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Eating, drinking and swallowing difficulties – raising awareness

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Many parents report that eating, drinking and mealtimes for their child can be a challenge. The WHO ICD11's definition of 'paediatric feeding disorder' is when a child has "impaired oral intake that is not age-appropriate which is associated with nutritional, medical, feeding, and/or psychosocial dysfunction". This wider definition explains the high reported prevalence of feeding difficulties 25%-40% in children with typical, and 85-99% with delayed development (RCSLT factsheet). Some of these children have dysphagia "problems with the oral and preparatory phase of swallowing (chewing and preparing the food), oral phase (moving the food or fluid posteriorly through the oral cavity) and pharyngeal phase (swallowing the food or liquid)", (Morgan et al. 2012) while some have feeding issues without dysphagia e.g., Avoidant Restrictive Food Intake Disorder. These difficulties affect a wide range of children with disabilities including autism, cerebral palsy, Down's Syndrome, neurodevelopmental disabilities, cleft palate or craniofacial conditions. Disabled children can be at risk of either over or under nutrition, and micronutrient deficiencies can co-exist alongside overnutrition. Whilst undernutrition is associated with children with disabilities who also have complex feeding difficulties such as dysphagia or enteral feeding, overnutrition is more common in those with Down's syndrome and Prader-Willi Syndrome (NHS Digital, 2019). Dysphagia and other feeding difficulties can have many consequences including physical health and quality of life of both the child and family.

Dysphagia is associated with a higher risk of malnutrition (Calis et al., 2008; Reyes et al. 2019). With dysphagia, the volume and variety of foods can be limited due to difficulties biting and chewing foods, eating & drinking taking longer, and using more energy to do so which can significantly impact quality of life. One management strategy is texture modification with specific textures recommended using the International Dysphagia Diet Standardisation Initiative (IDDSI). However, limiting the texture or volume of food that can be consumed can prevent nutritional requirements being met and negatively impact growth and development. Early dietetic and speech & language therapy input for these children is essential to ensure safe and adequate nutrition & hydration. This can include food fortification to increase the nutrient density without increasing the volume, prescribing suitable oral nutritional supplements and consideration for non-oral nutrition or hydration.

Some children's dysphagia is so severe that they require non-oral nutrition such as via percutaneous endoscopic gastrostomy (PEG). There are a wide variety of readymade commercial formulations for nutrition via PEG which must be tailored to meet the nutritional requirements of each individual. However, many children may continue to have small amounts of food and fluid orally which is important to preserve for improved quality of life. There are increasing numbers of children in the UK (& globally) who are being fed with 'blended diets', an umbrella term for a wide range of using any food or drink (except water, breastmilk, infant formula & commercial feeds) being given via an enteral feeding tube. This practice is growing in popularity with families due to reported improved feed tolerance, reduction in reflux, retching and vomiting, and improved bowel habits. There are also reported improved emotional & social elements as families can share the same meals (BDA, 2021).

Additionally, dysphagia can also hinder the ability to drink adequate fluid volumes to maintain hydration which also increases the risk of constipation. Historic practice has included recommending drinks of thicker textures that flow more slowly. However, the research evidence-base for this

practice is limited and needs to be considered alongside all other alternative management strategies, considering the potential harm of thickened drink use (RCSLT, 2023).

There is a wide range of other potential management strategies including mealtime adaptations that are often considered alongside other members of the multidisciplinary team including Physiotherapy and Occupational therapy e.g., feeding positioning, suitable utensils, pacing, foods to avoid/include including high fluid content foods such as soups/pureed fruit/yogurt (NICE, 2017). It is also important to consider alternate options for oral medications or tablet swallowing training (Tse et al., 2020), teeth brushing and oral hygiene.

Signs that a child may have dysphagia include coughing, wet/gurgly voice, wet breathing and gagging (Weir et al. 2009;2014) during a meal. However it is known that many children can have 'silent aspiration' where food or drink enters the lungs without these external signs (Arvedson et al., 1994, Jackson et al., 2016) so other signs need to also be explored including difficulty progressing through textures, refusing food/drink, a meal lasting longer than 30 minutes and the potential consequences of dysphagia e.g. chest infection, faltering growth. Awareness of dysphagia can be low, and it is under identified by carers (Robertson et al., 2018). There are some signs of change with nutrition, hydration and dysphagia being a core capability in the Core Capabilities Framework for Supporting People with a Learning Disability (2019) and an increase in the number of times dysphagia is being identified on GP health checks (14 years plus) but still more to do.

All disabled children need to maintain their health and a large part of that is nutrition and hydration. To acknowledge the value of food and drink in maintaining health and well-being in health and social care across the lifespan 'Nutrition and Hydration Week' was launched in 2012 and is held each March. A few years later Wednesday's 'Swallowing Awareness Day' was included and then 'Thirsty Thursday' in 2021, focussing on hydration. Many dietetic and speech and language therapy departments actively promoted Nutrition and Hydration week from 13-19th March 2023, with Swallow Awareness Day on 15th March. Maybe your team might run an activity for Nutrition and Hydration week and/or Swallowing Awareness Day next year?

To learn more about nutrition, hydration and/or dysphagia or signpost families to information you might like to access these resources:

British Dietetic Association (2021) The Use of Blended Diet with Enteral Feeding Tubes. Practice Toolkit.

<https://www.bda.uk.com/uploads/assets/33331d33-21d4-47a5-bbb79142980766a7/FINAL-Practice-Toolkit-The-Use-of-Blended-Diet-with-Enteral-Feeding-Tubes-NOV-2021.pdf>

Caroline Walker Trust (2007) - Eating well for children & adults with learning disabilities – Nutritional and practical guidelines

<https://www.cwt.org.uk/wp-content/uploads/2015/02/EWLDGuidelines.pdf>

Core Capabilities Framework for Supporting People with a Learning Disability (2019):

<https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Learning-Disability-Framework-Oct-2019.pdf>

Dysphagia: Swallowing Difficulties and Medicines e-learning course:

<https://www.futurelearn.com/courses/dysphagia>

International Dysphagia Diet Standardisation Initiative (IDDSI):

<https://iddsi.org/>

RCSLT paediatric dysphagia factsheet:

<https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/rcslt-infant-dysphagia-factsheet.pdf>

RCSLT statement on thickened fluids (2023):

<https://www.rcslt.org/news/our-statement-on-thickened-fluids/>

Mini Mouthcare Matters:

<http://mouthcarematters.hee.nhs.uk/about-the-programme/children/>

Nutrition & Hydration week website:

<https://nutritionandhydrationweek.co.uk/>

Swallowing Awareness Day:

<https://www.rcslt.org/events/swallowing-awareness-day-2023/>

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