

## Feeding Difficulties

**Feeding problems** make it difficult for a person to take in enough food or liquid by mouth. Some babies with 22q11.2 deletion syndrome (22q11.2DS) or 22q11.2 duplication syndrome (22q11.2DupS) experience feeding problems. In fact, for babies who do not have serious medical conditions at birth, feeding challenges may be the first sign of a 22q difference.

### Causes of feeding problems in 22q11.2DS

- **Structural abnormalities / other health conditions**
  - **Cleft palate** (see our info sheets in the [Palate Series](#))
  - **Reduced labial seal** – the baby's lips (e.g., cleft lips) cannot wrap around the mother's nipples properly for breastfeeding.
  - **Retrognathia** – The lower jaw sits farther back compared to the upper jaw, making it difficult for a baby to latch onto the nipple.
  - **Dysphagia** – difficulty swallowing. (see our info sheet on **Swallowing and Dysphagia** in the [GI Series](#))
  - **Vascular Ring** – When the aorta (large blood vessel that comes out of the heart) or its branches form abnormally, they may encircle and put pressure on the trachea and esophagus, resulting in difficulty breathing and swallowing.
- **Neurodevelopmental disabilities**
  - Abnormalities of the **muscles** or **nerves** in the palate or throat
  - Poor **suckling reflexes or timing**
  - **Dysphagia** – difficulty swallowing.
  - **Esophageal spasm** – Painful contractions of the esophagus
  - Difficulty with bolus control
- **Behavioral feeding disorders**
  - Babies who dislike certain textures may become pickier eaters.
- **Multi-factor**
  - **Gastroesophageal reflux** (see **GERD** in the [GI Series](#))
  - **Delayed stomach emptying** (see **Gastroparesis** in the [GI Series](#))
  - **Intestinal malrotation** – abnormal intestine position that may lead to vomiting and blockage (see **Structural Abnormalities** in the [GI Series](#))
  - **Constipation** (see **Constipation** in the [GI Series](#))
  - **Zinc deficiency** – which can affect the taste and intake of food

### Consequence of feeding difficulties

- Food or liquid goes down the airway (**aspiration**), leading to coughing, choking, difficulty breathing and frequent pneumonias (infections in the lungs). Note: **Aspiration can happen silently (without coughing), and the parents may not know.**
- The child does not get enough food to grow and thrive.
- Child-caregiver interactions may be stressful, and the child struggles when eating together with family and friends.

### Feeding problems in 22q11.2DS

- About 36% of babies with 22q11.2DS have feeding difficulties.
- Among babies who did swallow imaging studies:
  - Most have difficulty swallowing (at the mouth or throat).
  - Food/liquid go to the top of the airway or even into it.
- Among adults with enough info in their records for a GI study, about 1 in 10 have feeding problems, including difficulty swallowing.

### Signs of feeding difficulties

Among babies:

- Poor suck-swallow-breathe pattern
- Weak sucking action
- Feeding takes a long time
- Not taking in the volume of milk expected given the baby's age and weight
- Liquids coming out of the nose
- Coughing, choking, and congestion, which may mean that liquids are going down the airway
- Poor weight gain

Additional signs in older babies:

- Gagging or spitting when transitioning to solid food over at least months despite many tries
- Needing help to learn to chew
- Refusing foods with different textures or those that need more processing
- Difficulty with drinking using a straw

## Feeding Difficulties (continued)

### Helping babies with feeding difficulties

1. Special equipment
  - **Special bottles or nipples** to help the baby drink enough
2. **Tube feeding** (“Gastric tube” or “G-tube”)
  - A tube is inserted to the stomach or the intestines to deliver nutrients directly there. This feeding bypasses the mouth and esophagus entirely.
  - G-tube placement is more likely to happen in babies with 22q11.2DS and have:
    - Heart defects
    - History of heart surgery
    - Aspiration
    - Severe nasopharyngeal reflux
    - Subglottic stenosis
    - Laryngeal web
    - Tracheostomy
3. **Feeding Therapy**
  - The feeding therapist may use one or more of the following approaches to suit the child:
    - Sensory / motor / behavioral models
    - Improving posture and how muscles hold up the body
    - Improving motor functions and movements for the lips, cheeks, jaw, and tongue
    - Improving motor coordination during feeding
    - Building a trusting relationship with the child
    - Reward system for trying new foods

### Diagnosing feeding problems

A **videofluoroscopic swallow study (VFSS)**, also called **modified barium study (MBS)**, can assess the baby’s swallow function. Barium (a minty tasting liquid or paste that can be seen on x-ray images) is added to the food or liquid. While the baby eats/drinks, the technician takes x-rays of the mouth and throat so the speech-language pathologist (SLP) can assess if there are any problems with swallowing. For more information, please visit the [Videofluoroscopic Swallow Study](#) webpage from the American Speech-Language-Hearing Association.

### Professionals who can help

- Pediatrician
- Head and neck specialists
- 22q11.2 specialists
- Feeding or swallowing specialists
- Speech-language pathologists
- Radiologist and x-ray technicians
- Plastic surgeons
- Breastfeeding counselors
- Occupational therapists
- Pediatric psychologists

### References / Resources

#### Clinical practice recommendations and research reports

- [Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#) – 2023
- [Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#) – 2023
- [Gastrointestinal Features of 22q11.2 Deletion Syndrome Include Chronic Motility Problems From Childhood to Adulthood](#) – 2022
- [Feeding and Swallowing Disorders in Children with 22q11.2 Deletion Syndrome](#) (poster) – 2022
- [Percutaneous Enteral Feeding in Patients With 22q11.2 Deletion Syndrome](#) – 2021
- [Communication and Feeding/Swallowing Disorders in 22q11.2 Deletion Syndrome: A Primer for the Pediatric Speech-Language Pathologist](#) – 2019
- [Feeding problems of infants and toddlers](#) (general population) – 2006
- [Otolaryngologic Manifestations of the 22q11.2 Deletion Syndrome](#) – 2002
- [Dysphagia in children with a 22q11.2 deletion: Unusual pattern found in modified barium swallow](#) – 2000

#### Websites of medical institutions and specialty associations

- [22q11.2 Deletion Syndrome – Boston Children’s Hospital](#)
- [How Does Feeding Therapy Work? – Napa Center](#)
- [Videofluoroscopic Swallow Study \(VFSS\)](#) - American Speech-Language-Hearing Association (ASHA)



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