

Helping children stop or avoid enteral feeding

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Abstract

Long term enteral feeding is widely used to provide vital support for infants and children unable to feed orally, but once medically stable the transition to a normal diet can be difficult. Other children may need to commence tube feeding later in childhood because of difficulties associated with neurodisability, but recognising which children will benefit from tube feed is not straightforward. The Royal Hospital for Sick Children, Yorkhill set up a multidisciplinary feeding team in 2002 to help avoid unnecessary tube feeding.

We accept only children who are either artificially fed or with severe nutritional problems and only after attempted uni-disciplinary management. The team members are a clinical psychologist, paediatric dietitian and consultant paediatrician, supported by a specialist paediatric registrar, assistant psychologist and administrative support. We can see only a small proportion of all with complex feeding problems, but aim to improve the care of such children generally. We disseminate the lessons learned within the Feeding Clinic via education locally and nationally and have an active programme of research.

Over the first ten years of the clinic we have seen 222 patients of whom 67% were initially either tube or oral supplement fed, while only 29% remain so at follow up. In the first three years of the clinic tube fed children had spent a median of seven years on feeds before they were successfully weaned, but since then that has fallen to a median of 2.7 years. Of 53 other children referred for possibly tube feeding, 32 (60%) remain well on a normal diet and only ten (19%) have needed to start tube feeding.

The service is highly cost effective. Salary costs are only around £65,000 per year, while weaning five children per year, reducing their years on feeds by four years, saves the NHS £130,000.

Problem

Long term enteral feeding is widely used to support infants and children unable to feed orally. This provides vital support, but once medically stable the transition to a normal diet can be difficult. These children often lack interest in food, have difficult mealtime behaviour and have highly stressed parents. They have complex feeding regimens and often have major ongoing medical problems. As a result these children often remain dependant on artificial feeding for many years after the true need for this has passed. This is highly distressing for parents and expensive for the NHS. Other children may commence tube feeding later in childhood because of poor weight gain or oromotor difficulties associated with neurodisability. However it is often not clear how this life-changing decision is made and few trusts have any systematic approach to either starting or withdrawing tube feeding.

Background

It has been known for some time that withdrawal from tube feeds to oral feeds may be challenging (1-3). Children who are tube fed have often suffered traumatic experiences ranging from nasogastric tube placement to force feeding, resulting in a learned aversion to feeding(4). Children adjust energy intake automatically (5) so if they are fully enteral fed they will not experience hunger. Parents of children who have been very sick are understandably anxious; anxiety in relation to general feeding difficulties has been well described (1;6;7) but less is known about this in relation to artificial

feeding(1).

Although a multi-disciplinary approach is recognised to be helpful (8), few other interventions have been described in detail, apart from a trial of a behavioural regime (9). Other centres have described rapid withdrawal regimes, usually requiring hospital admission (1;10-13). However these regimes require the child to already have some feeding skills to avoid substantial short term weight loss (11;12). The risk is that this may lead to restarting of tube feeding during or after the admission (10;11) and in one series there was a death due to aspiration (10). However, most families do not have access to such regimes and would not be willing to take such a drastic therapeutic approach. Longer term outpatient schemes like ours have not generally been formally described, but research in our own clinic has shown that outpatient feed withdrawal can be achieved, usually in 6-18 months without cost to growth (14).

It has been suggested that there is a critical period for acquisition of solid feeding skills (15) and others have suggested that tube feeding may disrupt the establishment of physiological pathways allowing integration of sensory information (3). However our research has shown that tube fed infants show similar energy regulation and appetite to healthy toddlers (16).

Baseline Measurement

There was no system to collect information about these children until the clinic started. However in the first three years of the clinic

children were aged a median of four years when first referred and had spent a median of seven years on feeds before they were successfully weaned.

Design

A multidisciplinary feeding team to help avoid unnecessary tube feeding was proposed on the grounds that the cost would be offset by savings in the cost of long term enteral feeding. Strict terms of reference were agreed to make best use of this limited resource. Referrals are accepted only of children with complex feeding problems, either artificially fed or with severe nutritional problems, and only after uni-disciplinary management has been attempted. The core team members are the clinical psychologist, paediatric dietitian and consultant paediatrician, supported by a specialist paediatric registrar, assistant psychologist and administrative support, with speech and language therapy input if required. First appointments last one hour, where all team members co-consult to piece together the medical, developmental, behavioural and feeding history, parental management of meals and the family structure. Clarifying what the family are seeking from the team and explanation of the child's usually complex growth data are essential. We use a specially designed growth database as well as measuring skinfolds to assess body fat levels. We then explore what changes the family feel able to make. These commonly involve manipulation of feeds to induce hunger and a videoed meal, which the Clinical Psychologist reviews with parents to help them identify simple behavioural changes they can make, such as limiting meal length and offering more praise for food eaten. There is one clinic session per week and families are usually followed up in clinic every one to three months. After each clinic the team routinely address their joint clinic letters to the parents to ensure that the discussion has been fully understood. Between clinic visits one-to-one sessions and phone calls are delivered by individual team members, according to needs of individual families.

The time each member of staff can devote to the Feeding Team is limited. By consulting together, using a structured assessment and working with combined notes, we avoid duplication and ensure a focussed, consistent approach to families. We also prioritise skill mixing: for example all team members can explain the growth database to families. Our administrator rings families routinely a couple of days before the clinic. If we have non-attendance despite this, we use the unfilled slots to discuss business and case management. The dictation of letters is divided up among the team members and draft letters shared electronically. When patients are seen by individual team members we circulate a contact sheet electronically to other team members. We have developed a portfolio of leaflets and materials that we can give to parents, including existing published leaflets and our own leaflets developed for specific situations.

Strategy

We have undertaken three substantial audits of performance within the clinic, two of tube weaning and one of weaning from high energy oral sips feeds and these have been important in helping us

identify effective practice and weak points.

Our first published audit established that younger children made the transition to oral feeds much more quickly. As a result we actively encouraged our colleagues to refer earlier.

Results

Over the first 10 years of the clinic we have seen 222 patients. Of all patients seen, 148 (67%) were initially either tube or oral supplement fed, while at follow up only 64 (29%) remain so.

Of 77 children referred specifically for tube weaning, 58 (77%) are already on a normal diet and 13 (17%) are progressing well towards eating normally. This can take a long time: up to 10 years in one case. Our first published audit (see above) established that younger children made the transition much more quickly. Since encouraging earlier referral, the average age when first seen has dropped from a median (IQR) 4.0 (2.0-6.2) years to 2.0 (1.2-3.1) years and the proportion weaned within one year has risen from 57% to 76%. In the first three years of the clinic children had spent a median of 7 years on feeds before they were successfully weaned, but since then that has fallen to only 2.7 years. This suggests that each child successfully weaned has been spared over 4 years of tube feeding. We have also successfully weaned 32 children from long term reliance on high energy liquid feeds. Of 53 other children referred for possibly tube feeding, 32 (60%) remain well on a normal diet and only 10 (19%) have actually needed to start tube feeding.

The annual cost of tube feeding is around £6,500 per child per year. We successfully wean an average of 5 children per year, so with a reduction of 4 years tube feeding per child, we are saving the NHS £130,000 in direct costs for these children alone. In addition there are the savings from other children who avoided tube feeding altogether, children withdrawn from oral high energy feeds and children in other areas weaned by staff trained by the team. Team members work only between 1-5 sessions per week on the team, with salary costs only around £65,000 per year and there are no other drug or investigation costs. Thus the service is highly cost effective.

Lessons and Limitations

Team members work only between one and five sessions per week on the team, so we cannot undertake more intensive work or manage children as in-patients. We mainly co-consult, which is very effective, but this limits the number of children we can see to a maximum of eight per week. This can make it difficult to reappoint children timeously after a missed appointment and a recent audit suggested that this can lead to delays in the weaning process.

Early in the clinic we encouraged children who could drink to transfer straight from enteral feeds on to high energy oral sip feeds. While most of these children then progressed on to a normal diet, two children then remained on a wholly liquid diet for many years and one of these transferred onto adult service still not eating any solid food. Since then we have learned that a slower transition onto

normal food allows a gradual and more successful acquisition of feeding skills.

We have also managed a handful of children whose parents chose to withdraw their feeds very rapidly. In two of these cases the children had residual oromotor difficulties and became significantly undernourished before restarting tube feeds, while another young person showed no inclination to eat and after 10 days insisted on restarting enteral feeds. Only one of these children has since been successfully weaned. We learned from this that weaning should be only be undertaken at a pace congruent with the child's oromotor development and that over-rapid withdrawal may cause rejection of future attempt to wean.

Conclusion

Over the first ten years of the clinic we have seen over two hundred children of whom two thirds were initially artificially fed, while at follow up nearly three quarters were on normal diet. At first we were seeing many children who had been stuck on tube feeds for many years, but we are now seeing children younger and weaning them off feeds faster. This means that the average time spent artificially fed has been reduced by more than four years. The service is highly cost effective, since the saving in feeds costs is at least double the staff salary costs. We can see only a small proportion of all children with complex feeding problems, but aim to improve the care of such children generally via education locally and nationally and via our published research.

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Declaration of interests

Nothing to declare

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