Feeding guide for children with rare chromosome disorders
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Feeding problems in babies and children with a rare chromosome disorder are common. There are many possible reasons for these difficulties because of the different parts of the body and nervous system involved in this everyday activity. Sometimes the physical structures of the body are affected such as when babies are born with a cleft lip and palate, or a high-arched palate. Disturbances to the digestive system may result in babies having difficulty keeping their feed down (reflux). For some babies, it is challenging to organise movements required for feeding because of muscle weakness or difficulties in co-ordinating movement. For others it is challenging to organise the complicated task of breathing, sucking and swallowing. Some children may overcome these early feeding difficulties as they get older. It is important to realise that babies and children that are fed by tube when young can go on to develop skills needed to eat and drink.

Some children can develop feeding and swallowing (Dysphagia) problems in later years for no obvious reason.

This guide has been written to help parents of children with chromosome disorders find information and support.

Early Feeding

For some babies there may be a difficulty to latch onto the breast, this may be because of a poor sucking reflex or other problem such as cleft lip and/or palate. They then have to be fed expressed breast milk or formula milk.

Some babies can be diagnosed with an allergy to a milk formula and may need to be fed a replacement milk such as soya or goat’s milk. This could be described as failure to thrive.

Failure to thrive is simply being too weak to drink enough to meet their own nutritional requirements is very common, and helped by enriched formula such as Pediasure.

www.patient.co.uk/doctor/growth-and-failure-to-thrive
What causes feeding and swallowing disorders in children with rare chromosome disorders?

- cleft lip
- cleft palate
- high arched palate
- submucous (hidden cleft)
- conditions affecting the airway
- gastrointestinal conditions (e.g. reflux)
- head and neck abnormalities
- nervous system disorders (e.g. cerebral palsy)
- medications that may cause lethargy or decreased appetite
- muscle weakness and low muscle tone in the face and neck
- multiple medical problems
- prematurity and/or low birth weight
- respiratory difficulties
- Other – refusal to eat certain food/textures – gagging, spitting, vomiting etc, in some children diagnosed with Autism or other neurological conditions for example

“...A is always raspy we haven’t done the swallow study yet, but our play therapist recommended thickening. Keeping in mind A’s tummy doesn’t do well with oatmeal [constipation], we thicken with baby yogurt and it works GREAT, plus extra calories, and she loves it. ”

Cleft lip and palate

Typically, babies with a cleft lip or palate or submucous (hidden) cleft, which isn’t obvious but often causes feeding problems because it’s usually accompanied by abnormalities of the mouth muscles, have greater feeding difficulties until their condition is stabilised or surgically corrected. Babies with a cleft lip and palate might have to be bottle fed but not necessarily formula. They could be fed by Habermann or other specialist bottles with breast milk. There are huge numbers of different bottles, teats and methodologies of feeding babies with clefts. There is a UK organisation that has a wealth of advice and information called CLAPA (Cleft Lip And Palate Association)

- **CLAPA** [www.clapa.com](http://www.clapa.com) 020 7833 4883  Email: info@clapa.com

- **The Haberman Feeder** [www.mandyhaberman.com](http://www.mandyhaberman.com) and [habermanbaby.com](http://habermanbaby.com)

Mandy Haberman, herself the parent of a child with special needs decided to invent a way of feeding her baby daughter as she found no bottle or teat available in the marketplace to help her when she was born with feeding
difficulties. So Mandy created the Haberman Feeder. The Haberman Feeder has been used for over 30 years and recommended by professionals and hospitals throughout the world and is widely acclaimed by medical professionals.

**Reflux**

Gastro-Oesophageal Reflux (GOR) is very common in babies and young children with the normal compliment of chromosomes. Reflux is a self-limiting condition for the vast majority of babies. It usually improves completely by the age of 18 months, even without any treatment. However, this may not be the case for babies affected by a rare chromosome disorder.

Around one in two babies in the UK has regurgitation which is when some of their feed effortlessly returns into their mouth from their stomachs. This is most commonly caused by reflux. It occurs because the muscle at the lower end of the food pipe (oesophagus) is too relaxed, so some of the contents of the stomach then pass up into the oesophagus, leading to regurgitation or vomiting. As the contents of the stomach are acidic this can irritate the lining of the oesophagus. When gastro-oesophageal reflux is associated with troublesome symptoms (such as poor weight gain, unexplained crying or distressed behaviour) it is known as gastro-oesophageal reflux disease (GORD). Gastro-oesophageal reflux is more common in babies who are born prematurely and also in those who have a very low birth weight. It is also more common in babies or children who have some impairment of their muscles and nerves, or those with cow’s milk allergy. Reflux occurs in both breast-fed and bottle-fed babies.

What are the symptoms of reflux?

Not restricted to babies and children with a chromosome disorder. Many babies and children have some gastro-oesophageal reflux which leads to vomiting or regurgitation of some of their feeds. This is not always associated with other symptoms. Other symptoms of gastro-oesophageal reflux can include symptoms that are similar to baby colic. These may be uncontrolled crying, drawing the legs up towards the tummy and pain in the tummy after feeding. Some older babies may refuse feeds, as they associate feeds with pain on swallowing.

Older children with reflux may complain of heartburn and a foul-tasting, watery fluid intermittently coming into their mouth.

For most babies and children, further tests are not needed as your doctor will be able to make the diagnosis by talking to you and examining your baby or child. You may be asked to keep a diary of the amount of fluid and food your baby or child is taking and also how often they are bringing up food. Your doctor may refer your baby or child for further tests if they are having more severe symptoms. Many babies or children with reflux who are otherwise well do not need any specific treatment, as this condition improves with time without any treatment. Your child’s weight will be monitored closely to ensure they are growing well and putting on weight appropriately. Some babies have symptoms
of reflux due to a cow’s milk allergy. If cow’s milk is eliminated from their diet then their vomiting will reduce substantially over a two-week period. If cow’s milk is eliminated but your child’s vomiting remains the same, then it is extremely unlikely that your baby (or child) has cow’s milk allergy. If you are breast-feeding then this means excluding cow’s milk from your own diet.

**What medications are available to treat reflux?**
The vast majority of children do not need any treatment with medicines for their reflux. Medications used might be Domperidone (helps to stop sickness) or Omeprazole, Ranitidine or sodium alginate (which work by reducing the actual amount of acid produced in the stomach).

**Gastro-Oesophageal Reflux Disease (GORD)**
Gastro-oesophageal reflux disease (GORD) is a common condition where stomach acid leaks out of the stomach and into the oesophagus (gullet). The oesophagus is a long tube of muscle than runs from the mouth to the stomach. Common symptoms of GORD include:
- heartburn – burning chest pain or discomfort that occurs after eating
- an unpleasant sour taste in the mouth – caused by stomach acid coming back up into the mouth (known as regurgitation)
- dysphagia – pain and difficulty swallowing

Many people experience occasional episodes of GORD, but if people have persistent and reoccurring symptoms it is normally regarded as a condition that needs treatment. Treatment could include changing the diet or taking antacids to help neutralise stomach acid.

Some babies with GORD have poor weight gain and can be more unsettled than normal. Occasionally, babies may wheeze as a result of more severe reflux. It may be the case in children with rare chromosome disorders that a lot of the children have silent reflux that is painful, but they have no way to express their pain appropriately. They could make aggressive noises like growling, or some self harming behaviours as attributable to reflux.
Swallowing
Dysphagia is the medical term for swallowing, eating and drinking difficulties. Some people with dysphagia have problems swallowing certain foods or liquids, while others cannot swallow at all. Swallowing disorders (dysphagia) can occur at different stages in the swallowing process:

- **Anticipatory phase** – bringing food or drink to the mouth, organising breathing, mouth opening and feeling ready to take food or drink in the mouth.
- **Oral phase** – sucking, biting, chewing, and moving food or liquid from the front to the back of the mouth ready for swallowing
- **Pharyngeal phase** – starting the swallow, squeezing food down the throat, and closing off the airway to prevent food or liquid from entering the airway (aspiration) or to prevent choking
- **Oesophageal phase** – relaxing and tightening the openings at the top and bottom of the feeding tube in the throat (oesophagus) and squeezing food through the oesophagus into the stomach

Signs and symptoms of feeding and swallowing problems in children:
- difficulty breast feeding
- refusing food or liquid
- long feeding times (e.g., more than 30 minutes)
- arching or stiffening of the body during feeding
- irritability or lack of alertness during feeding
- unwilling or unable to accept different textures of food (e.g., only pureed foods or crunchy cereals)
difficulty chewing
- coughing, choking or gagging during meals
- food/liquid or saliva coming out of the mouth or nose
- difficulty coordinating breathing with eating and drinking

The child’s voice might be **hoarse** or **gurgly**; or they might frequently spit food out, gag or vomit. They could develop **pneumonia** or respiratory infections caused by aspirating their food. They may also have problems gaining weight or growing at the right level for their age. Children may be at risk for:

- **dehydration** or poor nutrition
- **aspiration**
- **pneumonia** or repeated upper respiratory infections

Dehydration occurs when your body loses more fluid than taken in. When the normal water content of your body is reduced, it upsets the balance of minerals (salts and sugar) in your body, which affects the way that it functions. Some of the early warning signs of dehydration include:

- feeling thirsty and lightheaded
- having dark coloured, strong-smelling urine
- passing urine less often than usual

A baby may be dehydrated if they:

- have a sunken soft spot (fontanelle) on their head
- have few or no tears when they cry
- have fewer wet nappies
- are drowsy

**How are feeding and swallowing disorders diagnosed?**

If you suspect that your child is having difficulty eating, contact your GP or paediatrician right away. Your paediatrician will examine your child and address any medical reasons for the feeding difficulties, including the presence of reflux or **metabolic** disorders. Your child will need to be seen by a Speech and Language Therapist (SALT) who specialises in the management of eating and swallowing disorders. Your child may also be seen by an ENT (Ears, nose and throat) consultant, a Physiotherapist and a dietician.

You will be asked questions about your child’s medical history, development and symptoms and they may:

- observe feeding to see your child’s readiness to feed, posture, behaviour, and oral movements during eating and drinking
- look at the strength and movement of the muscles involved in swallowing
- perform a test to evaluate swallowing, such as: a video Fluoroscopy, where your child will be given food or liquids to eat or drink and those items will have barium added to it, then the swallowing process is videoed on an X-ray.
Further additional tests may also be necessary

Your child’s posture, self-feeding abilities, medical status, and nutritional intake will be examined by the team. The team will then make recommendations on how to improve your child’s feeding and swallowing.

They may recommend any of the following:
- medical intervention (medicine for reflux)
- nutritional changes (different foods, adding calories to food)
- increasing acceptance of new foods or textures
- postural or positioning changes (different seating)
- referral to other professionals, such as a psychologist or dentist

The Speech and Language Therapist (SALT) can help with:
- coordinating the suck-swallow-breath pattern (for infants)
- improving chewing
- making the muscles of the mouth stronger
- increasing tongue movement
- thinking about the sensory experiences of mealtimes
- increasing acceptance of different foods and liquids
- improving sucking and/or drinking ability
- altering food textures and liquid thickness to ensure safe swallowing

Parents can help by asking questions to help them to understand the problems in feeding and swallowing, making sure that they understand the treatment plan for their child and following the recommended techniques at home. The SALT can also go into school/respite to help teach those supporting the child, so that the techniques are followed at school/respite as well. Parents can also contact their SALT to tell them about what is or is not working at home/school/respite.

**Tube feeding**
Naso-gastric intubation is the insertion of a plastic feeding tube (nasogastric tube or NG tube) through the nose down into the stomach. If your child needs to be fed through a tube that goes directly into their stomach (either temporarily or permanently); you can get advice from the support group pinnt.com/Half-PINNT.aspx

“L was tube fed from birth until 16 months of age. He was nil by mouth and the doctors/specialists told me he would never eat enough to sustain himself, ever. He was ng fed and they suggested he have a peg and a nissens at the same time as L suffered from reflux. I refused and after doing some research I took him to Austria (www.notube.com) and they had him eating orally within 9 days. He is now 8 and eats for England. Had I listened to the UK specialists, L would still be tube fed. They told me he was “orally aversive”, which we found out was untrue. His reflux also went as soon as the tube went, so the nissens would’ve been for nothing (it’s very invasive surgery).”

Gastrostomy
A gastrostomy is a surgical opening through the abdomen into the stomach. A feeding device is inserted through this opening into the stomach. This allows your child to be fed directly into his or her stomach, bypassing the mouth and throat. You can find out more from the Great Ormond Street Hospital website: www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/living-with-a-gastrostomy/

“The thing that helped A was her gastrostomy it means she has all the calories and nutrients she needs and I don’t have to worry myself sick and means we have had less hospital admissions and I can keep her hydrated. A can eat as much or as little food she chooses, it’s more a sensory/pleasure, it’s not a battle for us anymore”
Fundoplication

What is a fundoplication?
A Nissen’s fundoplication is an operation used to treat gastro-oesophageal reflux. It uses the top of the stomach to strengthen the sphincter so it is less likely to allow food, drink or acid to travel back into the foodpipe. Some babies and children have a gastrostomy during the same operation. The fundoplication operation is usually carried out using keyhole surgery (laparoscopy). You can find out more from the Great Ormond Street Hospital website: www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/fundoplication/

Weaning
Many of Unique’s children are extremely delayed – they might eventually get the hang of bottle/ breastfeeding, but then have to stay on soft/pureed food for much longer than other children.

Your health visitor can advise you on many aspects of feeding and weaning your baby. As your child grows, you might be able to get a referral from your GP or health visitor for any further specialist help you might need. For example:

- A speech and language therapist may be able to help with physical issues such as chewing and swallowing.
- An occupational therapist can advise you about aids that might help your child, such as special plates, bowls, cups, adapted cutlery or non-slip mats.
- A physiotherapist or occupational therapist can advise you on getting your child into the right physical position to eat.
- A dietician can help you if you’re concerned that your child isn’t eating enough.

“Our little girl had infant nutrini milk from the hospital to help her gain weight, despite being breast fed as well. When she was able to eat, eating at home was easier; as she wouldn’t eat a thing when we were out and was very unsettled, always having to be on my knee if we were out. Routine was and still is key for her. Textures of food were also an issue.”

Chewing
Chewing is far more complicated than you might think. Foods can react differently in the mouth, some need prolonged chewing and others just fall apart. Many children with chromosome disorders might have a physical reason why they can’t chew. Others might have an oral defensiveness that makes it difficult for them to accept foods into their mouth, particularly those with lumps or unusual textures. Some children do not know how to chew using their teeth and tongue correctly.
Develop chewing skills
The introduction of solids in your baby’s diet is not only important for nutritional reasons, but for the development of oral motor skills. These are the actions of the mouth, lips, tongue, cheeks and jaw as they suck, bite, chew and lick. These motor skills work the same muscles in the mouth as those which are needed for speech development.

“My son wouldn’t eat anything much, or ate the same thing over and over again, he didn’t drink much either. I bought a smoothie maker and started giving him fruit smoothies; he really enjoys them.”

“J lived of paediasure then paediasure with yoghurts and completely smooth puree until 7 years of age when we started and intensive feeding program. One of the best pieces of advice from our S&LT for severe intolerance to lumps in food was to VERY slowly build up – adding wheatgerm (from a health food shop) to the puree. Literally starting with a 20th of a teaspoon and building up over weeks and weeks – I was very doubtful J would tolerate this but he did, so we got to stiff purees which helped to exercise the mouth. The next clever thing was to add completely soft bits into this solid puree the texture being such that you cannot detect the difference between puree and bits. J is still learning to chew, but now can eat a wide range of soft mashed foods which is massive progress. To encourage chewing his IEP has a target to chew soft food 5 times on each side in front of a mirror and he gets stickers for each chew. He also has a chewy tube.”

Choking
Chewing difficulties and choking often go hand in hand for some children with chromosome disorders. Structural difficulties, muscle tone problems like hypotonia and sensory difficulties can make biting and chewing food challenging. Reflux, where food comes back up into the throat and mouth after a meal can cause choking, coughing or aspiration. Keeping your child properly positioned during eating and for at least half an hour afterwards will aid the digestion process. Helping your child to pace their mealtimes can also help: for example encourage your child to swallow one mouthful before putting more food in the mouth. Some children with chromosome disorders are known for over-stuffing food into their mouths and swallowing without chewing. Watch them closely when eating, making sure they don’t
throw their heads backwards whilst they have food in their mouths. Postural alignment, with trunk and head held straight, can improve swallowing and decrease feeding difficulties. For some children, you can get specialist seating e.g. chairs with a tray and/or footrest that allow them to sit upright at the dining table, or close to the dining table while they eat, which also helps to include them as part of family meal times. If your child doesn’t have the motor control to keep their body and head upright and straight while eating, they are more likely to choke. Although this isn’t always true because some unique children have found their own positions for feeding, which can also reduce the risk of choking. Some children may not be able to feed themselves because of constant body movements or needing to use their arms or hands to keep themselves balanced.

You can get positional seating advice from an Occupational Therapist (OT).

“My son had a video fluoroscopy and it was discovered he was aspirating on every mouthful - but he didn’t cough like you or I would. It showed that he wasn’t chewing his food, but rolling it about in his mouth with his tongue and then sucking it down his throat, he even does the same with drink. With the help of a specialist feeding Speech and Language Therapist, we devised an eating plan for him. Eating with his head in a downwards position works better for him.”

**Oral Defensiveness**

Babies who spent long periods of time in a Special Care baby unit (SCBU) or Neonatal Intensive Care unit (NICU) gaining nutrition through a feeding tube or IV often have oral defensiveness. They never learned to coordinate sucking and swallowing at the proper developmental age, and they often had to deal with people putting tubes in their mouth or nose. Overcoming oral defensiveness takes time and patience.

Oral motor and sensory therapy works on the oral skills necessary to support speech and feeding development. These skills include: awareness, strength, coordination, range, duration and speed of movement of the lips, cheeks, tongue, jaw and face.

You could use touch by play, either with your fingers gently touching their face or using soft objects, or their own fingers. Singing games can help with body
awareness, so they could also be used for facial awareness. If they can tolerate some of these touches, try the area around the mouth and lips before feeding. Then bring food to their mouths slowly and gently using only plastic or rubber spoons, as metal ones are cold, sharp and hard. Gum massage can also help oral stimulation.

“C.’s issues are mainly psychological. I read him lots of books about food and meal times. We also drew pictures of the food and talked about it before eating. He has tried ‘caring cutlery’ but it hasn’t helped much. Numbers and letters are his motivators so I add alphabetti spaghetti or similar to his food. We try hand-over-hand, where I hold his hand under my hand when feeding. We tried lots of desensitisation techniques around his mouth with cloth textures. Family meal times with us around the table seem to be counter-productive, so trying different places. Trying distractions; such as reading to him whilst he eats.”

**Teeth**

It is important to think about your child’s teeth. Painful or crowded teeth and sore gums can contribute to feeding problems. We also know that feeding problems can affect the teeth. Please read the Unique practical guide on Teeth and dental problems for more information.

**Pica**

Pica refers to eating objects which are not meant to be eaten. These can include stones, faeces, coins, acorns, leaves, shells, the list is endless. Whilst some objects pass through the body without harm, pica can be very dangerous.

**Drooling**

Drooling (also known as dribbling) is the unintentional loss of saliva from the mouth. It occurs naturally in babies, but as the child gets older it usually decreases. Daytime drooling stops within the first few years of life, though it may still occur in the older child during sleep. Drooling beyond the age of about four years is unusual, unless there is an underlying medical problem. Drooling can be related to:

- abnormalities in swallowing
- difficulties moving saliva to the back of the throat
- jaw instability
- limited jaw and lip closure
- tongue thrusting
- reduced awareness
- seizure activity

Drooling is fairly common in children and some adults with chromosome disorders. Children born with a cleft lip and palate, a high-arched palate or
decreased muscle tone (Hypotonia) can be affected by drooling. It can also cause a sore mouth and chin and clothing often needs to be changed regularly because of the wetness.

There are treatments available to help with drooling. Treatments may include:

- oral skills activities to increase muscle activity, improve oral-motor function and improve sensory awareness
- palatal training therapy where dental appliances are specially designed to increase awareness, and prompt more frequent swallowing and lip closure
- medication, where drugs might be used to dry up salivary secretions (Hyoscine hydrobromide patches [also used to treat travel sickness] or Glycopyrronium Bromide tablets are two of the most common medication treatments used for drooling)
- Botulinum toxin (Botox) injections to help prevent and control drooling
- surgery, where salivary glands are turned towards the back of the mouth so that saliva runs towards the back, rather than the front of the mouth, or removal of a salivary gland may be considered in extreme cases

“We have issues with his overeating, but as a small baby/infant, he was fussy with texture. We thought he was 'lazy' as he wouldn’t chew and wouldn’t eat anything with bits in until he was over 12 months. We had to simply persevere and keep trying things. I don’t have much advise, except don’t give in, you have to de-sensitise them as much as is humanely possible, without stressing them out. M still has some sensory issues with textures, smells, colours etc, but on the whole is a good eater.”
Growing up.................

For many children who have problems feeding as a baby, these problems often continue as they grow up but not always. Many of our parents have found help and solutions of their own.

“Have a little patience! Easier said than done, I know! .... My daughter has never had a problem, as such, with eating, as she has always loved food but she has never had a ‘stop switch’ or ‘full alarm’ and has always wanted to just continue to eat. As a baby she would always feed until she was sick and then want to continue again... So, I learnt very early on, that I had to take control of that. So I would just stop feeding when I thought she had eaten enough. As she has got older and as she found her own voice (she didn’t start talking until she was about 8 yrs old) this has become harder because she does love her food. But I have remained strong (mostly)! ...... She is now 15 yrs old and accepts that she (and I realise no two children are the same but this works for my daughter) cannot have second helpings of school dinners or puddings; she has learnt what is an acceptable amount of food on her plate at a buffet; she has also learnt to ask for healthier alternatives as snacks between meals; more importantly, she has actually learnt to say ‘No, thank you.’ to the offer of more food...! Anything is possible! Good luck everybody!”

Equipment to help with feeding

There are a huge variety of pieces of equipment that can help with eating and drinking including special plates, bowls, cups, caring cutlery, etc. Specialist seating may help to support your child’s posture at mealtimes. Larger items of equipment like a feeding chair can be provided by an OT, but most of the small items like plates and cups, you might need to fund yourself (check with your OT as even if they can’t fund items on the NHS, they should be able to support you in finding the right equipment and direct you to funders to help to pay for them)

“K. has a special plate that’s slanted and special cutlery from her OT. It really does help! She eats with little or no spillage, but only with these.”

“For K it was soft plastic spoons, different textures and colours that helped. Don’t set your own goals too high and at the start being prepared for lots of breaks . But persevere.”
Useful organisations and web links

(please note that Unique does not recommend any particular organisation. The links below are purely for information purposes)

- **National Breastfeeding Helpline**
  
  http://nationalbreastfeedinghelpline.org.uk/
  
  Tel: 0300 100 0212

  The Breastfeeding Network (BfN) is an organisation based in the UK. They are an independent source of support and information for breastfeeding women.

- **Living with reflux**
  
  www.livingwithreflux.org/
  
  and facebook group: www.facebook.com/groups/livingwithreflux/

  Offers support for families who have infants, children and young adults who suffer with Gastro-Oesophageal Reflux (GOR) and Gastro-Oesophageal Reflux Disease (GORD) and other associated conditions.

- **National Childcare Trust**
  
  www.nct.org.uk/parenting/feeding
  
  Helpline: 0300 330 0700

  - www.infantreflux.org/ and www.infantreflux.org/forum/

    Support for parents by way of a forum to chat with other parents.

  - www.reflux.org/

    Support for parents by way of a forum to chat with other parents.

  - www.dysphagiacookbook.com/index.htm

    A link to other links for recipes and ideas for those that have dysphagia.

- **www.notube.com**

  NoTube was founded to help children around the world to overcome the severe condition of tube dependency. The ultimate goal is to teach the child how to eat and to finally remove the feeding tube. They also have a facebook group: www.facebook.com/groups/404270672987962/
- www.sensory-processing-disorder.com
  A website for everything connecting to sensory processing disorder, also known as sensory dysfunction, including information for oral defensiveness and picky eaters.
- www.cincinnatichildrens.org/health/info/abdomen/home/g-tube-care.htm
  A video and useful cleaning care tips for g-tubes.

**Facebook groups for those whose children are tube fed or have feeding problems**
- www.facebook.com/groups/177590912307248/
  A tube feeding group for families in the UK
- www.facebook.com/foodfortubies?fref=ts
  Blended food for tubies – recipes and information
- www.facebook.com/groups/feedingtubeanswers/?fref=ts
  Feeding tube answers group
- www.facebook.com/FeedingTubeAwareness
  The Feeding Tube Awareness Foundation based in the USA
- www.facebook.com/groups/112864602056892/
  Parents of children with feeding problems
- www.facebook.com/groups/2374049168/?fref=ts
  Children with Coeliac disease
Glossary

**Aspiration** - food or liquid entering the airway or lungs below the vocal cords

**Barium swallow** – Barium liquid is often fruit-flavoured so it is pleasant to drink. You stand or sit in front of an X-ray machine whilst X-ray pictures are taken as you swallow. This test aims to look for problems in the gullet (oesophagus). These include a narrowing (stricture), hiatus hernias, tumours, reflux from the stomach, disorders of swallowing, etc. A barium swallow test takes about 10 minutes.

**Cleft Lip** - a split in the lip

**Cleft Palate** - a split in the roof of the mouth

**Gurgly voice** – voice sounds rather wet or bubbly

**High-arched palate** – the roof of the mouth is higher than usual

**Hoarse** – the voice sounds rough or harsh

**Metabolic** - metabolism is the process your body uses to get or make energy from the food you eat

**Nutrition** - the process of providing or obtaining the food necessary for health and growth

**Oesophagus** – also known as the gullet is the muscular tube that conveys food from the pharynx at the back of the mouth to the stomach

**Oral** – relating to the mouth (as in oral hygiene)

**Pharyngeal** – relating to the Pharynx - the back of the mouth and throat, with its surrounding membrane and muscles, that connects the mouth and nasal passages with the oesophagus

**Pneumonia** - lung inflammation caused by bacterial or viral infection, in which the air sacs fill with pus and may become solid. Inflammation may affect both lungs (double pneumonia) or only one (single pneumonia)

**Aspiration Pneumonia** (or pneumonitis) - occurs when food, saliva, liquids, vomit, or foreign objects are breathed into the lungs or airways leading to the lungs

**Video Fluoroscopy** - a moving or dynamic X-ray that looks at the way your swallowing works. It is one way of confirming the presence of aspiration because of problems with swallowing
Inform Network Support

Rare Chromosome Disorder Support Group,
G1, The Stables, Station Rd West, Oxted, Surrey. RH8 9EE
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can please make a donation via our website at www.rarechromo.org
Please help us to help you!

While every effort is made to ensure that the information contained within this guide is accurate and up-to-date, Unique is not responsible for the reliability of any information contained herein. This information guide is provided solely as a convenience.
Unique mentions other organisations’ message boards and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it.

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