Nutritional management of children with **neurodisabilities**



Children with neurodisabilities have complex nutritional needs. Difficulties in swallowing (dysphagia) are common, and calorie and nutrient requirements vary according to the child's anthropometrics, mobility level and individual needs.

Recent research has provided tools for assessing dysphagia, managing risk and improving the treatment of paediatric patients.

Introduction to nutritional issues and needs in children with neurodisabilities



Chairman - Dr Guy Letellier Paediatrician & PMR Specialist, Paediatric Rehabilitation Hospital ESEAN-APF, Nantes, France

Children with generalised severe motor impairment often experience swallowing problems and dysphagia. Common causes of dysphagia include traumatic brain injury, neurological disorders, cerebral palsy, prematurity, tracheotomy or ventilator dependence, craniofacial abnormalities and failure to thrive.¹

It has been established that higher gross motor function classification system (GMFCS) is associated with reduced growth in children, with growth velocity of around 7.5cm per year for GMFCS I-III and around 6cm per year for GMFCS IV-V).²

Red flags that indicate feeding and swallowing problems

There are four questions that parents should be asked to help indicate whether further assessment is required:

Questions	Red flag
How long does it take to feed your child?	Feeding regularly takes more than 30 minutes
Are mealtimes stressful to child or parent?	Stressful for one or both
Is your child gaining weight adequately?	Weight loss or lack of weight gain for 2-3 months
Are there signs of respiratory problems?	Increased congestion at mealtimes, gurgly voice, respiratory illnesses

Source: Joan C Arvedson, EJCN 2013

A screening tool to help assess feeding and swallowing difficulties in children with cerebral palsy has been developed. The Feeding and Nutrition Screening Tool (FNST) provides a scoring system, with a score of ≥3 indicating the need for a referral for further assessment.³

The Pediatric Eating Assessment Tool (Pedi-EAT) provides another tool to assess eating behaviours holistically, such as drooling or insisting on being fed by the same person.⁴

What are the needs of children with dysphagia?

A study of preschool children with cerebral palsy found that 39% required food/fluid modifications. There was reduced energy intake due to poor gross motor function, and around half the children had issues with swallowing and safety.⁵

Children with dysphagia often need support with nutritional status to support muscular strength and psychomotor development. Patients with low mobility or those in wheelchairs may have reduced metabolism, which can be evaluated through assessment of muscle activity, hypertonia, dystonia and abnormal movements.

Nutritional intake can be adjusted to help children maintain stature-ponderal growth. This might involve increased protein intake or reduced calorie intake.

The percentage of children who need nutritional support varies with GMFCS status. Around 2% of those with GCMFS I need support, compared to 42% of those in GMFCS III and 90% of those in GMFCS V.⁶ More than 40% of those in GMFCS IV and V require tube feeding.⁷

Study of children with neurodisabilities

A retrospective study looked at swallowing problems in 200 paediatric patients with neurodisabilities. The mean age was 3.6 years. Children were referred for respiratory problems (55%), feeding problems (44%) and weight retardation (8%).

Intra-tracheal aspiration was demonstrated in 32% of patients during the study. Half (50%) of children undergoing swallowing assessments have severe neurological disorders, and 100% of children with severe neurodisabilities have swallowing issues.⁸

Early detection of swallowing problems is key for improved disabled child management and outcome. Children with neurodisabilities should always be assessed for dysphagia. ESPGHAN recommends early detection of issues, assistance with installation and positioning, nutritional support and careful selection of food texture. Regular monitoring of anthropometrics and nutrition should help to identify any problems.⁹

Importance of early detection of swallowing problems – introduction to new PEDI-EAT-10 tool



Dr Selen Serel Arslan Hacettepe University Faculty of Physical Therapy and Rehabilitation, Ankara, Turkey

Swallowing functions as a pressure system to transport food and drink from the mouth to the stomach and prevent reflux into the oesophagus. Dysphagia can impact any stage of this swallowing process (oral, initiation, pharyngeal, oesophageal phases).

Dysphagia in children with neurological conditions

More than 90% of children with neurological impairment (NI) have dysphagia. In a study of 166 children with NI where the prevalence of dysphagia was 99%, the condition was mild for 8%, moderate to severe for 76% and profound for 15%.¹¹

Dysphagia can lead to related complications including undernutrition, dehydration, recurrent pneumonia, weakened immune system, prolonged and frequent hospitalisation, increased risk of morbidity and mortality and decreased quality of life for children and their parents.

Dysphagia Management

This should be performed as a clinical decision-making process. An initial evaluation (Figure 1) should be followed by detection of disorders, determination of feeding type and appropriate food textures. After this, an appropriate rehabilitation programme can be produced, along with consultation and follow ups.



The Paediatric Version of the Eating Assessment Tool (PEDI-EAT-10)

Although other non-instrumental assessments have been developed to evaluate swallowing and feeding function in children, these did not identify paediatric

patients at high risk of penetration and aspiration.¹² This is why a paediatric version of the EAT-10 screening tool has been developed. PEDI-EAT-10 was produced and tested in a study with two phases: phase 1 looked at item generation, content validity and normative data generation. Phase 2 reviewed data reliability and validity.

Validated items from EAT-10 were adapted for PEDI-EAT-10, informed by a comprehensive paediatric dysphagia literature review and expert opinion. This content was validated by seven experts. Normative data was generated by 51 healthy children.

In Phase 2, a reliability and validity study looked at 138 children with spastic cerebral palsy. Swallowing was evaluated using a Videofluoroscopic Swallow Study (VFSS) and the Penetration-Aspiration Scale (PAS) was used to assess penetration/aspiration severity.

PEDI-EAT-10 uses the same structure as EAT-10, with the ten questions. The content validity index was 0.91. PEDI-EAT-10 was found to be a consistent scale for determining risk of penetration/aspiration in children and had sufficient criterion validity.

Detecting aspiration in NI children

One of the key goals of PEDI-EAT-10 was to predict risk of aspiration in children. The scores range from 0 to 40, with a result above 4 indicating abnormality. A value above 13 correctly identified 77% of children with airway aspiration, while children with a value over 12 were 1.97 times more likely to aspirate.¹³

PEDI-EAT-10 has been translated into Arabic and Spanish, investigating validity and reliability. Further validation studies are ongoing. In collaboration with Nestlé Health Science a digital version of the tool was developed, accessible online by health care professionals and caregivers it helps ease the assessment of potential child swallowing difficulties.



Tolerance and effectiveness of new paediatric thickener



Paediatric Speech and Language Therapist, Chelsea and Westminster Hospital, London, UK

Analou Sugar

Management of paediatric dysphagia starts with a child feeding assessment, looking at oral and motor skills, mealtime observation, a medical history and input from other medical professionals. Research has indicated that this assessment is not always carried out using standardised assessment tools.

The new PEDI-EAT-10 has the potential to improve standardisation of assessment, as well as ensuring parental involvement in these assessments. PEDI-EAT-10 can also be used as a tool for identifying the right treatment. Instrumental assessment can be used alongside PEDI-EAT-10, for example to rule out silent aspiration.

Paediatric dysphagia management techniques: food consistency

Management of paediatric dysphagia may be direct, indirect or a combined approach. Issues such as feeding technique and utensils, positioning and consistency may be considered. Oral sensory-motor exercises may be recommended, behavioural training, training for caregivers, and environmental modifications.

In relation to food consistency, the **IDDSI Food and Drinks Classification and Testing tool** is used to describe the consistency of food on a scale of 0-7, where liquids are measured from 0-4 and foods measured from 3-7. This helps to ensure continuity of practice between healthcare professionals, parents and caregivers, to ensure safety of practice, and supports research.

Thickeners can be used to increase fluid consistency, supporting bolus transfer in the oral and pharyngeal stages of swallowing. The effectiveness of thickeners has been demonstrated to assist in the reduction of respiratory symptoms and liquid intake, with high levels of parental satisfaction.¹⁴

References:

- Lefton-Greif MA. Pediatric dysphagia. Phys Med Rehabil Clin N Am. 2008 Nov;19(4):837-51, ix.
- Oftedal S, Davies PS, Boyd RN, Stevenson RD, Ware RS, Keawutan P, Benfer KA, Bell KL. Longitudinal Growth, Diet, and Physical Activity in Young Children With Cerebral Palsy. Pediatrics. 2016 Oct;138(4):e20161321.
- Bell KL, Benfer KA, Ware RS, Patrao TA, Garvey JJ, Arvedson JC, Boyd RN, Davies PSW, Weir KA. Development and validation of a screening tool for feeding/swallowing difficulties and undernutrition in children with cerebral palsy. Dev Med Child Neurol. 2019 Oct;61(10):1175-1181.
- Thoyre SM, Pados BF, Park J, Estrem H, Hodges EA, McComish C, Van Riper M, Murdoch K. Development and content validation of the Pediatric Eating Assessment Tool (Pedi-EAT). Am J Speech Lang Pathol. 2014 Feb;23(1):46-59.
- Benfer KA, Weir KA, Bell KL, Ware RS, Davies PS, Boyd RN. Food and fluid texture consumption in a population-based cohort of preschool children with cerebral palsy: relationship to dietary intake. Dev Med Child Neurol. 2015 Nov;57(11):1056-63.
- Brooks J, Day S, Shavelle R, Strauss D. Low weight, morbidity, and mortality in children with cerebral palsy: new clinical growth charts. Pediatrics. 2011 Aug;128(2):e299-307.

Thicken Up Junior UK Trial

A prospective UK study evaluated the acceptability (GI tolerance and compliance) of a new thickener, Thicken Up Junior, Nestlé Health Science, suitable from age six months, in children with reflux, gastro-oesophageal reflux disease (GORD) and dysphagia. The product contains 10:1 locus bean gum and xanthan gum.

The age of study participants ranged from 9.5 months to 9 years, with various conditions. Children were already on a thickener or required a thickener for management of GORD and/or dysphagia. 15 patients met inclusion criteria, completing a 30-day diary recording volume of liquids consumed and details of tolerance, symptoms and stools.

Education of parents and caregivers is important to improve compliance. Parents were given information on how to use Thicken Up Junior specific to the required level of fluid consistency identified as safe for the child concerned. Parents were advised to use an online resource **preparation guide**

Trial results

The outcome of the trial was positive, with improved intake of thickened liquids and increased hydration. Some transient and anecdotal GI symptoms were reported. The study indicated that the the new thickener was well tolerated and helped, resulting in reduced incidence of coughing and vomiting when drinking.

Use of thickeners could potentially have a beneficial impact on the health care system by improving patient experience, enhancing safety and reducing costs (manuscript in preparation).

- Dahlseng MO, Finbråten AK, Júlíusson PB, Skranes J, Andersen G, Vik T. Feeding problems, growth and nutritional status in children with cerebral palsy. Acta Paediatr. 2012 Jan;101(1):92-8.
- 8. Letellier et al. Predictors for abnormal videofluoroscopic swallowing function study in children with dysphagia and clinical impact. Unpublished.
- 9. ESPGHAN. Recommendations for Nutritional Management of Children with Neurological Impairment. https://www.espghan.org
- Romano et al. European Society for Paediatric Gastroloenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment. J Pediatr Gastroenterol Nutr. 2017 Aug;65(2):242-264.
- 11. Dodrill P, Gosa MM. Pediatric Dysphagia: Physiology, Assessment, and Management. Ann Nutr Metab. 2015;66 Suppl 5:24-31.
- 12. Arslan S et al. The Pediatric Version of the Eating Assessment Tool (PEDI-EAT-10)
- Arslan S et al. The Pediatric Version of the Eating Assessment Tool-10 has discriminant ability to detect aspiration in children with neurological impairments.
- Duncan D et al. Clinical Aspects of Thickeners for Pediatric Gasgtroesophageal Refluc and Oropharyngeal Dysphagia. Current Gastroenterology Reports 21;30 2019