Tube weaning protocol

Preparing for tube weaning

It is important that tube fed infants receive tastes of food and other oral stimulation such as e.g. tooth brushing and that as they get older they are given opportunities for messy play, in preparation for oral feeding. It is also important to avoid over-feeding and excess fat stores.

Assessing whether capable of oral feeding

If they are already known to be able to swallow drinks or small quantities of food then this can be safely assumed. However some fully tube fed children may show no initial interest in food at all. However if they have near normal oromotor development and speech or if they are known to have swallowed effectively and safely in the past, then they will usually be capable of feeding orally and their swallow can be assumed to be safe unless they have shown signs of choking or coughing on liquids or saliva.

When should feed reduction begin?

Children should be reasonably medically and nutritionally stable before feed reduction is attempted. For complex, multispecialty patients, an MDT discussion may be arranged to discuss what is achievable and appropriate Major ongoing medical issues do not preclude tube weaning, but these should be stable and under control at the outset. In these cases there will need to be clear agreement with the child's medical team about how to manage feeds in the event of future of instability. Very low weights and BMIs are commonly seen in children on tube feeds, as a result of their underlying conditions, but tube weaning can still be safely undertaken as long as they are growing steadily, though often along a low centile, and have sufficient fat stores to withstand short term weight loss.

Feeding team, Royal Hospital for Children, Glasgow

Feeding team procedure

Before first appointment

- Review medical notes
- Collate and review all growth data
- Review prior Speech and Language feeding assessment

Send family leaflet about feeding clinic, 3 day food diary and FAS questionnaire about feeding behaviour problems with first appointment letter to complete and bring to clinic.

First appointment

One hour with all clinical team members 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 including skinfolds 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
- Where possible offer range of options for family actions or changes
- Agree actions to be taken before next follow up

Further assessment as required

- Video of home meal time, reviewed by parents and clinical psychologist: NB only helpful if child is already eating at least some food.
- One to one sessions with the clinical psychologist may be necessary in some cases where there are high levels of anxiety or distress.
- Contacting schools and associated nurseries can supply helpful behaviour and dietary information about the non home environment.

Starting tube weaning

In many cases families need to get to know the team before they have the confidence to make feed reductions. There may also be a need to simplify feed regimes or change them to a more modifiable pattern. In these cases further assessment (see below) may be needed and at least one follow up appointment before starting reduction. The key to successful reduction is to have the full agreement of families to implement the change and this agreement is more likely if they are encouraged to participate actively in the decision making process: deciding for example which feed would be most convenient to reduce or stop and when the best time to do this would be. The family should be informed that the process of weaning will usually take between 6 and 24 months, depending on the developmental stage and current levels of tube dependence, so that they have realistic expectations and are less likely to drop out or give up.

How fast to reduce the feeds?

The aim will be to make a reduction of a convenient amount which is around 15-20% of their total energy intake (if fully tube fed) or else their estimated requirement, whichever is larger. The exact regime used will depend on how much the child has in the way of fat reserves, as children with excess reserves may need to lose quite lot of weight before settling on a new more natural weight trajectory. It will also depend upon how dependant on feeds the child is and whether they have yet developed any eating skills.

Once feed reduction is agreed it is important to explain to parents that there is likely to be some short term weight loss and that their child may not show clear signs of increased appetite in the early stages.

Suggest foods for the family to try based on the child's developmental stage and their prior tastes. If the child has already become aversive to attempts at spoon feeding these may have to be soft or melt in the mouth foods that the child can self-feed.

Follow up

Children should generally not be reviewed for 2 months after a feed reduction, as before that usually the child will not yet have fully adjusted to the total reduction and may have persisting weight loss. For the same reason encourage parents to avoid weighing between clinics. Review sooner only if there are high levels of anxiety, or if the child is aged under a year, when adaptation and weight gain are faster.

When to make further reductions

Low risk weans

This will be where the child is medically stable and either

1. Has fat stores > 50th centile or
2. Is on volumes of feed: meeting less than half their of total energy requirements

In these children reduction can usually be made quite frequently, even if weight gain in limited.

After the first reduction at 2 months review, if the weight is stable a further similar reduction could be made, with further review in 2 months. If there has been steady weight gain try to reduce by a larger amount, as this implies that the child has good feeding skills and is adapting rapidly.

If there has been net weight loss since the last appointment the feeds should be left unchanged, with monthly review until there is any weight gain, at which point a further reduction can be made. If there is continued weight loss, or if weight regain is very slow the weight centile will drop. If this reflects previous overfeeding and high initial fat stores this will not be a concern, but where there are worries, the skinfolds should be remeasured. If they are now on average below the >10th centile, then the higher risk protocol should now be followed.

The key aim is to only reduce or maintain the feed prescription, as increasing the feed again greatly prolongs the weaning process. It is also important not to leave too long between clinic visits as this prolongs the weaning process, since in practice reductions are only made at clinic follow ups. Even if feeds cannot be reduced monthly appointments allow the family and the team to check that they are on track and give timely reassurance or redirection.

Higher risk weans

This is where a child is on volumes of feed meeting more than half their total energy requirements and with skinfolds < 50th . Children on larger volumes of feed will usually lack feeding skills and will need time to learn how to chew and move food around the mouth. They also usually have no experience of hunger and may have developed a tendency to gag and vomit when confronted with unwanted food. Older children in particular may struggle to develop a full range of normal oromotor skills. As these children also have low initial fat stores they run the risk of becoming worryingly thin.
For these children further reductions can usually only be made when there has been net weight gain following a reduction, so there may need to be a number of reviews before further reduction is possible. Continued weight loss of up to 10% is usually acceptable, as long as the skinfolds remain within the normal range, particularly if the child is showing increased interest in food.
If skinfolds drop below 10th and interest in food is not increasing, we would consider increasing feeds, but initially this would be by only half the amount previously reduced. That is, if the feeds were last reduced by 200 mls, then the increase should be only 100mls. Very occasionally, usually in the context of severe neurodevelopmental problems, children may show little or no interest in eating despite feed reductions and have prolonged weight loss. In these children the feeds should be increased until steady weight gain along an appropriate centile is achieved.

As the wean progresses

Families will usually need advice on how to maximize the energy content of solid foods taken and to progress the range of textures and tastes, as in younger infants starting solids. As the child develops more interest in food, tasting sessions with a clinical psychology assistant may be helpful. For older children visits at school may be helpful to support them in implementing recommended strategies around, for example meal time management or messy play. Further sessions and/or telephone contact with psychologist and/or dietician may be required between clinic appointments.

Each reduction has to be made with parental agreement. It is generally better to wait till a parent is willing to reduce, than over persuade them. A reduction made without parental

confidence may lead to excessive anxiety. In practice this may mean that they, or their local team, then put the feeds back up and then resist making further reductions. We always ask families to contact us if they are anxious, to try and avoid unnecessary feed increases and thus delays to the wean.

Once feeds are below 50% of total requirements, the dietician should review need for micronutrient supplementation and again at below 25%.

After all feeds have stopped

Once the patient has been stable on solely oral diet for 3-6 months, patients are referred back to the surgeons, gastrostomy or community nurses for tube removal as appropriate. This may be expedited if the tube or site is causing the patient/family lots of issues (e.g. site infection).

If the child still has limited oral skills or is still taking a very restricted diet, families usually require continued, though less frequent, follow up for a few months. It may only be at this stage that aversive feeding and eating behaviours emerge, once parents once the family lack the security of tube feeds.