Welcome to this special neurodisability edition of SmallTalk. We are delighted to be able to focus on this important area of paediatrics, and bring you a number of specialist articles introduced by an editorial from Dr Peter Sullivan on page 2. Detailed contents can be seen in the box opposite. We also report on our recent Neurodisability symposium held in London, and provide a focused CPD section on page 14.

Look out for details of the forthcoming Southampton Nutrition Study day and another neurodisability symposia in the autumn.

We hope you enjoy this edition, as ever if you have any comments, feedback or would like to contribute to a future edition, please do get in touch.

With best wishes...

Joanna

Joanna Hovey, Senior Medical Affairs Advisor, Nutricia Medical

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It is increasingly recognised by health care professionals in most of Europe and the US that children with cerebral palsy (CP) can have significant feeding and nutritional problems which lead to a number of adverse health consequences. This was not always the case: early textbooks on cerebral palsy made no mention whatsoever of these problems and it is only in the last couple of decades that research has thrown light on this issue. Moreover, in many developing countries and including parts of Eastern Europe, these problems remain unrecognised and untreated. We now know that the nutritional consequences or poor feeding due to oral-motor impairment in children with CP are remediable. Improvement in nutritional status in such children has been shown to be associated with improvement in general health, less usage of health care facilities, greater attendance at school and better societal participation for the family together with tangible improvements in growth, motor skills, neurodevelopmental status, bone health and survival.

This issue of SmallTalk focusses on neurodisability to provide an update on the latest research and changes in clinical practice in the management of children with CP who have feeding difficulties. It reports the proceedings of a neurodisability symposium on the topic of nutritional management held in April at the Royal College of Physicians; this provided an overview from Nikhil Thapar of the gastrointestinal problems encountered in children with CP, advice on nutritional management by Kanar Ahmed and preliminary research on the development of a screening tool (expanded in an accompanying article by Sarah Bushell in this edition).

Whether or not a sensitive, valid and reliable screening tool can be created remains to be seen but equally, if not more important, is knowing how to assess the nutritional state of a child with CP. Researchers have provided a range of tools for the assessment of nutritional status. We have learned that the standard growth charts and dietary requirements of typically developing children do not apply to those with CP. For years we have relied on the usual tools in paediatrics of weight-for-age and height-for-age but when used alone these are less helpful in children with severe motor impairment (Gross Motor Function Classification Scale IV and V) and in those with skeletal deformity and contractures in whom it can be impossible to get a measure of height. We know, therefore, that standard anthropometry may provide inappropriate measures of nutritional status in CP and that measurement of body composition is a more appropriate guide to nutritional management. Increasingly, clinicians are turning to the concept of ‘Energy Balance’ and assessment of this made by measurements of body composition. Body fat mass is a measure of energy balance; too little fat suggests a negative energy balance and too much indicates that energy input exceeds energy output and is leading to energy storage as fat. This is proving to be useful in children with CP because the most severely affected have limited energy expenditure through physical activity and thus have different energy intake requirements than typically developing children.
The tools used to assess body composition range from stable isotope techniques (D2O dilution) to dual-energy X-ray absorptiometry (DXA) and bioelectrical impedance analysis (BIA). These tools have been developed predominantly in research settings and have obvious limitations for routine clinical application. This has led to a search for reliable clinical estimates of body composition derived from measurements of skin fold thicknesses. Despite the relative ease of measurement of skin fold thicknesses, this technique has yet to be established as a part of routine clinical practice. Recent research has found that percentage body fat derived from skinfolds using a CP-specific equation is not significantly different from that measured by DXA.2. The important fact emerging from all these studies is that measurement of body composition must become a routine component of the nutritional management of children with CP.

What matters to the clinician is to find an answer to the question ‘Is this child in energy balance?’ If the child is in positive energy balance then they will lay down fat and one can pragmatically assume that the nutritional intake is sufficient to meet the metabolic, activity, and growth needs of the child. Recognition that this is so can avert the need for gastrostomy tube feeding in a child referred just because they are below the 0.4th centile of a standard growth chart. Conversely, recognition of low fat stores and negative energy balance can prompt the need for more effective nutritional intervention (including the possibility of gastrostomy) in a child who may not appear ‘from the end of the bed’ to be malnourished.

Growth restriction increases progressively with age and thus mandates early nutritional intervention. In children with severe CP such nutritional intervention is increasingly being administered by gastrostomy feeding tube but controversy surrounds the evidence-base for this approach3.

Moreover, mothers’ decisions about gastrostomy feeding are complex and difficult and must be taken into account in making therapeutic recommendations. This is made abundantly clear in Gill Craig’s contribution to this issue of SmallTalk.

Finally, in their contribution Hayley Kuter and Siobhan Jeffrey emphasise the crucial role of the multi-disciplinary feeding team in the nutritional management of children with neurodisability. They also underline the important need to always involve the family in a collaborative approach to nutritional and feeding management.

References:

Diary Dates

7th European Paediatric GI Motility Meeting
1st-3rd October 2015
Sorrento, Italy
Info: http://www.naspghan.org/content/3/en/Meetings

Southampton Children’s Hospital Nutrition Study Day
Journey of the cardiac baby - How do we improve growth in a regional setting?
13th November 2015
Southampton
email: southamptonstudy@gmail.com

International Conference on Cerebral Palsy and other Childhood-onset Disabilities.
Joint meeting of: 5th International Conference of Cerebral Palsy (ICPC), 28th Annual Meeting of the European Academy of Childhood Disability (EACD)
1st - 4th June 2016
Stockholm, Sweden.
Info: www.eacd2016.org

Look out for our next Nutricia neurodisability evening symposium
October 6th 2015
Birmingham Botanical Gardens
See advert on page 11 for more details.

CONTACT POINT

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SmallTalk, Nutricia Resource Centre, White Horse Business Park, Trowbridge, Wilts BA14 0XQ
Deadline for the next edition is 24th September 2015
The psychosocial support needs of parents of children with neurodisability and feeding difficulties

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Children with neurodisability experience high rates of feeding difficulties with implications for their nutrition, growth and overall health. Dysphagia, although often under-recognized in this population of children is common, with a reported prevalence ranging from 43% in children with cerebral palsy (CP) of any degree, to 99% in children with severe CP and intellectual disability. Estimates of frequency of oral aspiration range from 31 to 97%. Difficulties with chewing and swallowing food, excessive drooling, choking, vomiting and gastro-oesophageal reflux are also common in this group of children, impacting on their ability to achieve an adequate nutritional intake by mouth.

Not surprisingly mealtimes can be prolonged, and experienced as stressful as children become tense and rigid and refuse to eat in some cases. Mothers often draw on war metaphors to describe the “battle” of feeding and may spend in excess of three hours a day feeding a reluctant child. The demands of caring for children can result in significant maternal stress. A gastrostomy feeding tube may be recommended but this can be met with parental opposition, creating an ethical dilemma for both parents and Health Care Professionals (HCPs) on the feeding management of children.

Research suggests that a gastrostomy tube represents much more than an alternative way of feeding and that HCPs need to understand the symbolic meanings parents, particularly mothers, attach to feeding and its association with the mothering role and maternal identity. Additionally, a gastrostomy may be experienced as another “bad news” diagnosis; a further indicator of a child’s disability, and an unnatural way of feeding. The suggestion of a gastrostomy may challenge maternal competency as women blame themselves for their child’s poor growth or inability to feed. Moreover, blame may be reinforced through interactions with clinical services; for example, the language used to describe children: “failure to thrive” and “malnourished” may also (inadvertently) signify blame and maternal failure.

Whereas HCPs may emphasise the benefits of tube feeding in terms of weight-gain, parents often have additional concerns such as how they will manage tube feeding in the context of their everyday lives, including mealtimes, holidays, swimming and other activities. Many mothers also value oral feeding which they designate as a ‘special’ time for physical contact and intimacy and something they fear they will lose if they opt for a feeding tube. Parents report few opportunities within care pathways to explore the emotional aspects of feeding a child by tube, given appointments are often dominated by clinical tests and investigations; the value of which parents may question. Support to reinstate oral feeding post-gastrostomy may not be available and some HCPs may recommend a nil-by-mouth regimen although not all agree with this advice.

The conflict involved in making the decision to feed a child by tube was highlighted in a systematic review of 11 qualitative research studies. Using data from these studies Mahant and colleagues developed a model of decision conflict. Concepts that contributed to conflict were categorised according to three themes: child and family variables (context); the attitudes and belief systems parents hold about feeding (values) and parental interactions with health care systems (care processes). This model could provide a framework for HCPs to support parents particularly as the psychosocial support needs of families have been given increasing visibility in evidence reviews which have recommended that clinical care should address the needs of parents and ameliorate stress. The challenge for services will be how to embed structured support within care pathways, both before and after gastrostomy, to achieve better health outcomes for children and their caregivers.
For further information and to obtain copies of these tube feeding brochures, please contact your local paediatric representative.
The idea behind producing a nutritional screening tool for children with neurodisabilities started back in 2002. Moving to a new department, one of my responsibilities was to look after the nutritional wellbeing of a group of children with neurodisabilities attending a special needs school. However when I arrived, I discovered that the children’s disabilities were very severe, they all had nutritional concerns of one form or another, there were 105 of them and I had 6 hours a week in order to manage the caseload. At the same time, I started to get phone calls from other dietitians throughout the UK asking me for advice on their children, the school had a reputation at being first class for its therapy services and by association I was being considered an “expert”. Fortunately, a very small network of dietitians, from all across the south of England became my peer support, and we would meet regularly to discuss common themes. This group was the original ‘DISC’ (Dietitians Interested in Special Children) group and we all had the same concerns, one of which was that children were only being referred to us once malnutrition became obvious. It was in one of these meetings, that the idea of the Nutrition Screening Tool was born.

Children with neurodisability are at nutritional risk when their disability affects their eating and drinking skills. This includes:

- **Self feeding skills** – when children cannot adequately coordinate hand to mouth movement.
- **Oral motor skills** – including defective swallow, inadequate lip closure or persistent tongue thrust, which means the child has difficulty dealing with the food once it is in the mouth.
- **Sensory impairment** can also lead to problems, for example a child with visual impairment cannot ascertain the type or amount of food that’s being offered.
- **When mobility is impaired** the child cannot help themselves to food like others might do.
- **Communication difficulties** will also have an impact as the child may not be able to tell us when they are hungry.
- **Developmental delay or learning difficulties** play a role, when the learning stage for feeding skills is delayed or missed.
- **Poor muscle function** within the GI tract means it is not uncommon for these children to suffer with constipation, diarrhoea or gastro-oesophageal reflux, all of which make eating uncomfortable.
- **Uncoordinated motor function** commonly causes a poor seating posture and an unstable trunk, which can make it difficult and uncomfortable to eat.

Often children with neurodisability have a combination of several of these problems which is why it is entirely plausible for them to be at nutritional risk. It is widely documented that the prevalence of growth defects and malnutrition is high in children with neurodisability. Figures range from 13-52%1-3 and research suggests the more severe the disability the more nutritional problems a child might have4. Therefore it comes as no surprise that children with neurodisability are the largest group requiring home enteral tube feeding5. However it was felt that with nutrition screening and appropriate referral for dietetic intervention, malnutrition could perhaps be prevented or managed at an earlier stage.

At the beginning of this project my research question was...

“Is it possible to create an instrument that will accurately identify school aged children with neurodisabilities, for referral to dietetic services?”

Nutrition screening is commonly used in adults in both hospital and community settings across the UK. In 1999 the Professional Development Committee of the British Dietetic Association (BDA) released a briefing paper on Nutrition Screening Tools. They defined nutrition screening to be a simple and rapid process of identifying the clinical characteristics known to be associated with malnutrition6. Further guidance from the BDA was issued in 20097. 
A literature review revealed that there were 44 published nutrition screening tools. However, none of these showed adequate statistical validation to demonstrate reliability in their intended populations.

It was therefore vital to ensure that this new tool was correctly tested and validated to guarantee its reliability, so that it could be reproduced in any special needs school or centre across the UK. The tool needed to be a short questionnaire with multiple choice answers. Each answer needed a numeric score, weighted in terms of importance so when totalled showed:

**HIGH SCORE**
- high risk of malnutrition and immediate referral to the dietitian,

**MODERATE SCORE**
- the patient should be monitored

**LOW SCORE**
- low risk of malnutrition and thus no need to refer.

The nutrition screening tool content was formed by group discussion with the original DISC members, with reference back to the literature wherever possible but consideration was also given to clinical judgement. The content of the tool was based around the following known risk factors: growth pattern, including weight and height, food intake, fluid intake, bowel habits, oral motor ability and activity levels.

The tool was then taken to a group of dietitians working with children with neurodisabilities, to be tested for face validity by a group of 5 dietitians working with children with neurodisabilities, to be tested for content validity via a nominal group process. The tool was then taken to a group of dietitians working with children with neurodisabilities, to be tested for face validity by a group of 5 dietitians working with children with neurodisabilities, to be tested for content validity via a nominal group process. Afterward the tool was tested for face validity by a group of 5 school nurses who were trained to be the intended tool users. This was to glean subjective opinion on the tools clarity and ease of use.

The next stage was to test the tools psychometric properties, i.e. its validity and reliability by piloting it on a small group of children. It was also an opportunity to determine its practicality and usability and to produce useful training materials for the tool users to aid accuracy of completion.

Forty six of the 105 children attending the special needs school I worked at gave informed consent. A volunteer from the voluntary services department of my NHS Trust randomly selected a subset of 22 to enter the pilot study. The volunteer matched the children to the nurses to ensure concealment and avoid bias. Each child would be ‘screened’ by three different nurses, to determine inter reliability – i.e. are all nurses using the tool in the same way? At the same time a dietetic assessment was carried out on each of the 22 children to determine their true nutritional status, and the dietitian also completed a nutrition screening tool. The data was analysed for reliability (between nurses) and validity, i.e. was the nurse using the tool in the same way as the dietitian. Although numbers were small, a sensitivity and specificity calculation was also made.

The results showed us that the sample selected was reflective of the population for whom the nutrition screening tool had been designed. The children’s ages ranged from 5 years and 8 months to 18 years and 9 months suggesting that the sample was an adequate representation of special needs school children. All but one had an ethnic background of white British, the exception being one male child who’s parents classified him as ‘Black – other’. There were 9 female and 13 male children.

Levels of agreement between individual nurses were assessed by cross tabulation of the answers to each question. This showed that the nurses were using the tool in the same way the majority of the time, and therefore the tool had good inter-rater reliability.

Validly was determined by comparing the nurses’ answers with the dietitians. A kappa coefficient score was calculated for each of the questions as Kappa determines measures of agreement but also accounts for chance alone. Kappa scores indicating substantial or almost perfect agreement highlighted the questions which the nurse could report with confidence when compared to the dietitian. It was these questions that would therefore be more useful for inclusion in the screening tool.

Sensitivity and specificity are valid statistical tests to measure how well questionnaires are designed. For the tool to be clinically useful and comparable to the dietitian, the nutrition screening tool needs to demonstrate good sensitivity and specificity.

However, the sensitivity of the tool was poor at just 37% which means that only 37% of malnourished children were being correctly identified.

Specificity however showed perfect agreement which meant that no well nourished children would be inappropriately referred. Although sensitivity and specificity have been calculated in this pilot study it must be acknowledged that the sample size of just 22 children is very small and so this statistic should be interpreted with caution.

The pilot study has shown significant findings necessary to refine the nutrition screening tool into a second version which now needs to be tested on a large cohort of 250-350 children. Ethics approval for multicentre data collecting has been granted and I am now recruiting interested dietitians who would like to collaborate.
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The study day aims to:
• Consider the prevalence of malnutrition amongst a regional cohort - and why growth is affected
• Look at the challenges around achieving growth
• Consider practical aspects around feeding/ feeding difficulties
• Understand what tools are available/could be developed to improve regional management of children with CHD

TO REGISTER Please email: southamptonstudy@gmail.com with your name, job title, full address and any food allergies.
Please note: places are limited.
On the 29th April, Nutricia was delighted to host an evening symposium dedicated to Neurodisability in Children, held at the Royal College of Physicians, London. 139 delegates, comprising paediatric dietitians, speech and language therapists and paediatricians attended the event.

The objective of the symposium was to provide an update on the current status of understanding in the field. The topics chosen were designed to provide healthcare professionals with a simple, practical and as far as possible evidence-based approach to the nutritional management of these children, with a comprehensive background to the diagnosis, along with practical and psychosocial aspects of management.

Dr Nikhil Thapar chaired and provided the introduction to the evening, expertly setting the scene with a comprehensive background to the many factors that interplay in the nature of neurological disorders. He described the variation in severity and complexity of neurodisability, often involving several different physiological systems. He went on to explain the shared embryonic development of both central and enteric nervous system cells and showed the similar complexity of both systems. He explained the multifactorial nature of brain gut interactions – demonstrating why disorders of the central nervous system (CNS) have such a profound impact on gut motility and sensation,
both of which are essential to gut function. He ended by touching on the clinical symptoms that cause the high incidence of feeding and gastrointestinal (GI) problems which are often non-remitting, but which may still be overlooked.

Sarah Bushell then presented an overview of her work to date on designing and validating a nutrition screening tool for school-age children with neurodisability. She explained the background to her research and showed her results from the pilot study – for full details please see Sarah’s review article on page 6.

Dr Thakar then returned to the podium for his lecture on feeding and GI problems in children with neurodisability. Following on from his introductory session, he took delegates on a journey through the GI tract, describing in detail the changes in physiology in each area of the gut that cause the issues and problems that these children can face (table 1), along with practical considerations and management strategies. The mechanism of gastro-oesophageal reflux was shown using pH and impedance studies and Dr Thakar clarified that the most common cause for this is transient lower-oesophageal sphincter (LOS) relaxation, and not a weak LOS as is often assumed. Management strategies for gastro-oesophageal reflux (GOR) were discussed, including the indications for fundoplication which need to be carefully assessed. In the latter part of the GI tract, the varying causes for constipation were clarified along with appropriate use of laxative and other management options.

Dr Thakar explained how the issues in one area of the GI tract can impact on another, for example how slow transit constipation may contribute to delayed gastric emptying and impact on satiety through the colo-gastric reflex, highlighting that it may be necessary to treat one area of the gut to manage symptoms in another. He finished by touching on the increasing awareness of GI disorders in autism, and finally stressed the importance of multi-disciplinary nutritional management as a tool not only to improve nutritional status but also to allow functional and developmental improvements in these children.

Continued on Page 11

Table 1: Overview
Causes and consequences of feeding difficulties in children with neurodisability.

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<thead>
<tr>
<th>POTENTIAL ISSUES</th>
<th>OUTCOME</th>
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<td><strong>FOREGUT:</strong></td>
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<td>Oropharyngeal</td>
<td>Poor lip seal</td>
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<td>Poor suck-swallow co-ordination</td>
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<td>Chewing/dental problems</td>
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<td>Tongue manipulation</td>
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<td>Bolus formation</td>
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<td>Uncoordinated swallowing</td>
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<td>Spasticity</td>
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<td>- upper oesophageal sphincter</td>
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<td>Oesophageal</td>
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<td>Retrograde</td>
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<td>Gastro-oesophageal reflux</td>
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<td>– lower oesophageal sphincter (LOS)</td>
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<td>Hiatus Hernia</td>
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<td>Posture</td>
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<td>Transient LOS Relaxations (TLOSRs)</td>
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<td>Abdominal pressure</td>
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<td>Gastric volume &amp; compliance</td>
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<td>Delayed gastric emptying</td>
<td>Nausea and vomiting</td>
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<td>Rapid gastric emptying</td>
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<td>Retching /vomiting</td>
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<td>Dumping Syndrome</td>
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<td>Stress gastritis</td>
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<td>H. Pylori</td>
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<td>Chronic abdominal pain</td>
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<td>Delayed gastric emptying</td>
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<td>Duodenal ulceration/chronic gastritis</td>
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<td>Neuropathic intestinal dysmotility</td>
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<td>Gastro-duodenal reflux</td>
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<td>gastritis</td>
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<td>oesophagitis</td>
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<td>Superior Mesenteric Artery Syndrome (rare)</td>
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<td>Constipation</td>
<td>Abdominal distention</td>
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<td>Slow transit</td>
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<td>Abnormal defaecation</td>
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<td>Functional</td>
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<td>Incontinence</td>
<td>Bilious vomiting</td>
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<td>Abdominal discomfort/pain</td>
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<td>Nausea</td>
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<td>Early satiety</td>
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<td>Malnutrition</td>
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<td>Poor quality of life</td>
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Following a short break, delegates returned to the hall to hear a very informative presentation by Dr Gillian Craig on the psychosocial aspects of feeding children with neurodisabilities. Dr Craig explored the varied aspects of parental decision making around the progression to enteral gastrostomy feeding, and the ‘emotional conundrum’ this presents to families. She clearly explained the multifactorial emotional investments parents have given to orally feeding their child, and how these can impact on the decision making process. A review of Dr Craig’s presentation can be found on page 4.

The final presentation of the evening was from dietitian Kanar Ahmed, who discussed the nutritional management of children with neurodisability. Kanar recapped and highlighted the multiple difficulties in feeding this group of children. She described the importance of nutritional assessment and how this may be achieved from a number of different perspectives, including anthropometric, biochemical, and visual means. Strategies for nutritional support were comprehensively discussed, from oral diet manipulation with nutrient fortification and appropriate texture modification, to the use of specialised feeds to help with symptom management. Indications for enteral feeding and PEG placement from a nutritional perspective were also discussed, and it was suggested that from a practical perspective discussions about alternative feeding methods such as enteral feeding should commence as early as possible to ensure families are adequately prepared for this. Kamar ended her presentation with a thought-provoking case study.

Overall the symposium was very well evaluated and stimulated a lot of discussion; several areas for further research in this patient group were also highlighted throughout the evening. Delegates were particularly pleased that the topic of neurodisability had provided the focus of the evening, to promote awareness and provide practical support around the specific and complex issues faced in managing these children.

We are delighted to announce a further evening symposium dedicated to this area is planned for October, please see the invite below for more details.
The role of the feeding team in neurodisability - working better together

Feeding difficulties are common among children with neurodisability. This may have significant nutritional, psychosocial impact, quality of life and participation implications for the child, carer and wider family. Early involvement of a specialist multidisciplinary team is essential to reduce the impact of feeding difficulties and to improve a range of outcomes – including optimal nutrition, growth and emotional wellbeing.

Nutrition and growth deficits in children with neurodisability are often under recognised, or considered to be of low priority amongst the management of often very complex health problems. The fact that assessment of nutrition and growth in these children is challenging – both from a practical perspective and in interpreting the anthropometric data makes the recognition of concerns equally difficult.

There may be multiple causes of feeding problems in children with neurodisability. Feeding difficulties can arise from damage to the central nervous system and enteric nervous system. Poor oropharyngeal co-ordination can significantly reduce nutritional intake, and in itself, can be associated with slow rates of feeding, prolonged meal times, excessive spillage of food and can compromise the safety of the swallow. Gastro-oesophageal reflux, vomiting, gastric dysrhythmias, delayed gastric emptying and early satiety, poor dentition, communication difficulties and behavioural elements can all contribute to undernutrition.

Such undernutrition most obviously causes growth failure. However, other consequences are known: decreased cerebral function and the reduced potential for learning and development, reduced responsiveness, withdrawal and irritability, also impaired immune function – which increases infection risk, reduced circulation time – which increases the risk of poor healing and pressure sores, and diminished respiratory muscle strength – which is associated with a weak cough and more chest infections. Chronic constipation can occur in up to 57% of children with severe disability. The risk of morbidity and nutritional failure calls for careful assessment and intervention from a specialist team. “The importance of effective multidisciplinary team (MDT) working cannot be overemphasised”.

Our community feeding team consists of a community paediatrician, school nurse, school nurse support worker, school staff, dietitian, speech and language therapist, and physiotherapist, with occupational therapy also involved. We also work closely with the paediatric nutrition nurse from our contracted feed company. We have open channels of communication with the child’s GP, radiology department for videofluoroscopic swallow studies, community children’s nursing team and a direct link to the paediatric surgeon in the hospital. School aged children in the seven specialist school settings in Manchester are discussed by the team on a termly basis.

Assessment of feeding aims to consider the child and family as a whole - the medical, nutritional, and psychosocial aspects of the child’s growth and feeding. (Table 1) Home visits are almost always indicated and help to foster good relationships with the families/carers.

<table>
<thead>
<tr>
<th>Table 1: Assessment of feeding and nutrition – key questions</th>
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<tr>
<td>1. Is feeding adequate? Are the child’s normal physiological functions being met and is growth being promoted? Lack of weight gain (not just weight loss) over 2-3 months should be flagged.</td>
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<tr>
<td>2. Is feeding safe? Are there any signs of aspiration or respiratory problems: increased congestion at meal times, eye watering, multiple swallows to clear single bolus, ‘gurgly’ or wet voice, recurrent respiratory infections.</td>
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</table>

Monitoring of growth and nutrition of a child with neurodisability is crucial, but tools to interpret anthropometric data are limited. Although charts have been published for use in cerebral palsy and other conditions of neuro-disability, they are criticised for describing ‘what is’ rather than ideal growth.
We plot weights and reliable heights on standard growth charts, but very much focus on serial measurements rather than isolated readings. A study within our special schools has shown that bioelectrical impedance (BIA) may be a useful tool for estimating body composition – particularly where muscle mass will be reduced (publication pending). Weight loss or weight plateaus should ring alarm bells.

Evaluation of feeding skills will include discussion with families and observation of the child at a variety of mealtimes, ideally with a familiar caregiver. Instrumental swallow evaluation may be requested to further determine the safety of the swallow and guide further management of long term feeding including the need for supplementary enteral feeding and implementation of a range of compensatory strategies e.g. adequate positioning, adaptive seating and cutlery may all maximise safety and encourage oral (independent) feeding. Texture modification of food and liquids may also provide safer feeding and reduce fatigue at meal times.

Techniques to improve swallow function have a limited evidence base but can be incorporated into daily activities where there are no concerns regarding a negative impact on nutrition or respiratory health.

The mode of administering nutrition support should take into account the nutritional status of the child, the safety of oral feeding, and the wishes of the child and carers/family. Where possible, we aim for oral nutrition support in the first instance. Support for families and the school around feeding high quality, small, frequent meals is also instigated, but often a nutritionally complete oral nutritional supplement is required in addition.

Enteral tube feeding is frequently associated with benefits for children who cannot manage their full nutrition orally, but arriving at a decision to do so is often a difficult process for families and carers. Our experience is that the decision to commence tube feeding is different for all families; some find non-oral feeding a welcome relief and a great reducer of stress around meals and nutrition. Other families are insulted and angry at such a suggestion, and many will grieve the loss of feelings attached to food preparation and feeding a child with a neurodisability. Part of the decision making process should involve supporting parents to understand that they can still include their child at mealtimes. This may include offering small amounts of oral intake, tastes of the family meal or simply as a communication opportunity.

Should enteral tube feeding be commenced, our team works together to ensure appropriate care is given for the child and family to support this. Decisions about the actual tube and the care of it, the choice of feed and feeding regimen, equipment allocation and delivery, and monitoring tolerance and progress are all made as a team.

Successful management always involves the family in a collaborative approach. Intervention and support with feeding, whether oral or enteral is often required over the long-term; so establishing positive relationships throughout the child’s feeding journey is essential.

References
“A Practical approach to the Nutritional Management of Children with Cerebral Palsy” - was published as a supplementary edition of EJCN in December 2013 (EJCN 2013; 67, Suppl 2), with guest editors Prof Frederic Gottrand and Peter Sullivan. All papers are available to download from the EJCN website: http://www.nature.com/ejcn/journal/v67/n2s/index.html and a summary of these can be seen below.

The supplement comprises 7 papers: an introduction, five review papers, and finishes with a summary and recommendations which form the practical guide.

**Introduction:** a brief summary of the reviews that follow and highlights the aims of the supplement. F. Gottrand & P.B. Sullivan.

**Review 1: Nutrition and growth in children with CP: setting the scene** – P.B. Sullivan

This review highlights prevalence of CP, the multi-factorial causes and consequences of feeding problems in these children. It introduces the importance of accurate assessment and a multi-disciplinary approach in the management of feeding difficulties.

**Review 2: Assessment of growth and nutrition in children with CP** – L.Samson-Fang & K.L Bellthose

This review provides an update on practicalities for assessment of nutritional status and growth of children with CP; including the use of segmental measures in linear growth assessment; an introduction to other nutritional assessment tools specifically developed for use in this group of children; and discusses those assessment measures not valid in this population.

**Review 3: Feeding children with CP and swallowing difficulties** – J. C. Arvedson

This review focuses on dysphagia in children with CP: the types of deficits seen, clinical and instrumental evaluation, decisions regarding management along with evidence for effectiveness of highlighted interventions.

**Review 4: Nutritional management of children with CP** - K.L Bell & L.Samson-Fang

Determining the need and the mode of nutritional intervention for children with CP requires multiple methodologies, from oral nutritional support in children who are safe to consume an oral diet to enteral tube feeding in children with undernutrition, or oropharyngeal dysphagia and an unsafe swallow. This review also discusses the need for ongoing assessment and monitoring to ensure nutritional needs are being met, that complications are adequately managed and to avoid over or under feeding.

**Review 5: Psychosocial aspects of feeding children with neurodisability** – G.M. Craig

The psychosocial support needs of parents considering a gastrostomy feeding tube for their disabled child are often overlooked. This review highlights those issues and provides guidance regarding the support that should be available to families in their decision making, to ensure parental information needs, and any emotional, practical and financial issues are addressed.

**Summary and Recommendations:**


The practical guide takes into account all the previous review articles and suggests a number of questions to ask when considering the best management of a child with CP along with relevant pointers to consider; including:

- Have the psychosocial support needs of the child, family and caregivers been assessed?
- Is the child growing properly?
- Safety: is feeding safe?
- Efficiency: is feeding efficient for the child and for the family?
- Feeding route: how should the child be fed?
- Nutritional requirements: how much does the child need?
- Nutritional support: what should the child receive?
Review: The Importance of Good Nutrition in Children with Cerebral Palsy.


This paper summarizes the literature in this area and provides an overview of why children with a neurodevelopmental disorder such as CP are faced with many nutritional challenges. It includes reference to other studies such as the North American Growth in Cerebral Palsy Research Collaborative to highlight the negative aspects associated with a poor nutritional status at all levels of severity and that good nutrition is a powerful predictor of survival in CP. Those with low fat stores have increased health care needs and reduced social participation. Also, poor nutrition can negatively impact brain growth and motor skill development.

The full nutritional journey of a child with CP is described: from identification of nutritional risk, assessment of nutritional status, and the importance of setting goals of nutritional intervention and monitoring/evaluation of dietary management.

Feeding & swallowing problems affect 30-40% of children with CP and are the primary reasons for inadequate intake. Children at greatest nutritional risk are those with poor weight gain at a young age, those who have significant motor impairments and who have feeding and swallowing problems. It provides 5 key questions (who, what, when, where, how) that may be helpful in understanding a child’s feeding behavior and the feeding environment.

The challenges of measuring and weighing these children, particularly those with scoliosis or joint contractions are discussed. Practical solutions are given to help overcome this such as, taking knee height/tibial length measurements. Also it provides guidance on using other measurements including, triceps skin fold (TSF) and mid-arm circumference measurements (MAC) as further valuable tools to provide a broader nutritional assessment picture.

The author highlights that goals of nutritional rehabilitation should be clearly set to ensure macronutrients and micronutrients are met. Goals also help monitor nutritional progress and can be used to inform care providers therefore assisting the timing of introducing tube feeding. Conflicting from the ECJN publication and the consensus from the experts at ESPGHAN symposium last year, the use of CP-specific growth charts are advised. These growth charts identify a cut-off point, ‘zone of concern’ where morbidity and mortality increases. For this reason the author supports their use, particularly when dealing with difficult discussions with parents requiring tube feeding. Further research in this area is clearly needed.

It provides an insight into the complexity of caring for a child with CP and complements the ECJN publication “A Practical Approach to the Nutritional Management of Children with Cerebral Palsy”. It also includes a case example helping us to further understand the nutritional journey of a child with CP and how complex feeding is and how it is managed in practice.

Other recently published papers in this area:


Comparison of Micronutrient Levels in Children with Cerebral Palsy and Neurologically Normal Controls. Kalra S; Aggarwal A; Chilair N; Faridi MM. Indian J Pediatr. 2015; 82(2): 140-144

The Effect of Oral Sensorimotor Stimulation on Feeding Performance in Children with Spastic Cerebral Palsy. Kaviyani Baghbadorani M; Soleymani Z; Dadgar H; Salehi M Acta Med Iran 2014; 52(12): 899-904

