

Failure to wean?

Charlotte M Wright

Enteral feeding is a life-saver at the right time, but costs the NHS many thousands of pounds a year: £6500 in feeds and consumables alone for a 4-year-old child.¹ Yet many children who can eat remain tube fed for lack of help in feed withdrawal.

Wilken and colleagues² describe a case series of children who took part in a two-week home-based tube weaning programme where feeds were withdrawn over a matter of days. Rapid weaning is a controversial approach and this is probably the first article to describe longer term results for such children so thoroughly. It was not a trial, so cannot prove the relative effectiveness of the techniques used, but it does provide some much needed information on safety. The children's growth patterns were reassuringly steady and the number of total treatment failures was small. These are surprising results since fast weaning is an extreme approach that potentially places a major physical stress on the child. However, this programme involved much more than just rapid tube withdrawal. Children were carefully vetted in advance, seen daily by a paediatrician and the freelance psychologist lived nearby throughout the programme and undertook an intensive feeding behaviour regime with the family.

So, is this an option more mainstream services should consider? A very intensive short-term professional involvement is required, which would be difficult for most UK units to accommodate, although there are a few specialist services worldwide that are specifically set up to work in this way.^{3 4} Our experience in Glasgow has been that parents are very anxious about feed withdrawal⁵ and that few would be willing to allow their child to be weaned so quickly. However in our case series, half the preschool children had been successfully weaned within 6 months and Wilken's paper raises the question whether some of these children at least could have been freed from the constraints of tube feeding even faster.

While half the younger children could be weaned quickly, the remainder took much longer, because of complex medical problems, anxious parents or both. Older

children who have never fed orally also take longer. In our case series, there were nine children whom we had then failed to fully wean.⁵ Since then, we have succeeded in fully weaning four of these, but only after working with them for 4–10 years. Our limited experience of rapid weans, mainly undertaken without our involvement, was that children tended to later revert back to long-term tube feeding.⁵ Thus, rapid weaning is not feasible for all and certainly should not be attempted without careful preparation.

One of the main reasons parents seek care overseas or via private services is that they do not have access to a local clinic with tube weaning expertise. This is troubling, since the basic principles of tube weaning are actually fairly straightforward and should be achievable in any centre that undertakes long-term tube feeding. We have previously described our experience in detail,⁵ but it is worth here trying to summarise the most important principles.

WHEN TO WEAN?

Before starting tube feeding, clinicians should define clear objectives for feeding, including an exit strategy. All infants receiving long-term tube feeding should be prepared for future weaning with appropriate input from speech therapy and dietetics: regular oral stimulation and messy play. Feeds should be reduced if there is excessive weight gain and then reduced further once they start eating small amounts. For most infants this allows a smooth transition without the need for more specialist input. However, a child can only learn to eat and drink when exposed to food. If a child is fully tube fed and not hungry, they may show no interest in food at all, or even aversion if there has been reflux or previous attempts to force feed. Thus, feed reduction should be started once the child has reached an appropriate developmental stage, even if there is no interest in food. Practitioners may worry that a child has insurmountable oro-motor problems or an unsafe swallow, but if the child has no other motor problems this is unlikely. Often on closer enquiry, the child is already drinking without choking and even swallowing small amounts of favoured foods, which offers important reassurance.

HOW TO WEAN?

The key act of tube weaning⁵ is to make successive reductions in feeds to stimulate hunger. In practice if feeds are reduced by 20% of total energy intake most children will show more interest in food within a couple of weeks, even if their oral intake remains negligible. Younger children often rapidly develop feeding skills, continue to gain weight and their feeds can then be further reduced. These are the children who might respond well to a rapid wean. But not all children are so straightforward. Children who have been overfed long term and have substantial fat stores may have to lose substantial amounts of weight before they truly feel hunger (see figure 1). Children with neurodevelopmental problems and older children may take a long time to acquire the complex oral motor skills needed to eat a normal diet. While they are doing this, they may become quite thin and this can be an anxious time, so effective monitoring is essential (see below). In some cases, where children do have significant developmental disorders, it may have to be accepted that the weaning process needs to progress very slowly to allow them time to acquire new skills.

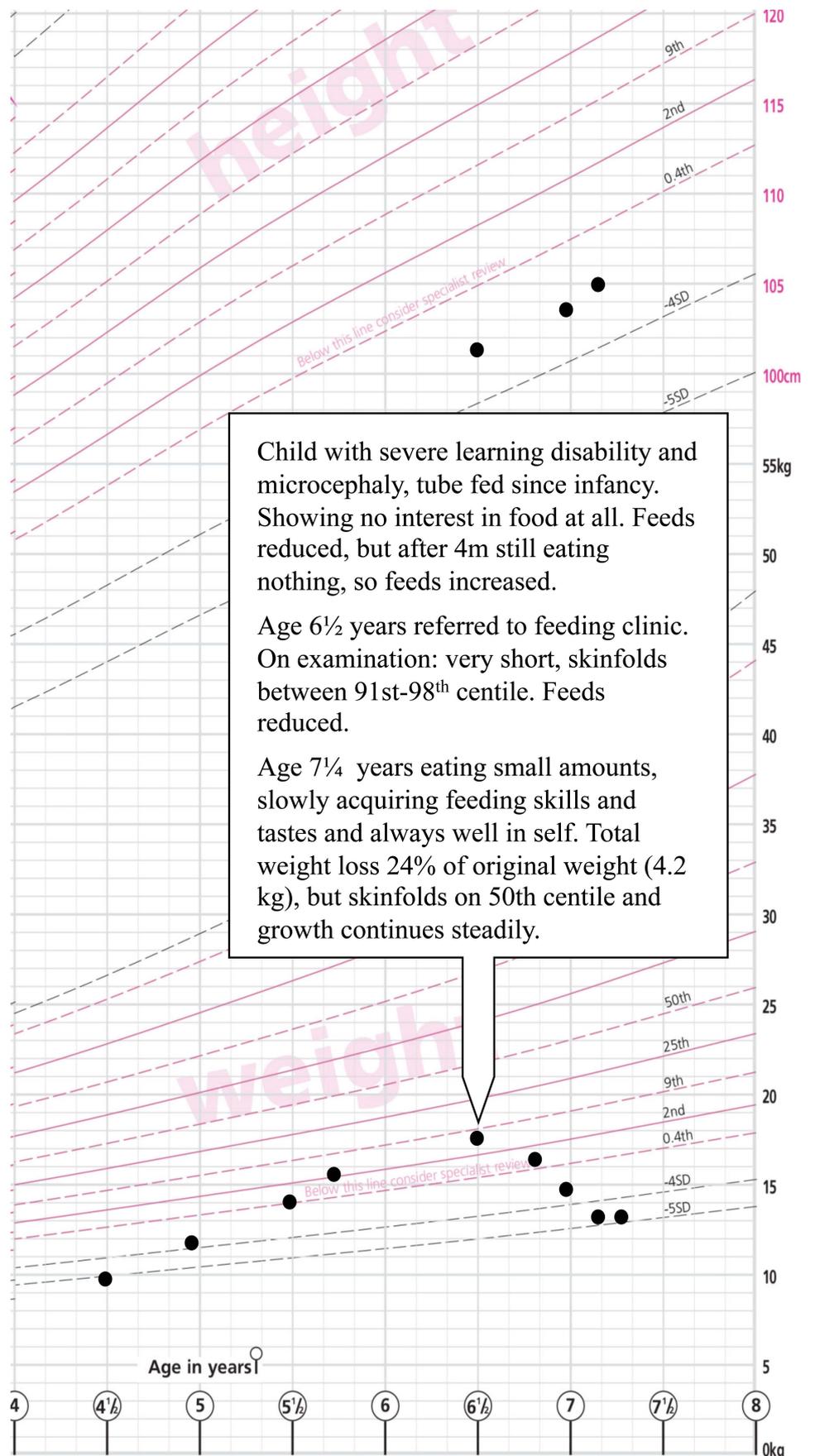
Families commonly become preoccupied with the need for the child to eat and this can lead to intrusive feeding behaviour with aversive responses in the child. A videoed meal with feedback from a clinical psychologist is a powerful tool to avert these behaviours, as well as providing the opportunity for emotional

Box 1 Using skinfolds to assess nutritional status

- ▶ More discriminating in children with disability where height may not be accurate and who may have low lean mass
 - ▶ Useful for establishing general status, not exact centile
 - ▶ Expect a fairly wide error and repeat if in doubt
- ▶ Always measure at two sites, triceps and subscapular, to sample both trunk and limbs
 - ▶ Encourage one member of team to become an expert measurer
- ▶ Plot on WHO charts till age 5 years
 - ▶ Can be downloaded from WHO website
 - ▶ Use Tanner Whitehouse (Castlemead) charts beyond 5 years

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Figure 1 Example of child with excess fat stores at start of weaning process. Chart image reproduced with permission of Royal College of Paediatrics and Child Health.



support. Thus, successful tube weaning teams must include a range of disciplines who need to work together to avoid giving mixed messages. Consultations can be lengthy, but this is time well spent. We recently calculated that our clinic staff costs were met at least twice over by the savings in feeds costs from successfully weaned children.¹

Many of these children see multiple specialists who all need to support the weaning process. Where there is uncertainty about safety, the professionals involved need to formally discuss this and agree on action, not just change the feeding regime unilaterally, as one feed increase may delay weaning by many months.

HOW TO MONITOR NUTRITIONAL STATUS?

Height as well as weight need to be measured regularly and we now also regularly measure skinfolds (see box 1). Most children referred for tube weaning are very small, usually because of their underlying condition, and often also have a low body mass index due to low lean mass.^{5 6} In contrast, they usually have skinfolds well within the normal range.⁵ In these circumstances, one can be confident that a child has sufficient reserves to see them over this

period of poor oral intake. As long as their skinfolds remain within the normal range and they are growing steadily in height, the clinicians can be reassured, even if the weight chart looks alarming (see figure 1).

CONCLUSIONS

The process of tube weaning should be straightforward for younger children. If a family have to travel abroad or pay a private psychologist and achieve a rapid wean for their child, this could be seen as a failure of the UK health service. For other children rapid weaning is not the answer, but these children can still be 'slow weaned' with patience and persistence. Tube weaning services should be available throughout the UK, both to relieve children and families from unnecessary distress and the health service from needless expense.

Competing interests CMW works in an NHS clinic serving children in the West of Scotland that specialises in tube weaning.

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