



NORTHERN IRELAND  
CEREBRAL PALSY REGISTER



# Merry Christmas from the NICPR!

Welcome to the fourth newsletter from the Northern Ireland Cerebral Palsy Register (NICPR). We would like to thank Teresa Noble (Lead SLT for Physical Disability Schools, Belfast HSCT) for preparing this short newsletter on eating, drinking and swallowing (EDS) difficulties in cerebral palsy (CP).

## Presentation of EDS difficulties

EDS difficulties may present in children, young people and adults with CP due to the impact of the condition on the sensation and movement of muscles involved in the process of eating and drinking. In addition, abnormal postural tone associated with CP can impact on a person's ability to eat and drink safely. EDS difficulties can present in a variety of ways such as:

- Difficulty managing a range of food textures in the mouth due to restricted speed, range and accuracy of oral motor movement affecting the ability to move the lips, jaw, tongue and palate.
- Uncoordinated and/or disorganised swallow which can result in

- aspiration of food and liquids into the lungs.
- Dysmotility that can affect the muscles of the pharynx, oesophagus, stomach and intestine. This can result in reflux, slow gastric emptying, constipation and aspiration.
  - Difficulty achieving a stable position to be able to eat and drink safely.

# Classification of eating and drinking ability

The [Eating and Drinking Ability Classification System \(EDACS\)](#) can be used to categorise level of ability to eat and drink safely and efficiently in children aged three years and over with CP ([Sellers et al 2013](#), see EDACS levels below). The research team that produced EDACS is currently working on developing a mini-EDACS for children aged 18 to 36 months.

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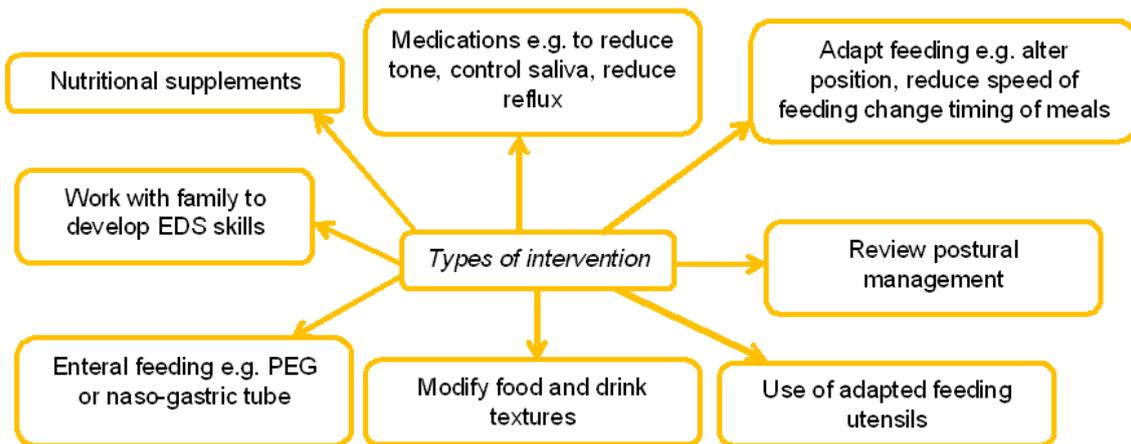
## GENERAL HEADINGS

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- Level I** Eats and drinks safely and efficiently.
  - Level II** Eats and drinks safely but with some limitations to efficiency.
  - Level III** Eats and drinks with some limitations to safety; there may be limitations to efficiency.
  - Level IV** Eats and drinks with significant limitations to safety.
  - Level V** Unable to eat or drink safely – tube feeding may be considered to provide nutrition.
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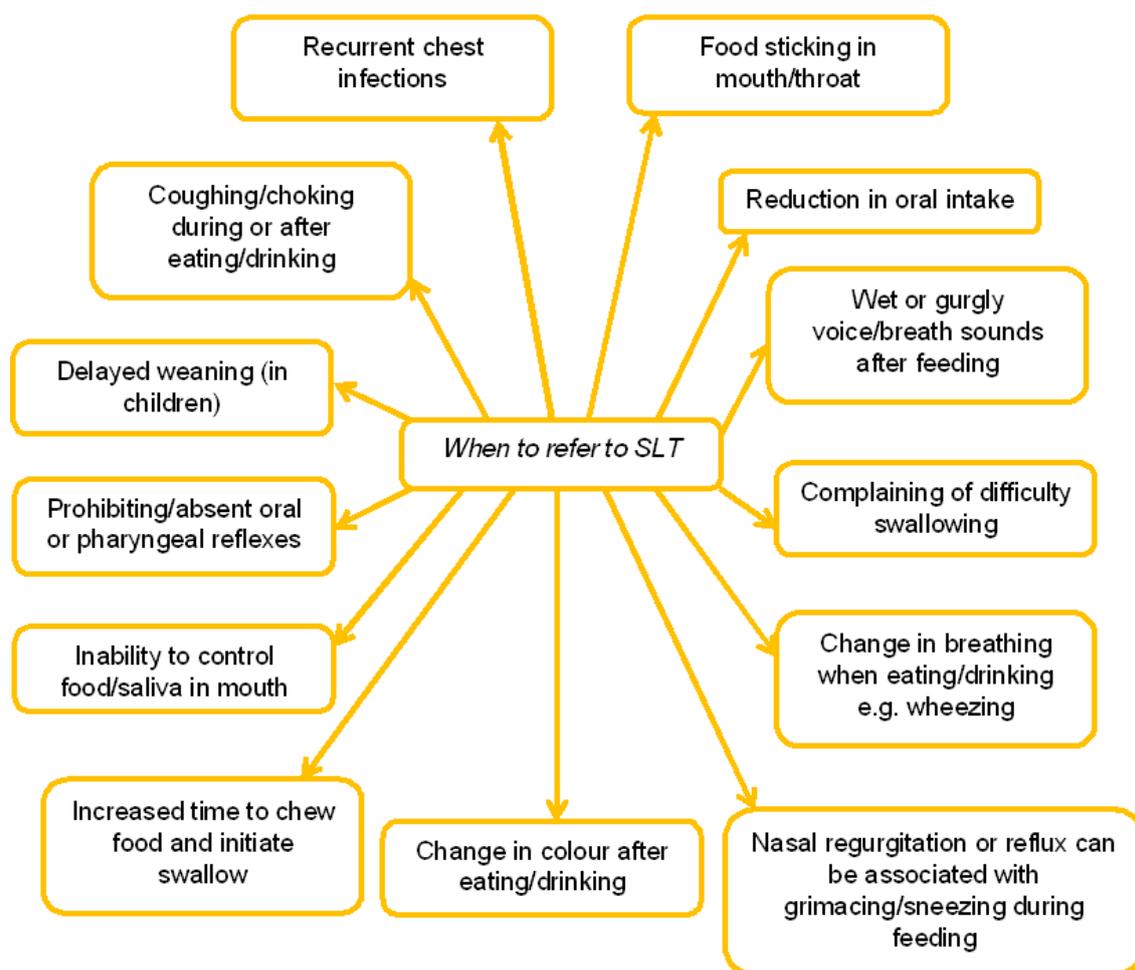
# Management of EDS difficulties

Management of EDS difficulties requires a multi-disciplinary approach due to the complexity of the issues involved. EDS difficulties can have a significant impact on a child's physical health and emotional well-being and can result in significant stress for a family. Types of EDS interventions are detailed in the diagram below.



## Indicators of aspiration

A referral to a SLT for assessment should be considered if you have concerns about the person's EDS skills and they present with any of the indicators in the diagram below.



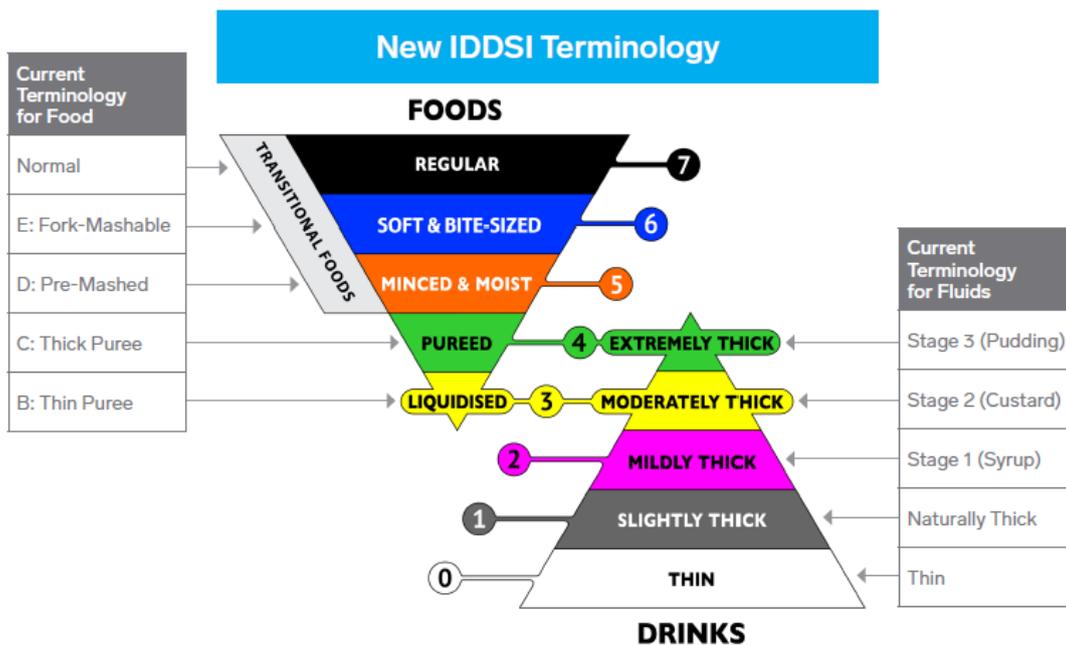
## Change in terminology

The way in which dysphagia diets are categorised is changing from subjective descriptors (e.g. fork mashable diet) to a more standardised method. It is important that healthcare professionals, families/carers and all staff working with patients with swallowing difficulties are aware of the change and what this means to people with dysphagia.

The [International Dysphagia Diet Standardisation Initiative \(IDDSI\)](#) framework

is currently being rolled out across the UK. This process is due to be completed by April 2019\*. This framework consists of a continuum of eight levels (0-7) and includes descriptors, testing methods and evidence for both drink thickness and food texture levels (see diagram below). It is hoped that the use of IDDSI will improve patient safety by ensuring that patients receive the correct fluid and food consistencies. It has been agreed at a national level to map the current national descriptors across to the new IDDSI descriptors.

\*Please note that during this transition period some manufacturers and HSC Trusts have already changed to IDDSI and this cross over will mean that different information, labelling and scoop sizes may be given to patients. This applies to thickening products, pre-thickened drinks and modified textured food.



29/08/18

# Thank you!

We would like to take this opportunity to wish you all a very Merry Christmas and a Happy New Year. Thank you for your support during 2018!



# We welcome your comments

Feedback and suggestions for further content are welcome at [nicpr@qub.ac.uk](mailto:nicpr@qub.ac.uk) at any time - we look forward to hearing from you! You can sign up to this Newsletter [here](#).