

# Feeding and swallowing difficulties in children with heart conditions

**This leaflet explains the feeding and swallowing difficulties your child may experience with their heart condition. If you have any further questions or concerns, please do not hesitate to contact your child's doctor, nurse, speech and language therapist or dietitian.**

## What are the signs and symptoms?

- Difficulty putting on weight
- Tiring or becoming sleepy during feeds or at meal times
- Becoming disinterested in or refusing food or drink
- Becoming anxious and stressed about eating and drinking
- Noisy breathing when swallowing
- Coughing or choking
- Pain during or after feeds/meal times

In some cases there are no obvious signs and symptoms.

## Why do children with heart conditions have feeding difficulties?

Not all children with a heart condition or who have had heart surgery have difficulties with feeding. Children needing surgery are often required to be a certain weight and it is not surprising that feeding difficulties can be a cause of anxiety.

In some rare cases, the surgical procedures carried out to help your child can cause damage to their recurrent laryngeal nerve. This nerve makes the vocal folds work and, if damaged, causes a vocal fold palsy. The vocal folds are important in swallowing because they move together to stop food or drink entering the windpipe and they help to protect your child's lungs. If a vocal fold doesn't work, food and drink may enter the windpipe and cause damage to the lungs. This is called 'aspiration'. Aspiration can also occur if your child has difficulties coordinating their swallow with their breathing. In most cases children's feeding and swallowing difficulties improve as their cardiac condition improves, unless these are caused by other factors, such as vocal fold palsy.

In some cases children with heart conditions have difficulties absorbing their feeds through their gut and need a special feed to help them get the nutrition they need.

## Are there other reasons my child may have difficulties?

- If they were born prematurely
- If they have a genetic syndrome or other medical condition
- If they have gastro-oesophageal reflux disease
- If they have spent a long time on intensive care with a breathing tube
- If they have a tracheostomy

## Does my child need any tests to confirm the diagnosis?

Your child may need a feeding/swallow assessment carried out by a speech and language therapist. This involves them being watched very closely when they feed. In some cases your child may need a videofluoroscopy swallow study which is a moving X-ray taken while they are swallowing food/drink.

## What advice may I be given to help my child?

The speech and language therapist and dietitian can give advice to help with your child's feeding. This may include:

- a feeding plan
- a special feed
- pacing (slowing down the speed your child is fed to promote safety)
- positioning (changing the way your child sits/lies)
- utensils (changing the bottle teat/cup/spoon)
- texture (changing or limiting the textures of food and drink)
- feeding tubes.

## What happens if my child does not receive treatment?

It is important to treat any feeding or swallowing difficulties as early as possible. Help from your child's speech and language therapist or dietitian will support them to grow, enjoy meal time experiences and protect their lungs from aspiration.

## Useful sources of information

Little Hearts Matter: [www.lhm.org.uk](http://www.lhm.org.uk)

British Heart Foundation: [www.bhf.org.uk](http://www.bhf.org.uk)

ECHO: [echo-uk.org](http://echo-uk.org)

NHS: [Dysphagia \(swallowing problems\) - NHS](#)

American Speech-Language-Hearing Association:

[www.asha.org/public/speech/swallowing/Feeding-and-Swallowing-Disorders-in-Children/](http://www.asha.org/public/speech/swallowing/Feeding-and-Swallowing-Disorders-in-Children/)

### Contact us

If you have any questions or concerns about your child's feeding or swallowing please contact the Acute Speech and Language Therapy service on 020 7188 3992 (Monday to Friday, 9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets).

### **Evelina London Medicines Helpline**

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003 10am to 5pm, Monday to Friday      **e:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

### **Your comments and concerns**

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)  
**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### **Language and Accessible Support Services**

If you need an interpreter or information about your care in a different language or format, please get in touch.

**t:** 020 7188 8815      **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### **NHS 111**

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

### **NHS Choices**

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

### **Get involved and have your say: become a member of the Trust**

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

**t:** 0800 731 0319      **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)      **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

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