Birmingham Food Refusal Services

UNDERSTANDING TUBE FEEDING AND IMPACT ON ORAL FEEDING

*Please note that this handout is to help you understand why your child may find oral feeding difficult if they are tube fed. It is **not** a tube weaning programme. You should seek advice from a health professional before on embarking on tube weaning.*

Tube feeding is a necessary part of a child's medical care when the infant or child is unable to take in enough calories by mouth. For example, the child may be too ill to physically ingest the food or use too much energy feeding to get the benefit of the calories. However, tube feeding has an impact on oral feeding development, particularly in the early stages of life. It is important to understand how this happens and why it can be difficult to wean a child off the tube once they are medically well enough to do so.

Some children are put on tube feeding if they develop an aversion to oral feeding that has probably arisen because of sensory issues. This can result in very stressful mealtimes, where it is almost impossible to feed the child without using coercive feeding strategies. This might mean, for example, very prolonged mealtimes and excessive use of distraction that in the end lead to more refusal by the child. The purpose of tube feeding is to reduce the stress and create a breathing space in which food can be re-introduced in a more gentle way. It is very important that the tube does not become a long term substitute for oral feeding.

The effect on appetite

Very soon after birth, the brain regulates how many calories the body needs to grow and thrive. It will take these calories from the easiest source and this will be from tube feeding. This means that it is difficult to maintain oral feeding a long side tube feeding.

Parents are usually advised to keep trying oral feeding while tube feeding is necessary. However, this is often a disheartening process as the infant or child will tend to take less food by mouth as time goes by. Some parents may

give up offering foods while others may try a little too hard and end up increasing the child's refusal of foods. Even if parents manage to get it right and continue offering foods in an encouraging way, only small amounts may be taken by mouth.

The infant or young child does not make a link between eating food by mouth and satisfying hunger.

Sensory Sensitivity

Babies receive a lot of sensory information when they are feeding. At birth, the 'gag' reflex is activated by touch to the anterior part of the tongue but this reflex quickly moves back to the posterior part of the tongue as it is exposed to milk and then food in the mouth. This may not happen when tube feeding is in place. The gag may become stronger rather than weaker due to the limited amount of oral experience. The gag reflex may also be increased in some children who have frequent vomiting and/or need regular re-placement of an NG tube or have other invasive oral procedures. An over active gag reflex can interfere with attempts to feed a child by mouth.

Oral-motor skills

At birth, babies are able to suck from a nipple or teat and swallow liquid. There is very little room in the mouth for the tongue to move and the lips, tongue and jaw all more together. Over time, there is more space in the mouth and the lips and tongue move independently. Movements like biting, moving food from side to side, licking lips, munching and chewing are all learned through practice with food in the mouth. The tube fed child may have delayed oral-motor skills because they have not had experience of different foods and textures.

Developing food preferences

The first two years of life are particularly important in the development of food acceptance. Babies are born with an innate liking for sweet and fat foods but learn to like other foods by trying them. They are programmed to accept new foods into the mouth during the first year and through this experience they develop food likes and dislikes, based on smell, taste and texture. In the second year of life, the infant becomes more reluctant to try new foods. This is called neophobia and it becomes more difficult to get a toddler to try unfamiliar foods, especially from the age of about 18 months. A tube fed child who has had limited exposure to foods may be reluctant to try new foods.

Lack of an oral feeding routine

Tube fed babies and young children will have a fixed routine for tube feeding but they may not experience all the things that go with a normal mealtime. They may not see and smell food being prepared, watch the table being laid or watch other people eating at mealtimes. These are all 'external' cues to eating and supplement the 'internal cue' of hunger.

What does this mean?

When the time comes that the consultant says a child no longer needs tube feeding, it is distressing for parents to find that their baby or child won't start eating more food by mouth. The baby or child seems to be dependent on the tube and they don't know how to go about changing this.

One of the most important things to develop is appetite. Without it, the baby or young child will lack the drive to accept food and swallow it. If they have already tasted food, it is more likely that they will put familiar food in their mouth and explore it, sometimes swallowing small amounts but it will be difficult to encourage them to take more than usual. Think about your own appetite. If you are full after a large meal, the thought of swallowing more food might be off putting but you might manage one more of your favourite chocolates!

A tube weaning programme must have hunger provocation as a central component. This means that the amount of calories given by tube within a 24 hour period must be reduced. The idea is to stimulate the brain to look for calories from another source i.e. from the oral route. This is different from offering food orally and then topping up with a tube feed afterwards.

The brain should be able to adapt and take more food orally if the infant of young child is already allowing some food in the mouth and is swallowing small amounts. It is more difficult if the child has sensory sensitivity and/or has never experienced any food orally. In these circumstances, the child may get hungry but still refuse foods with resultant weight loss. Preliminary work has to be done around sensory sensitivity and food acceptance.

Assessment of the young child's oral motor skills and sensory sensitivity, experience of taking food by mouth, likes and dislikes and current feeding regime allow us to develop the appropriate programme for your child. It is very important to take into account your child's baseline height and weight, and the growth lines they are following, plus their state of health. This is to ensure that the programme does not compromise their well-being and growth.

We believe in a small steps approach which maximises long term success, minimises parental anxiety and reduces the need for backward steps.

Some important considerations:

- With a tube weaning programme, it is important to prioritise calorie intake over other aspects of feeding development e.g. extending range of accepted foods and textures. The focus is on high calorie foods that the child likes and are easy to eat.
- Research tells us that coercive feeding practices do not work – they lead to more food refusal. Therefore, when food is offered, it is important to do so in a relaxed and positive way.

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