Weaning the TOF baby a practical and personal guide – Part 1

Julia Faulkner, Paediatric Dietitian, Musgrove Park Hospital, Taunton, Somerset

I had been working as a Paediatric Dietitian for seven years before having my first child, Alex, who surprised me firstly by arriving early and secondly by having a tracheo-oesophageal fistula (TOF) and oesophageal atresia. Right from the start I wanted to use my experience positively to help with my work, and to do something to help other parents in a similar situation using my dietetic knowledge.

So here goes, and hopefully this will help those about to wean or going through weaning at the moment.

When to start

Firstly, it is essential that you check with your medical team that they are happy for you to start weaning your child. If your child is seeing a speech and language therapist (SaLT), they will be able to provide the best individual advice for your child.

A proportion of TOF babies will be born prematurely, that is before 37 weeks' gestation. BLISS, a UK charity working to provide the best care for premature and sick babies, recommends[1] that five to eight months after their actual birth date is likely to be the best time to start weaning. Most preterm babies won't have sufficient head and neck control to start weaning until they are over three months corrected age (that is three months past the date they were due),[2] and it is important to check with your medical team that they are happy that your baby has sufficient head and neck control to commence weaning.

For term babies (that is those born at or after 37 weeks' gestation), the Department of Health recommends introducing solid food 'at around 6 months of age'. The British Dietetic Association recommends that solid food is introduced no later than six months (26 weeks) of age, and not before four months (17 weeks) of age.[2]

As TOF babies need a bit more time to progress with weaning, I would personally recommend starting after 17 weeks and before six months of age. I would encourage parents to be proactive and ask their TOF specialist hospital if it is safe for them to commence weaning before six months of age.

Developmental window for acceptance of tastes

Studies indicate that there is a period for the introduction of tastes between four and seven months of age,[3 4] when children are more receptive to trying new tastes. Infants who are exposed to a wide range of vegetables during this time are more likely to accept new foods from any food group.[5] In particular, home cooked fruit and vegetables or raw fruit have been associated with a higher intake of fruit and vegetables in later childhood.[6]

TOF considerations

Oesophageal dysmotility is very common, reported in 75–100% of children post repair.[7] This means that the oesophagus either doesn't contract or contracts in a disordered fashion so that it doesn't effectively push food down into the stomach. This means that food/fluid mainly gets down into the stomach by gravity,[8] and it is helpful to bear this in mind when weaning as it helps to understand which foods are going to be the easiest to manage and why it's important to offer drinks frequently to help food down.

A **stricture** is a narrowing in the oesophagus that usually occurs at the site of the oesophageal repair. It is more common with a tight join or with oesophageal reflux. Symptoms include the baby being slower to feed and choking/spluttering during a feed, and usually starts a few weeks or months after repair. Symptoms of a stricture are more obvious to spot with solids as babies will struggle with these before the stricture has narrowed sufficiently to effect the passage of milk. With weaning, if a stricture occurs it will become apparent first with thicker purees or lumps. TOF infants can struggle managing lumps at first in any case so the best guide is if your infant starts to struggle swallowing a texture that they have previously managed, then they may have a stricture.

Gastro-oesophageal reflux (GOR) is also common and occurs when stomach contents make their way back into the oesophagus. Symptoms include spitting up milk during or after feeds, refusing feeds, gagging or choking, excessive crying or crying while feeding.[9] Reflux may also cause or contribute to respiratory problems so it's important that it is managed effectively.[8]

A lot of the symptoms described above are similar for dysmotility, stricture or reflux, so it's important to discuss them with your specialist team to try to work out what exactly is going on.

It is not surprising that the factors above can lead to aversive feeding behaviours, and that feeding problems are a major source of concern in early childhood.[10] If an infant builds an association of pain or choking with eating you can see how this may lead to food refusal. Therefore, it is important to ensure that GOR is managed and that any strictures are dealt with. It's also important that drinks are offered frequently throughout meals to help with dysmotility, and ease the passage of food into the stomach.

Food bolus obstructions - 'stickies'. These can be quite frightening for parents and the infant. They occur when food gets stuck in the oesophagus possibly due to stricture, dysmotility or insufficient chewing. Signs of 'stickies' are coughing or choking when eating food.

If the oesophagus is completely blocked the infant will be unable to swallow saliva, so will be drooling. It's important to know what to do in the event of choking to help your child (as it is with any child during weaning). See the British Red Cross website (link below) for instructions on what to do with a choking baby.

If the child is coughing but not drooling they may be able to manage sips of water or other drinks to help move the obstruction on. Some children will be able to cough and bring up the obstruction, whereas others may not be able to bring it up, but the obstruction may move down with time and sips of fluids.

What to start with?

Start at a time of the day that is convenient for you and your baby. Your baby should be wide awake but not over-hungry. First foods are for tastes only so just offer a few teaspoons initially. Start with thin purees that easily fall off a spoon and offer a few tastes.

First foods – fruit or vegetable purees thinned down with baby's usual milk. I started Alex off with fruit and vegetable purees thinned down so that they were only slightly thicker than the milk he was already managing. I also pushed any purees through a sieve where I was worried that they might be fibrous or contain seeds.

First texture	Description	Examples
Smooth thin puree	Quite runny (easily drip off spoon) with no big lumps, pips, seeds or skin	Pureed stewed fruit Pureed fresh fruit (banana, strawberries, blueberries) Pureed stewed vegetables Weetabix soaked in baby's usual milk Fromage frais Smooth yogurt Stage 1 baby foods (all above thinned down with baby's usual milk to make them quite runny)

It's not uncommon for babies to pull faces when trying foods as this is the first time they have experienced these different tastes; as they continue to be offered them they learn to accept the tastes. As mentioned above, the more tastes that can be introduced into the early weaning diet, the more likely a child is to be accepting of other new tastes in childhood. The key message is keep offering new tastes and offer a variety of new tastes.

Once your baby has mastered a few tastes once a day you can increase to two-to-three times per day, and then offer increasing amounts.

It's also important with weaning to let your baby get messy, allowing your baby to play with the food and get it on their hands and face. Delay wiping hands and cleaning them up until the end of a meal. This encourages them to be happy with the smell and touch of different foods and will allow them to be more accepting of new foods.

The noise

As both a dietitian and a new parent I was not prepared for the noise that TOF babies can make! Unfortunately, I can't insert a video clip here to show you. The best description I have heard from other TOF parents on the Facebook group is that it is like 'Darth Vader'. We refer to Alex as 'growling' when he makes this noise. With Alex it started after a few spoons of solids so I used to stop feeding him and see what happened and it always stopped within a few minutes. As Alex wasn't coughing and didn't seem to be struggling to swallow I wasn't too worried but I did record it to show the surgeons and seek

reassurance. Alex was also able to make a 'honking' noise when he was excited in anticipation of having some food.

If you are concerned about how your baby is swallowing, discuss it with your team and request a SaLT referral ideally with a therapist familiar with TOF. A SaLT will be able to assess your baby feeding, and if required give individual advice on the safest way to feed your baby.

Drinks

When you realise that food is mainly moving into the TOF baby stomach by gravity, it is clear that having frequent sips of drinks is important, especially as your baby moves onto thicker purees. A cup can be introduced at around five-to-six months of age when your baby is sitting up and able to hold their head steady.[11] An open cup is the best choice to encourage the skill of sipping. Free-flow lidded beakers (those that let the liquid run out when tipped upside down) are also suitable but ideally the lid should be removed and it should be used as an open cup as soon as the infant has learnt how to drink.

Julia and Alex

'No spill', or 'anyway up' cups/beakers aren't recommended as these have to be sucked and don't teach the skill of sipping, which is also important in the development of the muscles used for babbling and talking.[11] More importantly for our TOF babies, if you've ever tried drinking from one of these yourself you will know how hard it is to get a drink out.

This concludes part 1 of my weaning article; in part 2 I will discuss moving on with textures and lumps and introducing finger foods. So be brave, get messy, and speak to your specialist team if you have any concerns.

Useful information

British Red Cross – First aid for a baby who is choking
http://www.redcross.org.uk/What-we-do/First-aid/Bay-and-Child-First-Aid/Choking-baby
General advice on weaning and recipes (not TOF specific)
The Caroline Walker Trust, Eating well: first year of life – practical guide
http://www.cwt.org.uk/publications/

References

1. BLISS, Weaning – When to start. www.bliss.org.uk/when-to-start.
2. BDA Policy Statement, Complementary Feeding: Introduction of solid foods to an infant's diet. (April 2013) https://www.bda.uk.com/improvinghealth/healthprofessionals/policy_statement_complementary_feeding (accessed 16 October 2016).
3. LL Birch, L Gunder, K Grimm-Thomas (1998) Long-term consequences of early fruit and vegetable feeding practices in the United Kingdom. Appetite 30, 283–295.
4. G Harris (1993) Long-term consequences of early fruit and vegetable feeding practices in the United Kingdom. British Food Journal 95, 7–10 .
5. CJ Gerrish and JA Menella (2001) Long-term consequences of early fruit and vegetable feeding practices in the United Kingdom. American Journal of Clinical Nutrition 73, 1080–1085.
6. H Coulthard, G Harris, P Emmett (2010) Long-term consequences of early fruit and vegetable feeding practices in the United Kingdom. Public Health Nutrition 13 (12) 2044–2051.
7. E Somppi, O Tammela, T Ruuska et al (1998) Outcome of patient operated on for oesophageal atresia: 30 years' experience. Journal of Paediatric Surgery 331341 –1346, 1346
8. PFM Pinherio, AC Simoes e Silva, RM Pereira (2012) Current knowledge on esophageal atresia. World Journal of Gastroenterology 18 (28) 3662–3672
9. NHS choices website, Reflux in babies https://www.nhs.uk/conditions/reflux-babies/Pages/Introduction.aspx (accessed 26 October 2016).
10. A Goyal, MO Jones, JM Couriel, PD Losty (2006) Oesophageal atresia and trachea-oesophageal fistula Archives of disease in childhood fetal & neonatal edition 91 (5) F381–F384.
11. BDA Policy Statement, Introducing a cup to an infant's diet (March 2015) https://www.bda.uk.com/improvinghealth/healthprofessionals/introducing_a_cup_to_an_infants_diet (accessed 16 October 2016).

TOFS Conference

Saturday 14 October 2017 – Luton

This will be another all-day hotel-based conference, similar in format to our 2014 and 2016 conferences:

- Hear from the experts on various aspects of TOF/OA;
- Meet and chat with other TOF families – and the experts;
- For TOF adults as well as those with TOF children;
- Four speakers lined up already, including two professors;
- Holiday Inn, Luton-South, AL3 8HH;
- Easily accessible by road – just over a mile from M1 Junction 9, close to M25;
- Close to Luton Airport and its Parkway train station. If you are in Scotland, Ireland or Wales, think about flying in. Direct trains too from Gatwick Airport;
- Frequent train services from South, Central and North London. Direct trains also from East Midlands towns and Brighton;
- Refreshments and full lunch provided, within the TOFS-subsidised pricing. Onsite crèche at extra cost;
- Make a weekend of it! Special rates at the hotel, which has gym and pool. Whipsnade Zoo only five miles away, Hemel Hempstead indoor real-snow slope eight miles.