Supporting Feeding & Oral Development in Young Children

Guidelines for Parents

Support Feeding & Oral Development in young children with Down Syndrome, Congenital Heart Disease and Feeding difficulties.

A JOINT PROJECT WITH

Down Syndrome Ireland

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HEART CHILDREN IRELAND

CONTENTS

1. INTRODUCTION

This booklet is intended to be used as a reference for the first 2 or 3 years of life. You are not expected to read it from cover to cover, but to dip in and out of it as questions arise or as you need guidance regarding your baby's next step. It is also not intended to replace direct contact with the multidisciplinary team.

Feeding is one of the most basic functions of the newborn baby. Likewise, the desire to feed one's newborn baby is one of the strongest and most basic instincts of a new mother.

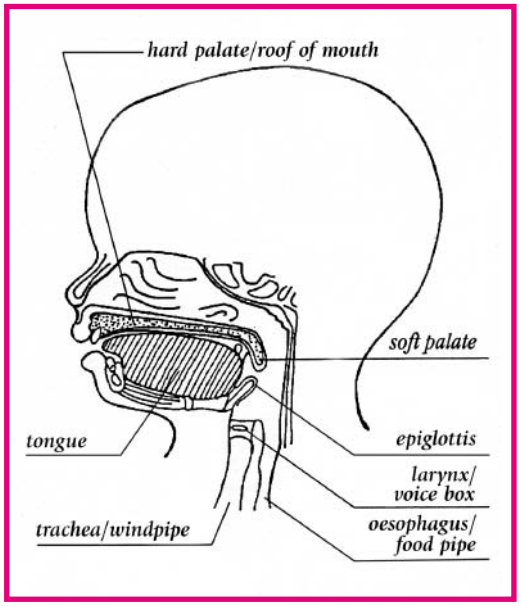
Watching the newborn baby feeding is a wonderful experience. The baby searches for the breast or bottle teat and quickly latches on. This searching behaviour is soon followed by rhythmic sucking, swallowing and breathing. The pace of feeding slows down a little after the initial hunger pangs have been satisfied. Mother and baby gaze at each other and often engage in little 'conversations'. All of this makes for a very satisfying and nurturing experience for both mother and baby!

Unfortunately, this is not always the scenario for babies with certain disabilities or for babies with congenital heart disease (CHD) who typically have trouble feeding. In order to understand why some babies have feeding difficulties, it is helpful to understand how normal feeding develops.

Note: Throughout this publication, the baby is referred to as "she" to make reading easier.

2. HOW FEEDING WORKS

Even though babies make it look very easy, feeding is a very complex sequence of events. Feeding involves 26 muscles and 6 major nerves, all of which have to work in a coordinated and timely fashion. The feeding process follows 3 distinct phases:



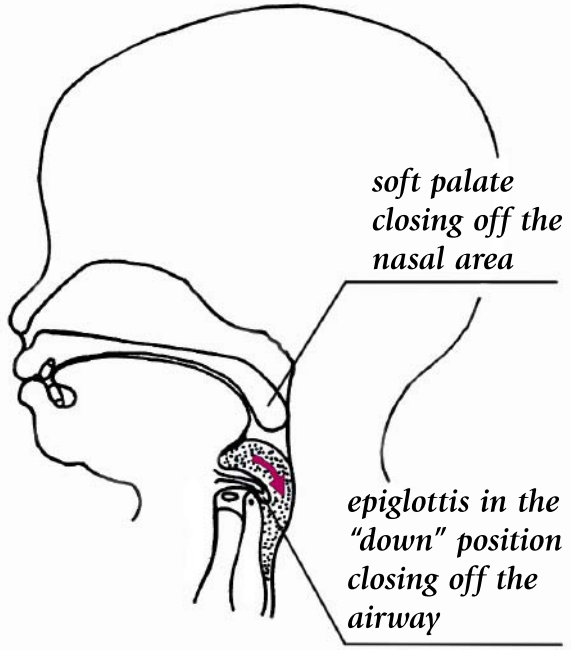
2.1 Oral Phase

This is where the mouth prepares the food or liquid for swallowing. It is essential that the jaw, lips, cheeks, tongue, hard and soft palate (roof of mouth) are all working together so that the milk can be drawn from the nipple and made into a 'bolus' or cohesive mouthful ready for swallowing. The tongue moves the bolus towards the back of the mouth where the swallow reflex is triggered.

2.2 Pharyngeal Phase

The next stage of swallowing sets a complex sequence of events into motion:

- The back of the tongue lifts to prevent the milk from returning to the mouth.
- The soft palate lifts up to touch the back of the throat so that milk does not enter the nose.
- Muscles in the throat (pharynx) move in a wave-like action to move the milk towards the food pipe (oesophagus).
- The epiglottis is like a trap door which covers the wind pipe (trachea). During breathing the door is open, but once the swallow reflex is triggered it closes over to stop the milk from entering the trachea and to direct it into the oesophagus.
- Inside the voice box, the vocal cords close to give an added layer of protection to the trachea.



2.3 Oesophageal Phase

The bolus moves safely past the airway. The muscles at the top of the oesophagus open to allow the milk to enter. These muscles then close to prevent the milk from coming back up. The muscles of the oesophagus move in a wave and the milk passes through to the stomach. At the entrance to the stomach, there is an important valve which closes once the bolus has passed into the stomach. This prevents the milk from going back or **refluxing** out of the stomach.

2.4 Breathing and Feeding

Successful feeding depends not only on the swallow reflex but on the coordination of sucking, swallowing and breathing. Feeding is hard work for babies! Using and coordinating all these muscles requires extra oxygen. The demand for increased oxygen leads to changes in heart rate and breathing rate. You could say that feeding is a baby's aerobic exercise. This is why babies with CHD so frequently have problems in the area of feeding.

3. PRINCIPLES OF GOOD FEEDING

3.1 Breast and Bottle Feeding

Breastfeeding is the most appropriate method of feeding the newborn. The advantages are numerous and long lasting. Demand breastfeeding will automatically ensure that the healthy baby gets the correct volume of milk and nutrients. In addition to the nutritional benefits, breastfeeding protects against various acute and chronic illnesses and can also have positive effects on maternal health.

Sometimes no matter how much a mother may want to breastfeed her baby, it may not be possible. The energy needed for successful breastfeeding may be too great a demand on your baby's heart. If this happens, the mother may express her milk and, under the supervision of a dietician, this milk can be modified / fortified to suit the sick baby's requirements.

For some mothers breast feeding or breast milk feeding (using a bottle or a tube) may not be possible or may not be the mother's preferred choice of feeding. In such cases it is necessary to use an infant formula and there is a wide range from which to choose. In certain situations, your dietician will recommend a higher nutrient density and your baby will be closely monitored as a result.

3.2 Nutrition

In order to grow and develop we all need adequate calories and nutrients. The nutrients feed our bodies and the calories give us the energy we need to function. Unfortunately, sick babies and children may not want to feed or may be unable to do so. In these cases, a dietician will assess a baby's growth and nutritional needs and advise accordingly. It is important to monitor weight and height of all children with CHD because in some cases they may benefit from a nutritional supplement and / or a high protein, high calorie diet. If you ever have concerns about your child's growth or food intake you should consult a dietician or your GP.

3.3 Positioning

Another key consideration for good feeding is to ensure that your baby is positioned well during feeding. There are four important principles which must be addressed to achieve a good feeding position:

Stability: your baby's body should be stable when feeding.

Alignment: the head, neck and body should be lined up / aligned.

Flexed: the body should be in a slightly flexed or 'curled up' position.

Comfort: being comfortable is vital

Babies who have low muscle tone and reduced muscle strength can find it difficult to hold their head, neck, shoulders, trunk and / or hips in an aligned and slightly flexed position. We can improve a baby's position and posture, either by holding her in a specific way or, for the older baby, by using a good chair which will support and align her body.

Using proper positioning during feeding leads to improved feeding / swallowing ability, helps in the development of oral motor control and swallowing control and improves sucking through better strength and organisation of movements.

Your occupational therapist can recommend treatment techniques to help stimulate / increase muscle tone and improve overall posture and positioning.

Following are some suggested ways of achieving proper positioning during feeding.

POSITIONING OF THE VERY YOUNG CHILD

Baby held in a cradle position

Holding a baby in this position can be suitable for very young children. It allows full body contact which provides stability and also holds the baby in an upright position; care should be taken to support the head. The chin should not be pressing against the chest or raised and pointing upwards from the chest as these positions make swallowing more difficult. Instead, the chin should be 'in-between' and comfortable.

For babies who experience vomiting, spitting up or reflux, a straighter more upright back position is required. You can achieve this through adjusting your holding position or by using a rolled-up towel or pillow under your baby's back.

Baby held on caregiver's lap, facing caregiver

This position provides excellent stability and keeps the baby's head and body aligned. It also provides opportunity for eye-contact and interaction between the baby and carer.

In these positions, it is important to bring your baby's arms slightly forward as this comfortable position makes swallowing easier. By holding the arms at the elbow, you can help maintain this forward position. Gradually, as she is able, encourage your baby to place her arms further forward until her hands are around the bottle.

POSITIONING OF THE OLDER INFANT/CHILD

Place your child in an upright position as this will encourage your child to see the food, to pick it up /take from fingers and to function more independently by feeding herself.

It is important that your child's seating position is stable. If she can balance independently, a highchair can be used. Feet should be supported to give a stable base as this encourages better head, trunk and arm function. If your child needs help to sit, she will require additional supports to hold her in a stable upright position. Your occupational therapist can advise on these.

Being comfortable is vital for your child as this will allow her to focus all her attention on feeding!

A variety of equipment / specialist seating systems are available to provide support with feeding and can be accessed through a medical card or long term illness card. Your occupational therapist can advise on these.

3.4 Feeding as a Social Event

When we feed young babies, we hold them close, talk, sing and stroke them. We enjoy the sensation of holding our child near to us and relish the emotional closeness that we feel. This strong positive emotion that we feel with the young baby helps to create a 'bond' that makes the baby feel secure and the carer feel connected with the child. We do not focus too much attention on the task of feeding; instead we expend our energy on the social context. Unfortunately, when a child has feeding difficulties, it is easy to forget the social side of mealtimes. This can be compounded by the concern and worry we might have about our child's feeding and / or calorie intake. It is important to remember that your baby has the same emotional needs as any other baby. Hold your child close, look her in the eyes and coo at her. You may need to elicit the help of other members of your family or friends to give you a break if the feeds are normally quite difficult or you feel particularly stressed. Ask them to remember to cuddle and talk gently while they feed.

"After being in hospital so long, it was great to see Cliona sitting at the table with us at mealtimes even though she wasn't able to eat orally. She really enjoys being there and I know she will be eating with us after her surgery."

3.5 Setting up Good Routines

For the older baby and child, make sure that she is sitting at the table to join the family at mealtimes. This allows her to learn to view food and eating as part of a social occasion even if she is not eating in the same way as everyone else. From an early age, babies and young children learn about food and eating by observation. Establish a routine for your child based on language, manners and the enjoyment of mealtimes. It doesn't matter if your child is not eating at the same time, she can 'mess' around with food on a plate while the rest of the family eats. Encourage tasting and self feeding activities as much as possible. Involve your child as appropriate with table conversation and passing foods to members of the family. Again, do not focus on the differences in feeding methods or foods consumed. The focus is on the family gathering around the table and conversing with each other. Make sure a feeding routine is established to allow your child to learn that drinking and eating are part of daily living.

4. FEEDING PROBLEMS ASSOCIATED WITH CERTAIN MEDICAL & GENETIC CONDITIONS

4.1 Feeding problems associated with CHD:

4.1.1 Decreased endurance. Babies with CHD tire easily and often become fatigued before they can finish a feed. The baby also feels full more quickly.

4.1.2 Decreased arousal. Babies may be so tired that they do not wake for feeds or fall asleep very quickly after the start of a feed.

4.1.3 Weak sucking. Even though there may be nothing wrong with the tongue, lips or jaw in themselves, the baby often lacks the strength to produce an effective suck.

4.1.4 Short sucking bursts. Another common problem is the baby who 'stops and starts'. An initial sucking burst may be followed by a rest period. After a quick rest, the baby may begin feeding again for a short time before stopping again. Feeds go on for too long and the baby can't finish the feed.

4.1.5 Aspiration. This is where the milk goes the wrong way and enters the wind pipe (trachea). We have all probably experienced the unpleasant sensation of something 'going against the breath', usually in a social situation when we're talking, eating and drinking all at the same time! If this does happen in a healthy individual it immediately triggers a strong coughing reflex so that our lungs are protected. In babies with CHD the coordination of the swallow can go wrong resulting in aspiration episodes. Sometimes this is apparent because the baby coughs and splutters a lot during feeding. It can also lead to breathing difficulties during the feed. However, for some babies the aspiration can be 'silent' and no coughing or spluttering is observed. Aspiration is dangerous as it can lead to chest infections and even pneumonia.

The child with CHD can have one or more of these difficulties. Apart from the problems it presents for the child, long and difficult feeds can be very distressing and disruptive to the whole family.

"I wanted so badly to breastfeed Sean and I was really very distraught when the doctors told me that he wasn't able to feed because of his heart condition. I cried a lot."

In addition to the problems associated with CHD, babies with other medical diagnoses may have additional feeding problems.

4.2 Feeding problems associated with Down syndrome.

Babies with Down syndrome typically have low or "floppy" muscle tone. This not only affects the muscles of the arms and legs but also causes the muscles in the neck, face and mouth to be weaker as well. Feeding problems associated with low muscle tone include:

- Difficulty latching on to the breast or teat.
- The mouth may be less alert or ready for feeding.
- Swallowing air leading to tummy cramps / discomfort during feeding.
- Loss of interest in feeding before the feed is finished.
- Problems with moving on to spoon feeds and different food textures.

"Matthew has Down syndrome and a book I read said that because of the syndrome he would have trouble sucking. Not at all!! From day 1 he was breast feeding and he could suck for Ireland. It just goes to show..."

4.3 Feeding problems associated with CHARGE

Babies with CHARGE commonly have problems with coordination of the muscles during swallowing, often leading to aspiration of milk into the windpipe or 'trachea' (see description of aspiration, page 10).

4.4 Feeding problems associated with DiGeorge.

Babies with DiGeorge can have a number of feeding difficulties in addition to their cardiac related feeding problems. These may include:

- Problems with the palate or roof of the mouth. This may be a cleft palate or a problem with the muscles of the palate causing difficulty with lifting the soft palate to close off the nose during swallowing, (see page 3 for description of how the soft palate functions during swallowing) causing milk to flow out of the nose.

- Problems with coordination of the muscles during swallowing, often leading to aspiration of feeds into the windpipe or 'trachea' (see description of aspiration, page 10).

- Vomiting or 'gastro oesophageal reflux' can add to feeding problems.
- Problems with moving on to spoon feeds and different food textures.

4.5 Weak Sucking

There are a number of ways that you can improve your baby's suck:

- Make sure your baby is in a good position. (See page 7).
- Never feed your baby in a lying down, head back position as this can make the suck even weaker. It can also cause milk to flow into the tube which connects the ears to the throat (the Eustachian tube) and can cause ear infections. Remember that the mouth should always be lower than the ears.
- If bottle feeding, select the teat which your baby seems to like. If she has used a soother, a teat which is similar in shape is probably best. Don't be tempted to buy every teat and bottle in your local pharmacy! This will only confuse your baby (and cost you a fortune!).
- Make sure the nipple or teat is in the correct position over the tongue (and not under it).
- Lips should be in full contact with the breast or wider base of the teat. They should be slightly curled outwards so that a good latch is achieved.
- If your baby has low muscle tone you may need to given extra help by gently bringing the cheeks forward so that the lips close more tightly around the nipple / teat.

- Jaw support can be given by placing your index finger on your baby's cheek and your third finger under the jaw. This can help to maintain a good latch and also helps to reduce wide, less effective up and down jaw movements.

- **Never** enlarge a bottle teat by cutting it or adding more holes. This can cause the milk to flow too fast and could cause aspiration (refer to page 10). It also promotes incorrect tongue posture as the baby pushes the tongue forward to stop the flow so that she can swallow. Pushing the tongue forward like this is called tongue protrusion which should not be encouraged as it interferes with more mature feeding skills and with speech development.

If you have concerns about your baby's suck or any other aspect of oral feeding skills ask to see a speech and language therapist who can assess your baby's oral feeding skills and devise an individualised programme.

4.6 Baby Disorganised and/or Disinterested in Feeding

This problem is characterised by one or more of the following observations:

- Baby doesn't settle down and keep still during feeding.
- Sucking stops and starts and doesn't 'settle down'.
- Baby becomes distracted by people, voices, noise etc.
- Baby may become frustrated and cries during feeding.

Techniques which may help include:

1. Make sure your baby is hungry. Babies with a history of tube feeding sometimes have difficulty recognising hunger. Others seem to never be hungry. Talk to your dietician about timing and volume of feeds.

2. Positioning is crucial. Hold a fretful baby close to your body as this can calm them. Some babies like to be slightly swaddled in a sheet or blanket. However, be careful that (see page 7) they don't get too cosy and fall asleep!

3. Look at the feeding environment. A hospital ward is probably the worst place to feed an easily distracted baby! All babies differ so watch your child to see if she feeds better in a quiet room. Does it help if the light is dim? Some babies are calmed by soft music or singing. Notice which factors are influencing your baby and make changes that help her become more organised and interested in feeding.

If you have any questions regarding these ideas or are worried that your baby is not interested in oral feeding ask to talk to a speech and language therapist who can discuss your concerns with you in more detail.

4.7 Tube Feeding

While oral feeding is the preferred method of providing nutritional support to babies and children, sometimes it becomes necessary to feed directly into the stomach and digestive system (gastrointestinal tract) via a tube. Some children require partial or total nutrition via a tube due to poor feeding skills, reduced feeding endurance to meet their increased nutritional needs, or in some cases if there is significant weight loss due to chronic illness. Many babies with CHD will need to be tube fed at some stage. The decision to tube feed a baby can be a very difficult one for parents. What should be a rewarding experience is turned into yet another medical procedure. Coming to terms with tube feeding is built on the knowledge that it enables the baby with CHD to survive, grow and develop. Every child is assessed individually and the decision to tube feed is made by a multidisciplinary team involved in the child's care. As parents you will be fully informed as to why tube feeding is necessary and shown how to administer and care for your child's feeding needs. It is important to remember that however a child feeds, she still has the same emotional and social requirements and therefore feeding should never be viewed as a 'medical procedure'.

"It was a shock at first but the tube was there to help her and I just had to accept that. A few days later I was doing all the feeds myself, it was just like I'd always known how to do it."

There are a number of different types of tube used in feeding and the decision of which type used will depend on the babies medical condition and the expected duration of tube feeding. Basically, tube feeding is feeding the baby through a fine tube inserted in one of three parts of the digestive system:

1. Nasogastric (Ng tube) - down the nose into the stomach.
2. Gastrostomy - directly into the stomach.
3. Jejunostomy - directly into the small bowel. Ask your medical team for more information about the jejunostomy.

A) Ng Tube

There are two main types commonly used:
1. A Polyvinylchloride (PVC) tube, e.g. Portex.
This is for single use only and primarily for short term feeding problems. This tube should be changed every seven days.

2. The Polyurethane tubes, sometimes known as "silk" tubes.
These are for longer term use and can be reused if your baby pulls it out. The tubes should be changed as indicated to prevent increased risk of bacterial contamination and the material of the tube being eroded by gastric juices.

B) Gastrostomy Tube

Gastrostomy tubes are made of silicone. There are three main types:
1. Percutaneous Endoscopic Gastrostomy (PEG)
(PEG) is a gastrostomy tube that is inserted in the operating theatre through the skin into the stomach under ***Endoscopic*** control, therefore avoiding the need for a full, surgical procedure. It can stay in place for up to 2 years.

2. Foley Catheter / Malecot
This type of gastrostomy tube is usually only inserted following surgery eg. when a Nissen's Fundoplication is necessary. This is usually in place for approximately 3 to 4 months after which time a 'MIC-KEY' button is often recommended.

3. Skin-level 'Button' or 'MIC-KEY' Gastrostomy
The gastrostomy button is a device in which the exterior of the tube sits against the skin and when not in use, resembles a button on the surface of the skin. It is usually changed once every 3-4 months.

Once healed, the skin around a gastrostomy site should be washed daily with Savlon antiseptic wound wash to prevent the skin around the site becoming sore. If you are concerned about the condition of the skin around your child's gastrostomy contact your GP or nutrition support nurse.

The gastrostomy tubes should only be changed by a surgeon or nurse who has received training in the procedure. Gastrostomy tubes are most commonly sized between 8 and 15 Fg, although smaller or larger tubes may be used in small babies or older children. The nutrition support nurse and medical staff can advise you on your particular gastrostomy tube type and care.

C) Modes of tube feeding

It is the dietician's role to recommend the most appropriate mode or combination of modes of feeding. Sometimes the child is prescribed continuous feeds or regular 'bolus' feeds through a syringe. The type of feeding i.e. bolus or continuous should be individualised for each child with the help of the multidisciplinary team. The best is a combination of oral and tube feeding that fits into a child and family's schedule.

Bolus Feeding:
Bolus feedings are delivered four to eight times per day; each feeding lasting about 15 to 30 minutes. The advantages of bolus feedings over continuous drip feeding are that bolus feedings resemble a normal feeding pattern, are more convenient, and less expensive if a pump is not needed.
Furthermore, bolus feedings allow freedom of movement for the patient, as the child is not attached to a feeding bag.

Continuous Drip Feeding:
Continuous drip feeding may be delivered without interruption for an unlimited period of time each day. However, it is best to limit feeding to 18 hours or less. Commonly, it is used for 8-10 hours during the night for volume-sensitive children so that smaller bolus feedings or oral feeding may be used during the day. Continuous drip feeding is delivered by either gravity drip or infusion pump.

Positioning during tube feeds

Hold your baby in a comfortable position as if you were breast feeding or bottle feeding. You might like to hold your baby in skin-to-skin contact. This has lots of benefits including helping to keep your baby warm and calm, providing your baby with lots of positive touches, and also helps stimulate breast milk production if you are breast milk feeding.

In order to build up pleasurable oral experiences, ***non nutritive sucking*** should be encouraged, especially during feed time. This is the sucking behaviour which all babies enjoy such as sucking a soother or a finger and helps to make tube feeding more 'normal'.

Place a soother or your (very clean) finger in the baby's mouth to suck on while the feeding is taking place. In this way the baby learns to associate sucking, cuddling and having her tummy filled.

It is also the perfect time to get to know your baby, to talk and sing to her, to look at each other and have those little 'conversations' that are the foundations for later speech and language development.

N.B. It really helps, especially in the beginning if someone else is available to help with the technical aspects of tube feeding.

"It was a real struggle to decide upon inserting a peg. The doctors seemed to feel it was necessary. I hope we can get rid of it in the near future."

5. DEVELOPING GOOD FEEDING AND COMMUNICATION SKILLS

5.1 Babies with Down syndrome and Protruding Tongues

Parents are often very concerned that their baby with Down syndrome will have a large and protruding tongue and are often given advice about how to manage this. Much of this advice is unhelpful and can even make tongue protrusion worse. Firstly we need to dispel the myths – babies with Down syndrome do not have big tongues – they often have small mouths and tongues with poor muscle tone (just like the muscles in the rest of their bodies). Muscle tone in the tongue will improve as muscle tone in the rest of the body improves and as your baby learns to feed orally and use her mouth for oral play. Advice such as pushing your baby's tongue back into her mouth, telling her to "put that tongue away" or even pinching the tongue will probably only result in increased tongue protrusion or even the development of tongue protrusion as an attention seeking behaviour.

It is also important to know that there are times when tongue protrusion is unavoidable, for example when your baby has a cold and can't breathe through her nose, when she is tired, when she is learning a new skill which takes a lot of concentration such as sitting on her own, or if your baby has increased respiratory effort as is sometimes the case with babies with CHD. The best treatment for protruding tongues is oral feeding and mouth play!

5.2 Mouth Play

Babies first learn about the world through their mouths. Hand a baby a toy and she will usually put it straight to her mouth. This behaviour is called 'mouthing' or 'mouth play' and it allows the baby to learn about shape, size, texture and tastes, and to practice skills such as chewing, biting, licking and sucking. It can also make the transition from the teat to the cup, spoon and to solid food much easier. These initial experiences allow the baby to practice the skills and movements necessary for later speech development.

It should be noted, however, that some babies may not go through this very important stage in their development automatically. This may be because they have less energy (this is especially true for babies with CHD) or it may be that they have difficulty with muscle strength and coordination (as in children with Down syndrome). Some children, however, are less likely to

engage in mouthing because they find oral sensations difficult or unpleasant.

If a baby has not been receiving food or any stimulation in the mouth for extended periods of time she can develop hypersensitivity or over-sensitive reactions. This is because the baby is unused to anything being in her mouth. Negative and unpleasant oral / facial experiences can also add to this problem e.g. passing and taping tubes, suctioning etc. Hypersensitivity is characterised by gagging when something is placed in the mouth. In more severe cases the baby can become very distressed when her mouth and face is touched, making the reintroduction of oral feeding at a later stage very difficult.

Encouraging mouthing can ensure that your baby is exposed to the rich sensory world needed for normal development and can compensate for lack of oral sensations due to tube feeding. For tube-fed babies, tube feeding can be made more bearable if parents are actively involved in 'normalising' the feeding routine and developing the baby's oral skills, ready for the day when oral feeding may be possible.

Because of the important role that this behaviour has on the child's oral development, mouth play should be actively encouraged. You can help to encourage mouth play and discourage hypersensitivity from developing by providing lots of suitable toys and helping your baby to use them appropriately.

Items which can be used for this kind of play include:

• Baby's own fingers and toes! These toys are readily available and an endless source of amusement to your baby. At a young age the typical infant will discover hands and watch them with great interest. This is the first mouth toy a child should be introduced to because it promotes sensory development of both hands and mouth and is a gentle introduction to oral stimulation.

• Soft rubber toys, especially ones with smooth surfaces which can fit in your baby's mouth. Look for toys that have long extensions which are helpful for encouraging biting and chewing at the back of the mouth e.g. an animal with a long tail. Toys which have shorter 'bits' are used for encouraging biting with the front of the mouth e.g. animals with ears or pointy noses. Don't wait for your child to start teething before introducing these teething toys. When your child is used to smooth surfaces, get toys with various and more complex textures - don't get just one or two, have a collection they can choose from. Look for toys that your child can comfortably hold and are not too large or heavy for your infant. Observe your child and notice what he likes. Some children like firmer textures and some dislike mouth toys that make sounds.

• Play with your child while looking in the mirror together and talk about the faces you make e.g. where is your nose? Blow kisses. Research has shown that babbling during mirror play increases a child's attempts at sound making.

• Rubber or soft plastic spoons make great toys because the child can hold them easily and they introduce the child to the whole idea of self feeding.

• Velour wrist toys. Toys can be attached to baby's wrist with Velcro. Some have noses which can be sucked. They also provide visual and auditory stimulation.

• Toothbrush trainer sets (gum massagers). Don't wait for teeth before you try introducing a toothbrush. Gum massagers are designed to help babies become accustomed to toothbrushes and the NUK gum massager is the one that most therapists and dentists recommend. It is available from Down Syndrome Ireland.

• Vibrating toys. The First Years market a massaging water teether for infants without teeth and a star vibrating teether for infants who do have teeth. Both supply a vibrating sensation which is great for building sensory awareness.

However be careful and always follow your child's lead. Some babies may not like the sensation of a vibrating toy so take it slowly.

• Wiping. Don't be too quick to wipe away mess from the face and hands during feeding. The feeling of food on the face and hands provides sensory information and can lead to oral movements such as lip smacking and licking.

Making mouth play fun and interesting plus plenty of touching and kissing on the face, cheeks and lips should ensure that your baby develops good oral skills and avoids the development of hypersensitivity.

5.3 Working on Sensation within Everyday Activities

Children who experience sensory difficulties can be helped by applying firm touch to the body during everyday activities. Here are some examples of daily activities which provide opportunity for sensory input and are fun too!

• During dressing, explore the feel of different items of clothing. How does your child tolerate pulling on garments over the head?

• During bath time, drip water onto your child's face and body to encourage play with water.

• After bathing, if your child can tolerate it, dry her face and body with firm pats using a towel.

Preparation for feeding

In very young infants, it is important to make sure they are not experiencing 'sensory overload' from excessive noise and / or light.

This can be achieved by paying attention to the environment e.g. by turning off radios, switching off fluorescent lights, by using a soft voice and asking others not to shout or have loud conversations near your baby, by asking people not to bang doors or dustbin lids etc.

Your speech and language therapist and occupational therapist can offer guidance on specific activities which could be introduced to help with sensory difficulties.

The main thing to remember with all these activities is that they should be FUN!

5.4 Developing a Tolerance to Texture and Developing Tone

5.4.1 Introducing Spoon Feeds

Children who are feeding orally

Introducing tastes: Follow the examples given on page 19 for mouth play. Babies who put toys to their mouth may enjoy the additional sensation of taste which can be added by dipping the toy / object in a puree. The baby who enjoys this activity is developing early self-feeding skills.

However some babies dislike this unexpected addition to their play. If your baby reacts negatively to this it may be better to restrict tasting to feeding times.

Introducing solids: First foods should be of a pureed and soft runny consistency without lumps. Suitable first foods include baby rice, fruit and vegetable purees. New foods should be introduced gradually, one at a time. Never put rusks, cereals or other foods into the bottle, it is better for a baby to learn to take solids from a spoon. If you find that your baby is starting to refuse certain foods, refrain from giving them temporarily but reintroduce them at a later date. While as adults we don't forget the tastes we dislike, babies have a different memory capacity to ours so it's important to keep trying / testing new foods.

Spoon feeding (4 - 6 months)

Don't delay spoon feeding simply because a baby has a cardiac condition or another condition such as Down syndrome. Starting spoon feeding will be a joint decision for you, your doctor, the dietician and the speech and language therapist. The decision to start spoon feeds is often based on weight rather than chronological age. The first spoon feed can be a bit of a slow process. Remember at this stage it's quality rather than quantity!

When introducing the spoon for the first time try the following:

- Place the spoon slightly sideways on so that it touches both corners of the baby's mouth and is resting on the lower lip.

• Don't empty the spoon into your baby's mouth and don't pull the spoon out. Wait for the baby's lips to close to let the mouth do the work. You want your baby to be as active as possible while feeding, this is especially important for babies with Down syndrome who often have poor muscle tone in the lips.
• It is usual for a baby to push food back out with her tongue when you place it in her mouth when spoon feeding is first introduced. This is because babies 'eat' using the same mouth movements which they use when sucking the bottle or breast. This forwards and backwards movement can result in the food which has just been taken from a spoon reappearing on a protruding tongue. Don't worry if this happens, your baby will soon learn to control the food from the spoon and pass it backwards instead of forwards.

When your child is ready you can give slightly thicker purees so she can learn to manipulate food in the mouth. This will prepare her for chewing and eating more textured food.

5.4.2 Cup Drinking *(usually introduced about 2 months after beginning to spoon feed)*

Cup drinking develops the muscles of the jaw, cheeks, lips and tongue. Fast flowing liquids may be difficult to control from a cup at first, in which case thickened liquids may be advised. Your speech and language therapist and/or dietician will advise you about thickened drinks if this is necessary.

5.4.3 Straw Drinking *(usually introduced about 2 months after cup drinking)*

Drinking from a straw is a great work out for the mouth. This drinking posture facilitates improved muscle tone as it exercises the lips, jaws, tongue and face muscles more than cup drinking. It is also helps a child learn to pull back or retract the tongue into the mouth.

You can teach straw drinking with a box of ready-prepared infant formula or (if allowed) fruit juice. Place the straw into the child's mouth and gently squeeze, being careful to only deliver a small amount into the child's mouth. At the next sip, squeeze to make sure the fluid is at the top of the straw before giving to your child so that the taste is readily evident, thus encouraging a suck. When your child is successful with a straw, move onto longer and

thinner straws to give more of a challenge. Party shops have "crazy straws" which can be fun as well as useful.

For children who are having difficulty handling thin liquids, you can continue to thicken the fluid but use shorter straws as this makes straw drinking harder.

5.4.4 Increasing Texture

Eating solids is important for all children both in terms of nutrition and to develop oral motor skills. Many children who have poor muscle tone will have a tendency to prefer soft, smooth foods such as yoghurt. It is very important to not make life too easy so that your child is continuously encouraged to develop more mature skills. This means that you may have to very slowly increase food texture to facilitate oral skills such as biting and chewing. The following tips may help:

1. Introduce new textures and flavours early, don't allow serious preferences to develop.
2. Gradually make blended food less smooth by liquidizing it less (if you are making your own) or adding texture such as bread crumbs or biscuit crumbs. Keep the texture consistent – no hidden or unexpected lumps as this can cause gagging.
3. Move from textured puree to well mashed foods and then on to chopped foods. Remember not to mix textures in the beginning e.g. thin soup with lumps of vegetables, custard with pieces of fruit in it, etc.

5.4.5 Promoting Self Feeding

Finger feeding: Once your child can manage mashed and chopped foods she is probably ready to move onto finger foods. 'Bite and dissolve' foods such as rusks, 'Liga,' boudoir biscuits etc are an ideal introduction to biting and chewing. Gradually move on to soft bite foods such as cooked vegetable strips, ripe fruit, cheese slices, sandwich meats and bread. Expect lots of mess to begin with as your baby practices the skills which are necessary for independent feeding.

Spoon Feeding: This is also the time to encourage participation in spoon feeding by giving your baby a spoon as you are spoon feeding and encouraging her to do it for herself. Once again the skills necessary for independent spoon feeding are complex, so be patient and expect lots of mess!

Equipment: A variety of adaptive equipment is available to assist your child to feed more independently, especially if she has a physical difficulty. Examples include cutlery, bowls and cups.

Cutlery: Children with low tone and a loose grip can feed more successfully with cutlery which has built-up handles and / or straps on the handle. Cutlery which is angled can help children with difficulty co-ordinating the movement to feed more independently. Cutlery can be plastic or metal and can vary from lightweight to more heavy-weight.

Bowls: Scooping food onto the spoon can be made easier with the introduction of a 'scoop dish' which is a small dish with a raised edge. Scooped dishes often have suction pads underneath to secure them to the table and if not, a non-slip mat could be used.

Cups: A variety of cups are also available which can help your child to drink independently. Cups with lids can reduce spillages and cups with built up or angled handles can help your child to grip more easily. Straws can help a child to drink without needing to lift the cup.

Children with low muscle tone and reduced muscle strength can become tired during feeding. This can be helped by taking breaks, for example the child and carer taking turns with spoon feeding and pacing the activity to suit your child.

6. COMING OFF THE TUBE

6.1 Tasting

Once the multidisciplinary team are happy that your baby doesn't have a swallowing problem it should be possible to offer her tastes.

Offering tastes allows your baby to practice feeding by mouth even though she cannot take enough to meet her nutritional needs.

Suggestions for introducing tastes:

A. Take it very slowly. Some tube fed babies have never experienced food or liquid in their mouth and may find it uncomfortable or even scary.

B. "Listen" to your child and observe them for any stress signals. Don't try to run before you can walk!

C. A good place to start may be during tube feeding. Follow the routine described on page 24 and introduce tastes by dipping the soother / finger in a small container of breast milk / formula. If you are hoping to breast feed you can put your baby to an empty (or almost empty) breast to suckle (e.g. after pumping). In this way the baby will get a few drops to taste and swallow without having to cope with the flow of milk from a full breast. (It will also help to stimulate further milk production).

D. For older babies you might want to introduce tastes of other foods. (Ask your dietician for advice about when your baby is ready for food tasting). This can be done initially by 'swiping' the lower lip with a small amount of puree. This should produce some lip licking and lip smacking activity.

Once this is tolerated you can place your clean finger (dipped in puree) inside the baby's lips. Introducing small amounts from a spoon is the final stage. This may be less acceptable than your finger so be patient!

6.2 Introducing solids:

Sometimes solids are better tolerated than liquids in infants with CHD, and in certain situations are introduced earlier than normal. For older babies with CHD the weaning procedure is the same as for non tube-fed children. See the suggestions for introducing spoon feeds on page 24.

6.3 The Oral Challenge (getting off the tube feeds)

The decision to move from tube to oral feeding is based on careful reassessment of the factors which led to the initial decision to tube feed.

For babies and children with CHD the decision to move to oral feeding is often made following successful surgery.

Some babies make the transition relatively easily. Once their hearts are repaired they have all the necessary energy and enthusiasm for oral feeding. As long as the foundations of non nutritive sucking, mouth play and tasting have been laid, the baby is ready to build up to full oral feeding.

However for some babies the transition is a little more challenging especially when there is an associated condition, e.g. Down Syndrome or Di George. Please refer to page 11.

"Jack ate so much better when he was home.
I think the more relaxed atmosphere combined with the familiar routine made things better. He also really missed his brothers!"

One of the most commonly asked questions is "how long will it take before my baby can do without tube feeding?"

The answer is (probably much to parents' annoyance!) "It's hard to say".
All babies differ in their transition from tube to oral feeding. Some make a relatively quick transition and quickly increase the volume taken orally in the space of a few weeks (occasionally even days).

Other babies take months to make the same progress and some may need a year or more before their oral feeding skills are sufficiently developed.

A major factor is of course your child's medical condition plus whether or not she has any associated condition which can impact on oral feeding progress.

As long as she is moving in the right direction, that is her oral volumes are slowly improving and tube volumes are slowly reducing, you should not be overly concerned.

During the transition period it is important to keep feeding time as relaxed and enjoyable as possible, for everyone involved. Setting unrealistic goals, e.g. "the tube will definitely be gone by baby's 1st birthday", will only create stress and may even stop your baby's progress.

Often babies reach a plateau stage when oral volumes seem to stay at the same level. They may take 50, 60 or 70% of their feed orally but just can't make that final leap!

The answer to this problem may be an oral challenge.

"In the end, Eibhleann forced the issue herself- she pulled out the tube 3 times in one day! So we thought right if this is what you want - here goes! Being reluctant to drink we decided to increase her spoon feeds - so she went from 3 to 8 or 9!! This is definitely what made it easy because we could mix her feeds with some milk."

The Oral Challenge

An oral challenge is when tube feeding is stopped and the baby is challenged to take all of her feeds orally. If she only takes, for example, 50% at one feed there is no 'top up' via the tube. She is left until the next feed in the hope that hunger may lead to a larger volume being taken.

The decision to proceed with an oral challenge is one which parents make with the input and guidance of the multidisciplinary team. An oral challenge cannot go ahead unless all of the following factors are present:

1. The baby has to be medically stable and well enough for the challenge.

2. The baby has to be in excellent nutritional status (a small weight loss is not unusual during an oral challenge).

3. The baby has to have well developed and safe oral feeding skills.

Once these requirements are met a decision can be made around when an oral challenge is appropriate and how it is going to be monitored. Some parents like the security and support of doing an oral challenge while their baby is in hospital while others prefer to do it in the more natural environment of the home with support and monitoring by the team. These are decisions which will be discussed with you in detail.

An oral challenge is sometimes that final push that your baby needs to become a full oral feeder.

"Looking back at how poorly Ailbhe fed before her heart surgery, I am amazed at how well she eats now! I never would have believed it."

NOTES

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