Institute of Health Visiting
Excellence in Practice

Babies and very young children with eating, drinking and swallowing difficulties

Background

Babies and young children with neurodevelopmental disorders, or children who are diagnosed with a neurodevelopmental disorder when they are older, often experience eating, drinking and swallowing difficulties (EDSD) in the first year of their life.

This Good Practice Point (GPP) will focus on babies and young children up to the age of 18 months with:

1. Physical EDSD caused by reduced control/sensation of the muscles of the lips, tongue, mouth and throat, or by reduced control of posture, such as babies and children with motor disorders like cerebral palsy.
2. Non-physical causes of EDSD caused by sensory and/or behavioural issues leading to restricted or selective eating and rituals associated with food or mealtimes, such as babies and children who may go on to have a diagnosis of autism spectrum disorder, and other conditions of sensory or 'behavioural' feeding conditions.
3. Children with mixed EDSD, both physical and non-physical difficulties, including reduced control of the muscles of the lips, tongue, mouth and throat and non-physical difficulties such as sensory or behavioural issues leading to restricted or selective eating and rituals associated with food or mealtimes.

The evidence

How to support babies and children with eating and drinking difficulties, and their families

The Focus on Early Eating Drinking and Swallowing (FEEDS) study was funded by the National Institute for Health Research (NIHR). The researchers worked with 400 parents, 450 health professionals and 10 young people to summarise the evidence base for the use of specific interventions for young children with EDSD, and to identify the important areas to focus on when measuring improvement in EDSD over time.

The FEEDS study found that there are several interventions that can be useful for babies and young children with EDSD – these are described in the FEEDS Toolkit research paper (https://bit.ly/3EKLZjL). In this GPP, a summary of relevant sections from the FEEDS Toolkit is included, focusing on the symptoms and signs of EDSD for babies and very young children (age 0-18 months) and some of the first interventions that can be used by health visitors to support feeding.

More information on page 2

The information in this resource was created on 05/09/2023.

Signs and symptoms of physical EDSD in children up to 12 months of age

Babies who are breast/chest or bottle-fed

Babies with neurological conditions with physical EDSD may cough, choke or splutter when taking milk or solid feeds (dysphagia). Milk feeds may stay in the throat for longer than usual. Milk may go toward or through the entrance to the airway (through the vocal cords) and down into the lungs (known as aspiration). This can cause aspiration pneumonia. Babies may turn away during feeds, due to breathlessness, and some babies can suffer from silent aspiration and do not cough when milk goes through the larynx.

Babies at risk of aspiration, or babies suffering from aspiration, may show other signs of feeding difficulties such as: taking longer to feed; eye-watering when feeding; or changing colour (turning pale or going blue). Babies may have repeated chest infections and suffer from more infections than other babies.

Risk of aspiration is important to identify. Aspirated milk may cause lung damage by blocking the airways, or causing infection. Aspiration pneumonia can lead to chest infections that require oral or intravenous antibiotics, and oxygen to support breathing.

Babies who are taking solid foods

Some babies can manage to drink milk safely but struggle to form a food bolus in the mouth, or to swallow solid food safely. This can lead to aspiration, with symptoms and signs similar to those described in the previous paragraph/section.

Most babies with physical EDSD also have some developmental difficulties. EDSD may be the first sign of a neurodevelopmental disorder and that further assessment is indicated. Observation of feeding is required by a specialist dysphagia speech and language therapist, and further assessment by a dietitian and paediatrician is usually needed. Some babies require a videofluoroscopy (a moving x-ray swallowing investigation).

Referrals take time to organise and, in the meantime, babies require fluid and nutrition. The FEEDS study reviewed the evidence about what interventions are appropriate to consider.

Interventions for all babies and children

Addressing the individual context

The following overarching principles should be taken into account when considering interventions:

- Consideration of how the parents/carers are feeling. This can be a difficult time for parents, and long feeding times can increase parents' stress levels.
- Understanding EDSD in the context of the diagnosis/es already given (for example, identifying whether a child with epilepsy is having seizures during feeds).
- Increasing parental awareness and insight of the difficulties with feeding, and the possible causes.
- Providing support for parents, such as helping parents with their baby's/child's feeding difficulties, including professional support, counselling and parent support groups.

Interventions for some babies and children

Some babies may be supported with feeding through modifications to their food and the ways in which it is given. There is evidence that the following adaptations might be helpful for some babies depending on their individual circumstances. These modifications should be made following specialist assessment by a speech and language therapist or paediatrician.

More information on page 3

Modifying the consistency of food or drink

Food and drink may be modified – for some babies and children, thicker puree or semi-solid food may reduce aspiration risk, which can be helpful if they don't have the chewing skills for solid foods. Modifying the consistency of food or drink can be defined as changing aspects of the:

- Consistency
- Temperature
- Taste
- Amount
- Presentation (pureeing, thickening or presenting different foods so they do not touch each other, including mixing 'liked' foods with previously rejected foods)

Speech and language therapists may advise mixing milk with a thickener, such as Carobel, to reduce the risk of aspiration. Thickness of fluid is standardised by adding a defined amount of thickener to a certain volume of fluid.

Identifying the safest consistency of fluid and food requires speech and language assessment and may require expert serial observation of feeding with different textures, and/or videofluoroscopy.

Positioning

Ensuring a child has the best posture to eat and drink food safely and efficiently, such as sitting upright and providing support for head control, can help safe feeding for babies and children with physical EDSD. Assisting with posture (sitting straight and upright) through use of an appropriately supportive seat/chair for feeding is essential. A slight recline of supportive seating may be recommended at certain times, to help a child with their head control. Expert advice about posture and straight seating requires assessment by a speech and language therapist, physiotherapist and/or occupational therapist.

Responding to cues for feeding

Helping parents/caregivers to recognise the signs that a baby or child is ready to take another mouthful of food or drink can be used to inform feeding – such as looking for breath alterations or repeated swallows from a child to indicate a lack of readiness.

Babies who turn away when being offered milk or puree may be doing this due to discomfort/breathlessness from dysphagia or aspiration. Some may refuse during a feed, indicating they can't take more fluid or food at that time. When unwell, infants may be more likely to refuse feeds, in part due to increased risk of aspiration. Parent and carer education about recognition of these cues and learning how to respond to them is helpful for both the parent/carer and the baby/child, and reduces the risk of continuing feeding during a period of increased risk.

Pace of feeding

Some babies and children feed more slowly due to reduced control of the swallowing muscles. Helping parents and carers understand this and adjust the pace of offering fluid/food can be very helpful and reduce aspiration risk – particularly when parents/carers are used to older siblings taking less time to feed, or due to time pressure for mealtimes. Taking more time between each spoonful to prevent overfilling of the mouth, and anticipating or being ready for the next mouthful can also be helpful. Feeding a baby/child quicker than they can safely manage increases the risk of aspiration.

Enhancing diet

Ensuring there is sufficient fluid and nutrition is essential for growth and neurodevelopment. When babies and children eat less food, and drink less fluid than usual per day, they may be at risk of malnutrition and lack the nutrients needed for growth and neurodevelopment. Dietary modification through added natural calories and protein (for example, addition of nut butters to puree), or addition of nutritional supplements may be needed. Regular weight reviews, as per the NICE faltering growth guidance (https://bit.ly/3R9EiL1), are required to monitor low weight or weight gain on supplements. Gaining information about the number of dry/wet nappies can help assess hydration. Some infants may require additional feed volumes (calories and/or fluids) through supplemental nasogastric or gastrostomy feeding.

Graded exposure to new textures

Graded exposure includes activities aimed at gradually introducing a baby/child to more challenging food textures and fluid consistencies such as:

- messy play activities involving a baby/child having opportunities to explore new or previously rejected textures
- using small steps to introduce a baby/child to lumpy food or foods that require chewing, e.g. starting with 'bite and melt' foods that dissolve in the mouth; introducing a single texture at a time

More information on page 4

Many babies and children who have physical EDSD also have sensory-based difficulties with textures. Introducing solid foods or moving on from smooth puree to textured food or mixed textures may be resisted due to sensory difficulties and physical swallow difficulties. Identifying the cause of difficulties requires specialist assessment and may need investigation. In this context, graded exposure to new textures is needed, whilst giving enough calories with preferred fluids and foods. Offering small amounts of safe to eat new foods or textures is appropriate. A key aspect of graded exposure is managing parental expectations, as changes are slow, and progress is made over many months of offering foods regularly.

Physical support

For children without sufficient motor ability to control their posture, or muscles of the mouth, physical support may be required at mealtimes to enable some food or fluid to be taken orally. Speech and language therapists can advise on how to provide this kind of support.

For example, placing a thumb underneath the chin bone to help a baby/child close their mouth can help to improve the movements needed to bite, chew and swallow. Placing the side of a finger underneath a child's chin bone can help stabilise their jaw when drinking from a cup.

Good practice points for health visitors

It is important to acknowledge that there are a number of reasons for EDSD and the support needs to be tailored to each individual baby, child and family. The key points to remember are:

- Take a full feeding history, including feeding-related medical history, and behaviours associated with feeding to enable you to fully understand the EDSD, including a review of growth and development.
- Consider the potential cause of the EDSD: physical, non-physical or a combination of both physical and non-physical difficulties.
- Offer all families:
  - Support and advice about responsive feeding, positioning, and understanding their baby's cues.
  - Support of the mental health and wellbeing of the whole family, as this can be a very stressful time, particularly if their baby has just been diagnosed or the parents/carers are anxious about their baby choking or growth.
  - Supportive conversations about the feeding environment, including equipment such as highchairs and eating together as a family.
  - Advice about and support for continuation of breast/chest feeding and its benefits for parents and babies.
  - Ensure families understand how to make up formula milk correctly and safely (https://bit.ly/3R8vcOE).
  - Advise that breast/chest milk (preferably) or first infant formula (first milk) are the only milks that most babies need before 12-months of age. However, following dietetic or medical advice, some families will be advised to continue formula milk after 12-months of age or be prescribed a specialist formula milk. If parents perceive that their baby does not tolerate a specific infant formula, advise them to seek support from their GP.
  - Offer support when introducing solid foods on graded exposure to new textures.
- If you are concerned about a baby's or child's feeding/eating/drinking, contact your local speech and language therapist to ask their advice.
- Find out your local EDSD support pathways and contact them if you have a concern to agree a plan of support.

More information on page 5

Useful links

- Unicef Baby Friendly:
  - Responsive Feeding Infosheet, Supporting close and loving relationships (https://bit.ly/3Z2xbWX)
  - Foreign language resources (https://bit.ly/3ufepOO)
- iHV: GPP Supporting children with Down's syndrome: growth, feeding and development (https://bit.ly/3rfL5po)

References

The authors point out that all content in this Good Practice Point is underpinned by the following sources. Therefore, individual citations have been deemed unnecessary.

1. The FEEDS report is open access and can be found at: https://doi.org/10.3310/hta25220
   Parr J et al. Parent-delivered interventions used at home to improve eating, drinking and swallowing in children with neurodisability: the FEEDS mixed-methods study. Health Technol Assess 2021;25(22)
2. Taylor H et al. Children with neurodisability and feeding difficulties: a UK survey of parent-delivered interventions. BMJ Paediatrics Open 2021;5:e001095. doi:10.1136/ bmjpo-2021-001095 https://bmjpaedsopen.bmj.com/content/bmjpo/5/1/e001095.full.pdf
3. Helen Taylor et al. Developing the FEEDS Toolkit of parent-delivered interventions for eating, drinking and swallowing difficulties in young children with neurodisability: Findings from a Delphi survey and stakeholder consultation workshops BMJ Paediatrics Open 2022; 6(1): e001425. https://bmjpaedsopen.bmj.com/content/6/1/e001425
4. NICE (2017) Faltering growth: recognition and management of faltering growth in children NICE guideline [NG75], available at https://www.nice.org.uk/guidance/ng75 [accessed 21/03/2023]

Acknowledgement and thanks

This Good Practice Point was developed by:

Jeremy Parr
Consultant Paediatrician

Lindsay Pennington
Honorary Consultant Speech and Language Therapist

Elisa Liu
Highly Specialist Speech and Language Therapist

Claire Pearson
Highly Specialised Paediatric Dietitian

from Newcastle University and Newcastle upon Tyne Hospitals NHS Foundation Trust, based on content from the FEEDS Toolkit.