Weight loss during ambulatory tube weaning: don't put the feeds back up

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ABSTRACT

Objective To describe the prevalence of weight loss during tube weaning and its impact on wean duration and growth.

Setting Tertiary feeding clinic, UK.

Patients All children seen for weaning from long-term enteral feeding between 2008 and 2016.

Interventions Outpatient withdrawal of enteral feeding.

Design Case series of children being weaned from tube feeding, documenting clinical details, periods of weight loss and timing of feed changes, as well as height and weight at baseline and within 1 year after feed cessation.

Main outcome measures Amount and frequency of weight loss, wean duration, change in body mass index (BMI) and height SD z score.

Results Weaning was attempted in 58 children, median age 2.7 years, and 90% had stopped feeds after median (range) 5.9 (1–40) months. Weight loss was seen in 51 (88%) children and was more common and severe in children with initially higher BMI. Time to feed cessation reduced by median 4.9 months between 2008–2011 and 2012–2016, while having feeds increased prolonged the wean duration, by median 13 months. After feed cessation, mean (95% CI) BMI had dropped by 0.84 (0.5 to 1.2) z scores, but neither change in BMI, nor the amount and frequency of weight loss, related to growth.

Conclusions Short-term weight loss is to be expected during tube weaning and is not associated with compromised growth. It is important to avoid overfeeding enterally fed children and not to increase feeds again in response to weight loss.

What is already known on this topic

⇒ Enteral feeding, while life-saving for severely ill neonates and infants, can prove difficult to withdraw, leaving children on long-term home enteral feeding.
⇒ If there is weight loss when feeds are reduced, this commonly leads to feeds being increased.

What this study adds

⇒ Some short-term weight loss was seen in most children and was greatest in children with higher initial body mass index (BMI).
⇒ Weight loss and a decline in BMI during tube weaning were not associated with slow subsequent growth.
⇒ Increasing feeds again during the weaning process greatly prolonged tube dependence.

How this study might affect research, practice or policy

⇒ Long-term enteral feeding places a substantial burden on families and health providers.
⇒ If clinicians can better manage the weight loss usually associated with tube weaning, the costs could be much reduced.

BACKGROUND

Enteral feeding is essential for many severely ill neonates and infants, but the transition to oral feeds is not always straightforward. Children who have been enterally fed since early infancy have often missed the usual transitions to complementary feeding, tend to lack feeding skills and may not have experienced hunger. Meanwhile, their parents commonly experience great anxiety around feeding and weight gain.[1] A number of programmes have been set up to address tube dependence worldwide.[2] Most descriptions in the literature are of inpatient programmes, with feeds being withdrawn over a matter of days.[2] There have been fewer descriptions of slower, outpatient tube weaning programmes,[3–5] although these will be more feasible in most settings. The clinic described in this paper was set up within a large National Health Service children's hospital in the UK (www.nhsggc.org.uk/rhcfeedingclinic) to provide an outpatient multidisciplinary tube weaning service.[6–8] The clinic accepts children where the referring team have been unable to withdraw tube feeding, who are medically stable and able to swallow safely, based on history and/or video fluoroscopy.[7 8] Sessions are run jointly by a paediatrician, dietitian and a psychologist. The team supports parents to gradually reduce feeds, each time by around 10% of total requirements. This then allows children to gradually experience hunger and develop feeding skills. Meanwhile, the team provide dietetic and psychological support for families, and a psychology assistant does individual work with some children on feeding skills. Further reductions are only made once any resulting weight loss has ceased, so the extent of weight loss and how it is managed is crucial. We previously described factors predicting successful weaning in the clinic's first 5 years.[6] We have since found that the great majority of children can be weaned successfully, but

Table 1 Diagnoses of children undergoing tube weaning

Problem		
Neurodevelopmental problems*	18	30%
Ex preterm	9	15%
Gastro-oesophageal reflux	8	13%
Neonatal surgical issues†	11	18%
Complex congenital heart disease	7	12%
Renal: cystinosis, diabetes insipidus, haemolytic uraemic syndrome	3	5%
Oncology: leukaemia, osteosarcoma	2	3%
Weight faltering/food refusal	2	3%
Total	60	

*Four children with developmental delay, two with autism spectrum, two epilepsy, one each with CHARGE syndrome, Costello syndrome, spina bifida, Edward syndrome, congenital myopathy, fetal alcohol syndrome, cerebral palsy, congenital zoster, chromosomal abnormality, undiagnosed syndrome.
†Three children with cleft palate, two with short bowel syndrome, two with diaphragmatic hernia, one each with Treacher Collins syndrome, tracheoesophageal fistula, exomphalos, anal agenesis.

that the time to feed withdrawal varies greatly. We thus planned a new retrospective audit of children to describe the prevalence of weight loss during tube weaning and how it relates to wean duration and growth.

METHODS

The study period was selected to start immediately after our last survey[6] and finish at a date that would allow the weaning process to have been completed for all included children when the data were collated in 2020. Thus, we studied all new patients accepted by the feeding clinic for tube weaning and seen between 1 January 2008 and 31 December 2016.

Data extraction

The children were identified from the clinic database and their records searched to identify the date feed reduction began and of subsequent appointments and feed changes. At most visits weight, and usually height/length, were measured by trained nursing staff using digital scales and stadiometers, and recorded on an electronic database. At baseline, we retrieved the measured weight and height and then the weight recorded at each subsequent visit, until the last visit within 1 year after feed cessation, where both weight and height were retrieved. We also retrieved basic clinical information and the volume of feeds at baseline from the electronic record.

LMSgrowth[9] was used to calculate weight and height and body mass index (BMI) SD z score (SDS) compared with the UK-WHO growth reference.[10] The type and volume of feeds just before feed reduction began were used to calculate the total daily energy supplied by feeds. The child's age-appropriate energy requirements per kilogram[11] were then used to calculate feed dependency: the percentage of total energy requirements supplied by feeds.

The lowest weight recorded after the first feed reduction was used to calculate initial weight change, as a percentage of initial weight. The weights at each visit were then examined to identify all periods of weight loss, defined as starting on the last date of measurement before a lower weight, and ending when a weight was higher than the starting weight. A semi-anonymised data set (without names or dates of birth) was then entered into IBM SPSS V.28 for analysis.

Table 2 Time to feed cessation, by amount of initial weight loss, number of periods of weight loss, age, level of feed dependence, developmental delay and date wean started

	Total	Per cent	Time to feed cessation* (months)	P value
Age				
<2 years	21	40.4	5.1 (0.1–33)	
2–5 years	17	32.7	6.9 (1.3–28)	
>5 years	14	26.9	6.4 (1.4–49)	0.67†
Sex				
Male	27	51.9	8.3 (0.4–49)	
Female	25	48.1	4.6 (0.1–26)	0.01‡
Feed dependence				
<50%	13	25.5	5.3 (0.06–20)	
50%–90%	20	39.2	10.8 (3.7–49)	
>90%	18	34.6	4.3 (0.4–33)	0.08‡
Year wean started				
2008–2011	23	44.2	10.4 (1.4–49)	
2012–2016	29	55.8	4.9 (0.1–31)	0.02‡
Developmental delay noted				
Yes	17	33	9.8 (1.2–49)	
No	35	67	4.9 (0.1–33)	0.05‡
Amount of initial weight loss				
<1% or gain	28	53.8	5.4 (0.07–49)	
1%–5%	15	28.8	6.9 (1.41–31)	
>5%	9	17.3	5.3 (1.25–26)	0.65‡
Periods of weight loss				
None	7	13.5	1.8 (0.1–12)	
One–two	32	61.5	5.2 (1.3–31)	
Three–four	13	25.0	14.9 (5.1–49)	0.002†
Feed volume increased again during weaning period				
Yes	12	24.5	18.0 (8–49)	0<.001‡
No	37	75.5	4.9 (1–30)	

*Missing for one child.
†Kruskall-Wallis test.
‡Mann-Whitney U test.

Analysis

The primary outcomes were wean duration (months from first feed reduction to when last feed stopped). Secondary outcomes were initial percentage weight loss, number of weight loss periods and change in height and BMI SDS between baseline and follow-up.

As the wean duration was markedly skewed, Kruskal-Wallis test or Mann-Whitney U test was used to compare median values. When modelling multivariable predictors of wean duration, all predictors with $p<0.1$ were placed together in a linear regression model with log duration as outcome and non-significant variables removed, until all variables in the model were $p<0.05$. As the number of periods of weight loss was strongly correlated with whether feeds were increased, these variables were added individually to separate models.

RESULTS

Weaning was attempted in 60 children, but 1 child proved unsuitable due to severe neurodevelopmental problems and 1 was lost to follow-up. The remaining 58 children (47% girls) had a variety of medical and surgical problems, often multiple, with 11 (18%) born preterm (table 1). Developmental status

Table 3 Height and body mass index (BMI) at baseline in all children (N=58) and change to end of tube weaning (n=52) by amount of initial weight loss, number of periods of weight loss, age, level of feed dependence and date wean started

			Baseline		Change to last follow-up	
	Total		Height SDS*	BMI SDS*	Height SDS†	BMI SDS‡
All children			Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	Number	%	−1.51 (1.2)	−0.18 (1.3)	−0.11 (0.84)	−0.85 (1.2)
Amount of initial weight loss						
<1% or gain	30	52	−1.35 (1.1)	−0.61 (1.3)	1.42 (0.7)	−0.55 (1.2)
1%–5%	16	28	−1.27 (0.9)	−0.06 (1.2)	−0.71 (0.5)	−1.00 (1.1)
>5%	11	21	−2.25 (1.4)	**0.79** (**0.9**)	0.17 (1.1)	−1.49 (1.1)
P value§			0.08	0.002	0.27	0.037
Periods of weight loss						
None	7	12	−2.31 (1.0)	−1.19 (1.1)	0.27 (0.82)	−0.57 (1.8)
One–two	35	61	−1.53 (1.2)	−0.29 (1.1)	−0.04 (0.83)	−0.87 (1.1)
Three–four	15	26	−0.97 (0.8)	0.53 (1.4)	−0.49 (0.75)	−0.90 (1.2)
P value§			0.01	<0.001	0.051	0.67
Age						
<2 years	23	40	−1.76 (1.3)	−0.63 (1.2)	0.05 (0.88)	−0.98 (1.3)
2–5 years	19	33	−1.28 (1.0)	0.26 (1.7)	−0.40 (0.84)	−0.87 (1.0)
>5 years	16	28	−1.40 (1.1)	−0.15 (0.6)	−0.01 (0.70)	−0.61 (1.2)
P value§			0.30	0.17	0.69	0.40
Feed dependence						
<50%	15	27	−1.15 (1.2)	0.21 (1.3)	−0.16 (0.6)	−1.30 (1.0)
50%–90%	23	41	−1.38 (1.1)	−0.16 (1.2)	−0.19 (0.9)	−0.85 (1.2)
>90%	18	59	−2.00 (1.0)	−0.47 (1.2)	0.03 (0.9)	−0.55 (1.2)
P value			0.033	0.13	0.54	0.11
Year wean started						
2008–2011	24	41	−1.50 (1.0)	−0.33 (1.5)	−0.22 (0.77)	−0.96 (1.3)
2012–2016	34	59	−1.52 (1.3)	−0.13 (1.1)	−0.03 (0.89)	−0.74 (1.1)
P value¶			0.95	0.56	0.43	0.53

*Missing for three children.
†Missing for 10 children.
‡Missing for 11 children.
§ANOVA trend.
¶ANOVA.
ANOVA, analysis of variance; SDS, SD z score.

was not recorded consistently over the whole period, but 20 (33%) children were recorded as having at least moderate developmental delay or learning disability. Nearly half (44%) were initially receiving 80% or more of their requirements via tube feeds (table 2).

After first feed reduction, 30 (50%) children showed little or no weight loss, 16 (27%) lost 1%–3%, 9 (15%) 5%–10% and 3 (5%) more than 10% of their initial weight. Other children lost weight later in the weaning process, with only 7 (12%) never showing any weight loss, while 17 (29%) lost weight two to four times. Children with higher BMI had more initial weight loss and weight loss episodes (table 3). There were no significant associations between age, gender or degree of feed dependence and either the amount or the number of weight loss episodes (data not shown).

After a median (range) of 3 (1–8) feed reductions over 5.9 (1–40) months, 52 children (90%) had stopped all feeds. Feeds were increased at least once in 12 (25%) children. These children showed similar characteristics to those whose feeds had not been increased, but had average feed duration 12 months longer (table 2). The number of periods of weight loss was strongly associated with wean duration, though not the amount of initial weight loss (table 2).

There was no difference over time in the amount of feed dependence or in baseline BMI z score or the underlying clinical features, but wean duration reduced by median 4.9 months between 2008–2011 and 2012–2016. Over time, the number of feed reductions made before cessation decreased significantly (median (range) 2008–2011 4 (1–8); 2012–2016 3 (1–7); p Mann-Whitney=0.023) and the proportion (number) of children where the feeds were ever put back up reduced from 38% (8) in 2008–2011 to 14% (4) in 2012–2016 (p χ^2=0.09).

The number of periods of weight loss was strongly related to whether feeds were ever put back up and this had a multiplicative effect on wean duration (figure 1, online supplemental table 1). Children who had three to four periods of weight loss and whose feeds were put up had median wean duration of 27 months, compared with 11 months for those who did not (p<0.001).

In a simultaneous linear regression model, log wean duration was longer for boys (beta=0.311, p=0.014) and children with developmental delay (beta=0.31, p=0.016) and shorter in recent years (beta=−0.35, p=0.006) (online supplemental table 2, model 1), but these effects were attenuated by the addition of number of periods of weight loss or whether feeds were increased, which were much the strongest predictors (number

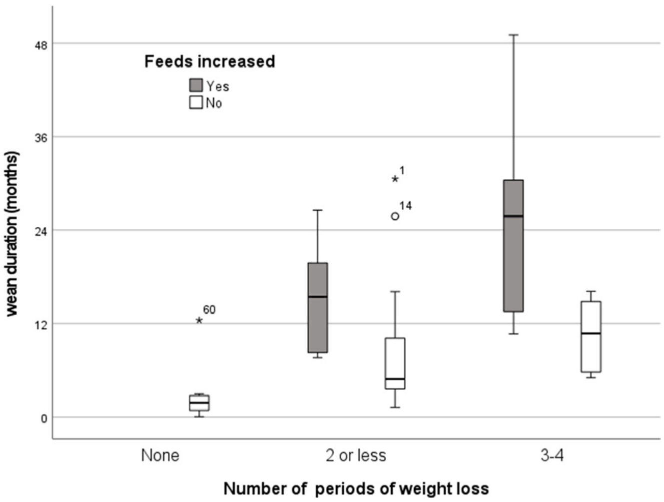

Figure 1 Box plot of association between number of weight loss episodes, feed increases and wean duration. The authors can confirm that we have permission to use the image which was created by Charlotte Wright.

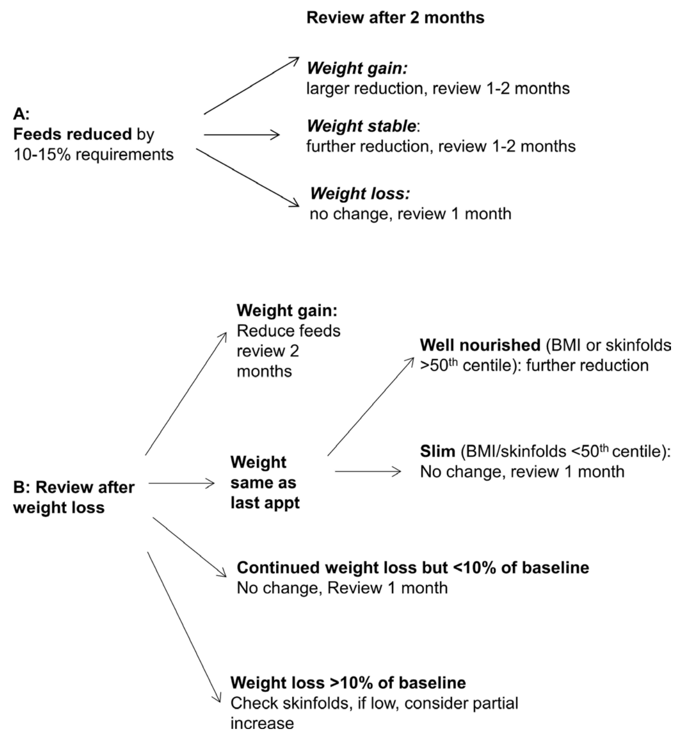

Figure 2 Protocol used for tube weaning (A) after feed reduction by 15%–20% of total requirements (B) 1 month after weight loss. For further details, see www.nhsggc.org.uk/rhcfeedingclinic. The authors can confirm that we have permission to use the image which was created by Charlotte Wright.

of periods of weight loss beta=0.55, p<0.001; whether feeds were increased beta=0.37, p=0.005) (online supplemental table 2, models 2 and 3).

At the last measurement, collected 7.2 (3.4) months after feed cessation, BMI had dropped 0.84 (95% CI 0.5 to 1.2) SDS to −1.1 (1.4) SD. Overall height SDS showed a slight decline, but only six (12%) children showed a fall greater than 0.7 SD. There was no association between initial % weight loss or change in BMI SD and subsequent height gain (table 3). There was also no association between baseline height or change in height or BMI z scores and time to feed cessation (data not shown).

In six children, complete feed withdrawal was not achieved and after follow-up of 4–9 years, all remained at least partially tube fed. They were no different in terms of initial BMI, feed dependency, age or amount of weight loss from those successfully weaned. Two children, both with learning difficulty, had shown no increase in interest in food after 5 and 7 years. The other four had acquired good feeding skills and reduced tube dependency but continued partial tube feeding due to a combination of medical and social complexity. One other child who had been weaned without weight loss, later lost weight for other clinical reasons and was restarted on feeds.

DISCUSSION

Long-term enteral feeding has substantial social and healthcare costs, but it is hard to develop expertise in managing tube dependency, as it presents relatively rarely in most centres. Our earlier study[6] and a recent larger case series using a similar outpatient feed reduction regime by Dipasquale *et al*[3] showed that children could be safely tube weaned. In this new series, we consider the role weight loss plays in how long the process takes.

Most children lost weight at some point, which is in keeping with two earlier case series of rapid weaning[12 13] although another found no net change in BMI.[14] While the wean duration was longer in boys, as found in another study,[15] and in children with developmental delay, much the strongest predictors were the number of weight loss periods and whether feeds had been increased (figure 1). We successfully weaned 90% of children, compared with 70% in Dipasquale *et al*'s series, where 11% of wean attempts feeds were restarted because of rapid weight loss.[3] The association of weight loss with initially higher BMI has not been reported before, but in another case series, children who failed to stop feeds had markedly higher BMI at baseline (+1 SD), compared with those successfully weaned (−0.41).[16] Thus, there is a risk that high initial weight loss will lead to termination of the weaning process before children have lost enough of their surplus weight to develop an interest in food.

A strength of this study is the inclusion of growth outcomes collected well after feeds had stopped. It was reassuring, as in our first series[6] to find no evidence that weight loss led to slowing of growth. Few studies of rapid tube weaning have tracked growth over time, but one found a marked decline in height centile,[17] while another did not.[15] Our slower approach, which avoids more drastic variation in energy intake, seems to successfully protect against growth compromise.

There are several limitations to this study. Like most previous studies, it lacks control data and the numbers available gave us only limited power to explore different predictors and to construct multivariable models. The children studied were necessarily seen for the first time 5–13 years ago, to allow enough time to track every child to the end of their weaning process. We also lacked any objective information on oral skills and feeding behaviour.

Although the case mix of children was unchanged over time, the median duration of feed withdrawal reduced from 9.3 to 4.5 months. We suspect that this reflects a trend to shorter follow-up intervals, which keeps the weaning process on track, as well as the team becoming more confident in the management of weight loss. We learned to make fewer, larger reductions, once parents were confident to proceed, and to give anticipatory guidance about likely weight loss. Where possible, we involve members of the referring clinical teams to prevent families from receiving conflicting messages. Further feed reductions are only made once at least some weight regain has occurred, but the aim is never to put feeds up again unless there has been substantial (>10%) weight loss and no improvement in appetite. We have now characterised this in our tube weaning protocol (see figure 2 and www.nhsggc.org.uk/rhcfeedingclinic).

CONCLUSIONS

Some short-term weight loss should be expected during tube weaning and should not be treated as an adverse outcome. It is important to avoid letting enterally fed children become overweight and to avoid responding to weight loss by increasing feeds, as this greatly prolongs tube dependence.

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Supplementary table 1:

Wean duration (m) by whether feeds ever increased during tube weaning and number of periods of weight loss (data used in Figure 1)

	N	75th	Median	25th	Minimum	Maximum
Never increased						
No weight loss	7	2.99	1.84	0.39	.07	12.43
1-2 periods of loss	24	10.25	4.90	3.61	1.25	30.59
3-4 periods of loss	6	15.19	10.76	5.63	5.07	16.15
Feeds increased						
No weight loss	0	-	-	-	-	-
1-2 periods of loss	5	23.19	15.43	7.98	7.66	26.58
3-4 periods of loss	7	32.93	25.8	10.95	10.69	49.05

Supplementary table 2:

Simultaneous linear regression models of significant predictors of log wean duration (Sex, developmental delay and year) with number of periods of weight loss and whether feeds were increased added into separate models because of collinearity

Coefficient	B [95% CI]	Beta	P
Model 1			
Sex	-0.72 [-1.3 to -0.1]	-0.31	.014
No versus any developmental delay	-0.76 [-1.4 to -0.1]	-0.31	.016
2008-11 versus 2012-16	-0.83 [-1.4 to -0.2]	-0.35	.006
Model 2			
Sex	-0.42 [-0.9 to 0.04]	-0.18	.075
No versus any developmental delay	-0.53 [-1.0 to -0.04]	-0.21	.035
2008-11 versus 2012-16	-0.59 [-1.15 to -0.1]	-0.25	.014
Number of periods of weight loss	0.59 [0.4 to 0.8]	0.55	.000
Model 3			
Sex	-0.60 [-1.2 to -0.03]	-0.25	.038
No versus any developmental delay	-0.62 [-1.2 to -0.03]	-0.25	.040
2008-11 versus 2012-16	-0.60 [-1.2 to -0.01]	-0.25	.045
Feeds ever increased	-1.01 [-1.7 to -0.3]	-0.37	.005