomy feeding, had a safe swallow and appeared neurologically capable of eating. All had had been enterally fed for 6 months or more.

**Clinical management**

The general assessment process and withdrawal regime followed in the clinic is shown in Box 1. The main role of the team is to support the family in making sustained feed reductions, to help families deal with anxiety and to manage stressful mealtime interactions.

Dietetic assessment always includes a 3-day food diary to allow an estimation of the types and textures of preferred foods (if any). Tailored advice is then usually given to maximise calorie intake, using readily available family foods such as double cream, butter or cheese, but specific quantities of food are not mentioned. Parents are encouraged to feed to appetite, offer little and often initially, ensure at least 1.5–2 h between eating events and spend no more than 20 min over a meal. Between clinic visits, phone calls are made by the dietician to support the family, who are also discouraged from weighing between visits, to minimise anxiety from small changes in weight.

A vital tool for the Clinical Psychologist is the videoed meal-time, which is then reviewed with the parents. This helps them to recognise the impact of their handling of meal times on the child’s behaviour and to identify effective strategies they could adopt. These include giving praise for food eaten, encouraging the child to self-feed and reducing distractions during meal-times. Further sessions then review progress with behaviour management and in some cases the video is repeated. Other work focuses on managing parents’ fears about their child’s weight and feed reductions, as well as around the impact of the feeding difficulties and chronic illness on the parent-child relationship. The clinical psychologist or an assistant psychologist might also work one-to-one with school age children, to help them overcome, for example, fear of trying new foods, choking or eating certain textures. In some cases assessment of how children feel about being tube fed is important; they can become attached to their tube and be fearful about a future without it.

The clinical psychologist routinely writes to parents following feedback sessions as well some clinics to reinforce advice given.

**Data retrieval**

All eligible children were identified from the team database and their basic clinical data retrieved from the database and their clinical notes. The last follow-up information was retrieved in May 2009.

Children were measured at most review appointments and feed status recorded. They were weighed naked or in light clothing on electronic scales and height or length measured using a stadiometer. All measurements were entered into a growth database and those collected nearest to three key events identified: initiation of reduction, feed cessation and last follow-up. Peak feed volume and type and volume taken at last follow-up were also recorded.

The team began to collect body composition measures from 2004, but did so routinely only from 2006. Bioelectrical impedance (BIA) was measured in children aged over 4 years using either leg to leg (TBF500 body composition analyser, Mettler-Toledo, Ltd, Oberhaching, Germany) or leg to leg (TBF300 body composition analyser, Tanita, Ltd, Tokyo, Japan) measurements.

**Box 1 Assessment and management protocol**

**Before first appointment**

Review of medical notes
Collation and analysis of growth data
Review of prior Speech and Language feeding assessment
3-day food diary sent to family

**First appointment**

One hour, all professionals present, gather information on
Medical and developmental history
Diet and feeding history from birth
Mealtime milieu and parental management of meals
Family structure and social issues
Child’s temperament and general behaviour
Anthropometric measurements, body composition and parental height.

Family leave room—team discuss individual options—family return to room
Explain growth data
Discuss further assessment and need for feed reduction then or in future
Agree management plan

**Further assessment as required**

Video of home meal time, reviewed by parents and clinical psychologist
One to one sessions with clinical psychologist

**Reduction regime**

Reduce feeds by 10–15% of current energy intake
Maximise energy content of solid foods
Avoid weighing between clinics
Review every 1–2 months
If gained weight—further reduction by same or larger amount
Static weight—further reduction by same or smaller amount
Weight loss—feeds unchanged, review in 1 month

Further sessions and/or telephone contact with psychologist and/or dietician as required between clinic appointments
successful withdrawal was defined as sustained cessation of both tube feeding and oral high energy sip feeds. All height, weight and body mass index (BMI) data were routinely converted to z scores compared to the UK (UK90) growth reference. The BIA data were expressed as lean and fat standardised residuals adjusted for, height, age gender and measurement method compared to external norms (referred to as lean and fat z scores thereafter). Triceps and subscapular skinfolds were measured using Holtain skinfold callipers and BIA data were collected for 17, after feed reduction in all but one (3 months to 5 years after). The median (range) z score was −0.72 (−2.5 to +0.7) and these showed only a weak decline as feeds were withdrawn (table 3). Most changes in height z score were slight, but changes in BMI varied more widely, with eight (26%) showing a BMI increase, while nine (29%) reduced by more than one z score. However there was no association between decline in BMI and height. Children showing >1 z score decline in BMI had a median change in height z score of −0.30 compared to −0.31 for those with <1 z score decline and −0.29 for those whose BMI z had increased (Kruskall–Wallis p=0.996) (figure 3).

There were 26 subjects with body composition measures. BIA data were collected for 17, after feed reduction in all but one (3 months to 5 years after). The median (range) z score for fat measured by BIA was 0.08 (−1.4 to +2.2) while the lean z score was −1.26 (−4.1 to +1.2). The fat z score tended to decline with length of time since feed reduction (Spearman’s rho=−0.46; p=0.04), but Lean showed no such decline (Spearman’s rho=0.5; p=0.21). None of the fat z scores dropped below the 9th centile. Skinfolds data were available for 12 children of whom three also had BIA data. Three were collected at or before feed reduction, three within a year and six up to 3 years after reduction began. The median (range) skinfolds z score was −0.72 (−2.5 to +0.7) and these showed only a weak trend to decline over time (Spearman’s rho=−0.12; p=0.77). Only one child had a z score for fat below −2SD, recorded as feed reduction began.

DISCUSSION
This paper describes the process of withdrawal from tube feeding in one of the largest and certainly the most detailed clinical series to date and these results have important lessons for other clinicians dealing with this often challenging problem.

What are the factors that delay feed cessation?
Parental anxiety tended to be a major obstacle. For most of these children enteral feeding provided life saving support in early life and gaining weight had been of critical importance when ill. Thus feed reduction followed by even a small weight loss was hard for parents (and sometimes other clinicians) to bear. Thus input from our psychologist in anxiety management...
was invaluable, while the team’s cohesive approach helped to build up parental confidence in their child’s capacity to feed. The role of parental anxiety in children with general feeding difficulties has been well documented but less so in relation to artificial feeding. In this study we lacked objective measures of anxiety and further research is required to examine further the role and management of parental anxiety in this context.

There may well be many other factors that delay or accelerate the cessation of tube feeds, but the small numbers, and the heterogeneity of this case series limited us to examining only two: age and gender. Later age at referral was quite strongly associated with delayed or failed withdrawal. A small published case series has described more rapid withdrawal in older children but in that study the children had all fed normally before the onset of tube feeding, while in this series a majority had been fed continuously since around birth. It has been suggested that there is a critical period for acquisition of solid feeding skills and others have suggested that tube feeding may disrupt the establishment of physiological pathways allowing integration of sensory information. Our results would suggest that while there may be an optimal period, older children can still acquire feeding skills, albeit more slowly. Withdrawal in older children may also be harder and slower simply because they have slower growth rates and thus less drive to eat.

The role of gender is more complex. After adjustment for age, male gender was not a significant predictor of failed withdrawal, but nearly two thirds of all referrals were boys. Boys are overrepresented in cohorts of tube fed children with cerebral palsy but the two largest previous studies of prolonged tube dependence did not find any substantial excess of boys and we found an equal gender mix on our hospital database of all children on long term feeding. This might suggest that more girls had been successfully weaned before referral.

The pace of feed reduction
Hunger is a powerful stimulus for the acquisition of feeding skills. If energy intake completely meets or exceeds needs then hunger is suppressed in the short term by gastric distension and in the longer term by leptin produced by fat stores. Healthy infants and toddlers have been shown to regulate energy intake quite precisely, so that hunger may be absent until enteral feeds are reduced sufficiently to place the child into short term negative energy balance. Once parents agreed to reduce feeds, children often made rapid progress, but for some the withdrawal process was very lengthy, mainly because of the slow pace of feed reduction. Few parents are willing to tolerate more than trivial amounts of weight loss, so our withdrawal protocol emphasised weight maintenance during the withdrawal process, which in practice usually means a decline in fat stores as the child grows. However the disadvantage of this approach is that it makes the withdrawal process protracted in older children where growth and weight gain is slower.

Rapid withdrawal regimes are widely publicised and are highly appealing in terms of apparent cost effectiveness, but no studies have described medium term outcomes in more than a handful of patients. In our series, four families decided to stop feeds immediately themselves and two of these children later restarted feeds at their family’s request and still remain artificially fed (table 1). There is thus a need for the long-term efficacy and safety of rapid withdrawal regimes to be more formally assessed, preferably via a randomised controlled trial.

Growth and body composition
The children in this series were unusual; most were extremely unwell as neonates, many had complex syndromic conditions and usually had continuing health or developmental problems. It is thus not surprising that on average they were extremely short and tended to grow slowly. Our results offer important reassurance, however, about the lack of impact of weight loss on their somatic growth, since there was no relation between degree of BMI change and change in height, with all children tending to decline slightly in height, whether their BMI had increased or declined. We have only limited body composition data, collected mainly after feed reduction began, with...
no baseline data for comparison. However, the data we have does somewhat clarify the more extensive anthropometric data. First nearly all the children had fat levels within normal limits. Since the majority had shown BMI reductions, this suggests that they all had ample fat stores before reduction. Second, while the children often had exceptionally low BMIs, even before feed reduction, for those with measures of body composition, it was their lean rather than fat that tended to be exceptionally low. There was no evidence that these children had lost lean mass during the weaning process, and this would be unlikely in view of their sufficient fat stores. A more likely explanation is that their lean mass was a longstanding feature, which is in keeping with other studies which have found low lean mass in nutritionally stable children with physical disability. Whether this reflects earlier undernutrition or just the children’s underlying syndromes is not clear, but in these circumstances aiming to attain an average BMI may well result in overfeeding and loss of appetite. Certainly there were individual cases where referred children were significantly overfed and needed to lose weight for some time before showing any increase in appetite. BMI may thus be a poor guide to nutritional state in previously sick children and it is important in such children to also collect

Table 1 Characteristics of those children who successfully ceased artificial feeding

| Age started (years) | Mode of feeding | Primary diagnosis                               | Age first seen (years) | Peak intake kJ/kg | Duration of feed reduction (years)* |
|---------------------|----------------|------------------------------------------------|------------------------|------------------|-----------------------------------|
| Birth               | NG             | Complex cardiac anomaly                          | 2.1                    | 341              | 0.0                               |
| 1.4                 | Gast           | Complications of prematurity                      | 3.9                    | 304              | 0.0                               |
| Birth               | NG             | Oesophageal atresia                               | 0.7                    | 490              | 0.1                               |
| 1.8                 | NG             | Imperforate anus                                  | 2.1                    | 328              | 0.1                               |
| Birth               | Gast           | Complications of prematurity                      | 3.2                    | 387              | 0.1                               |
| 6.5                 | Gast           | Myotonic dystrophy                                | 9.4                    | 87               | 0.2                               |
| 0.7                 | NG             | Complications of prematurity                      | 1.5                    | 263              | 0.3                               |
| 0.7                 | NG             | Complications of prematurity                      | 1.5                    | 233              | 0.3                               |
| 0.2                 | Gast           | Transposition of great arteries                   | 2.1                    | 389              | 0.3                               |
| 0.1                 | Gast           | Complex cardiac anomaly                           | 3.3                    | 168              | 0.4                               |
| 0.2                 | Gast           | Diaphragmatic hernia                              | 1.1                    | 665              | 0.4                               |
| 0.8                 | NG             | Non-Hodgkin’s lymphoma                            | 2.3                    | 302              | 0.4                               |
| Birth               | Gast           | Complex cardiac anomaly                           | 2.4                    | 334              | 0.4                               |
| 1.7                 | NG             | Idiopathic weight faltering                       | 2.8                    | 272              | 0.6                               |
| 0.3                 | Gast           | Diaphragmatic hernia                              | 1.3                    | 392              | 0.7                               |
| 1.4                 | Gast           | Idiopathic weight faltering                       | 6.3                    | 149              | 0.8                               |
| Birth               | NG             | Cardiac anomaly, renal problems                   | 1.4                    | 374              | 1.0                               |
| Birth               | Gast           | Diaphragmatic anomaly                             | 7.1                    | 285              | 1.1                               |
| Birth               | Gast           | Exomphalos                                       | 5.3                    | 346              | 1.1                               |
| Birth               | NG             | Complications of prematurity                      | 5.5                    | 238              | 1.3                               |
| Birth               | Gast           | Complex cardiac anomaly, pulmonary hypertension   | 4.2                    | 523              | 1.4                               |
| 0.2                 | Gast           | Heart transplant                                  | 4.0                    | 410              | 1.5                               |
| Birth               | NG             | Down’s syndrome                                   | 1.7                    | 361              | 1.6                               |
| Birth               | Gast           | Ellis Van Creveld syndrome, home ventilation      | 2.8                    | 282              | 1.9                               |
| Birth               | Gast           | Oesophageal atresia                               | 1.1                    | 437              | 1.9                               |
| Birth               | Gast           | Diaphragmatic hernia                              | 6.7                    | 151              | 2.0                               |
| 2.7                 | Gast           | Preterm, developmental delay                      | 5.1                    | 293              | 2.2                               |
| 1.0                 | Gast           | Goldenhar syndrome                               | 2.3                    | 459              | 2.2                               |
| 0.4                 | Gast           | Russell silver                                    | 4.5                    | 605              | 2.7                               |
| Birth               | Gast           | Myotonic dystrophy                                | 5.2                    | 190              | 3.1                               |
| Birth               | Gast           | Tracheal rings                                    | 5.8                    | 243              | 3.1                               |
| 0.8                 | Gast           | Complications of prematurity                      | 8.3                    | 216              | 3.4                               |

NG, nasogastric; Gast, gastrostomy.

*Years from feed reduction to stopped altogether.
measures of body composition in order to estimate true feed requirements.

CONCLUSIONS
The key event in the withdrawal process is helping parents to reduce feeds sufficiently to stimulate hunger and to tolerate anxiety about short-term weight loss. With a combination of psychological support and sound medical and dietetic advice younger children can be ‘off’ all feeds within a year, but slow and failed withdrawal is more likely if started after age 5 years. Feed reduction tends to cause relative weight loss, but there was no evidence that this was associated with compromised growth.

Table 2 Characteristics of those with continued artificial feeding

| Gender | Started enteral feeding | First seen | Diagnosis | Duration of follow-up (years) | OM impairment | Learning disability | Intake kJ/kg | Feeding when last seen | Comment |
|--------|------------------------|------------|-----------|------------------------------|---------------|---------------------|-------------|----------------------|---------|
| 1 Female | 0.5 | 6.8 | Quadriplegic cerebral palsy | 1.4 | Yes | Yes | 343 | 180 | Enteral |
| 2 Male | 1 | 11.3 | Quadriplegic cerebral palsy | 2.4 | Yes | Yes | 176 | 188 | Enteral |
| 3 Male | 1.2 | 1.6 | Preterm, chronic lung disease | 3.7 | Yes | Yes | 377 | 255 | Enteral |
| 4 Male Birth | 11.3 | 3.2 | Multiple orofacial anomalies and deafness | 4.6 | No | Yes | 247 | 146 | Supplements |
| 5 Male Birth | 6.1 | 3.9 | Tracheomalacia, multiple neonatal complications | 4.6 | No | Yes | 339 | 339 | Supplements |
| 6 Male Birth | 5.0 | 1.4 | Complex cyanotic cardiac anomaly | 1.4 | No | Mild | 540 | 180 | NG |
| 7 Male | 3.4 | 4.1 | Preterm, weight faltering | 2.7 | No | No | 209 | 146 | Enteral |
| 8 Male Birth | 12.0 | 1.3 | Congenital herpes zoster | 1.3 | No | No | 230 | 205 | Enteral |
| 9 Male Birth | 15.1 | 2.2 | Multiple congenital gut anomalies | 2.2 | No | Mild | 322 | 322 | NG |

OM, Oromotor.

Table 3 Growth status before and after reduction of feeds for those where feeds were successfully withdrawn (a) in all patients and (b) in those with complete growth data

| Treatment stage | Age (years) | Weight (z) | Height (z) | BMI (z) |
|-----------------|-------------|------------|------------|--------|
| (a) All patients (N=32) | | | | |
| At peak feed intake, before reduction* | 3.14 (1.98 to 4.68) | −1.80 (−2.60 to −0.70) | −1.34 (−2.54 to −0.82) | −0.81 (−2.16 to 0.23) |
| When enteral feeding stopped† | 3.93 (2.17 to 7.01) | −2.31 (−3.18 to −1.12) | −1.55 (−2.99 to −0.87) | −1.09 (−2.37 to −0.24) |
| When last seen | 5.24 (2.98 to 7.88) | −2.20 (−3.09 to −1.25) | −1.81 (−2.73 to −1.09) | −1.30 (−2.11 to −0.02) |
| (b) Those with complete growth data (N=22) | | | | |
| At peak feed intake, before reduction* | 2.08 (4.05 to 5.38) | −2.01 (−2.49 to −0.40) | −1.15 (−2.92 to −0.70) | −0.28 (−2.04 to 0.25) |
| When enteral feeding stopped† | 2.44 (5.28 to 7.60) | −2.24 (−3.70 to −1.01) | −1.54 (−3.00 to −0.80) | −1.16 (−2.41 to −0.33) |
| When last seen | 3.37 (6.50 to 8.35) | −2.12 (−3.41 to −1.02) | −1.68 (−3.10 to −0.92) | −0.92 (−2.53 to 0.09) |

Values are median (IQR).
*Height and BMI missing for one child. †Weight missing for one child; height and BMI missing for nine children.
BMI, body mass index.

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