

# Nutritional Management of Children with Cerebral Palsy

Children living with Cerebral Palsy (CP) have a better prognosis, longer life expectancy and better quality of life than ever before. Nutrition is important to enhancing both health and quality of life – so in this symposium we learned about the latest advances in feeding practices, plus the vital role supplementary fibre can play in digestive health and wellness.

## Tube Feeding in CP Children: Energy Needs and Importance of Percutaneous Gastrostomy



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### Nutrition in CP children: a multifactorial condition

Low feed intake and feeding problems are very common in children who live with CP. There are many factors at play here as CP is a complex disease, and different patients have different progression and needs.

### Mental and emotional factors

Dependency on parents and carers, emotional and cognitive problems all can lead to a lack of appetite. Depression is common, and feeding times can be long, which affects the child – and family's – feelings about food.

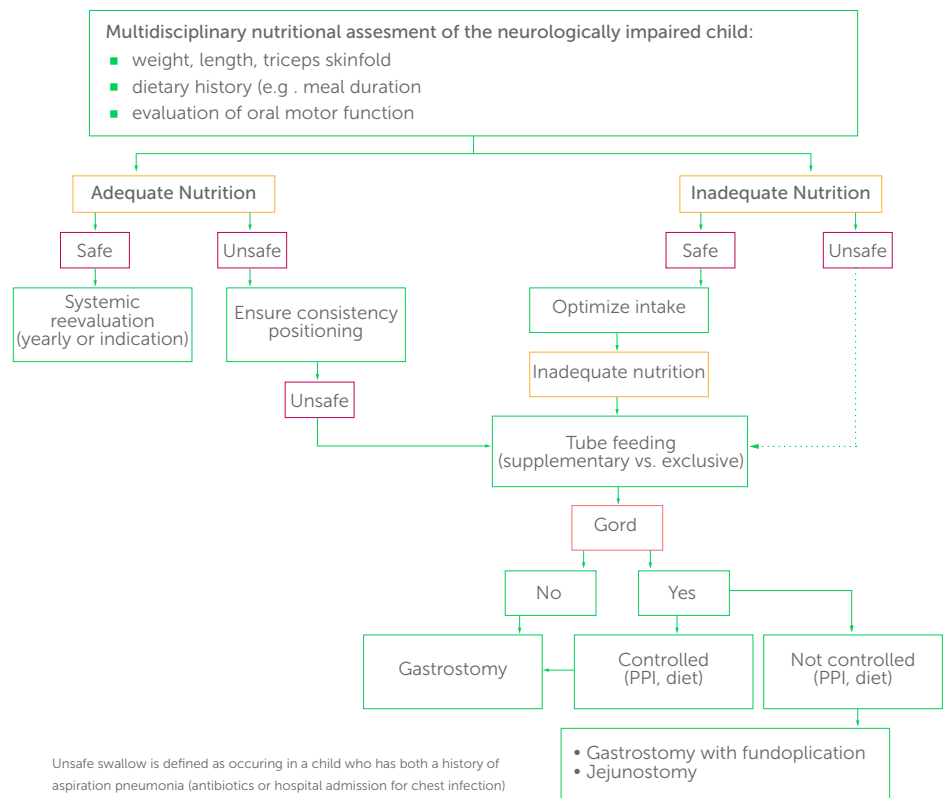
### Physical and medical factors

Pain can be an issue, and it can be hard to diagnose, especially in cases with spasticity and hip luxation. Stomatology, Enterology, Pulmonology, drooling, macroglossia, swallowing difficulties, dental anomalies all make feeding challenging, and medication can bring with it side effects. There can also be ENT and digestive issues at play: GERD, constipation, aerophagia, chronic emptying, gastric obstruction.

Taken as single issues, many of these problems are easily solved, though can be challenging to identify and manage as part of a more complex case.

### ESPGHAN Guidelines to support care

To ensure children living with cerebral palsy get the nutrition they need, **ESPGHAN Guidelines Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children with Neurological Impairment<sup>1</sup>** provide support.



Unsafe swallow is defined as occurring in a child who has both a history of aspiration pneumonia (antibiotics or hospital admission for chest infection) and objective evidence of aspiration or penetration on contrast videofluoroscopy  
GORD: gastro-oesophageal reflux  
PPI: proton pump inhibitor

## An overview of the approach

### Your first questions should be: firstly, is nutrition adequate; and secondly, is it safe?

- If you can say yes to both, only monitoring is required.
- If nutrition is adequate but unsafe, first look to improve safety through positioning and consistency – though if this does not help, you will need to look at tube feeding part or all of the time.
- If nutrition is inadequate but there are no safety concerns, first optimise the diet with supplements. If this doesn't work then look to tube feeding. If nutrition and safety are both concerns, move straight to tube feeding, then
- Once tube feeding begins, your eventual treatment path depends if gastro-oesophageal reflux (GORD) presents.
- If there is GORD – and cannot be controlled with PPIs – the path leads to either Gastrostomy with fundoplication or Jejunostomy.

### What does optimal nutrition look like?

#### Assessing energy needs

Defining the optimum diet can be very difficult because there are no appropriate reference standards for this particular group<sup>1</sup>. We tend to use the recommended daily allowance for chronological age for energy, proteins and micronutrients, but this can be inaccurate, overestimating energy as since weight and height of the children we are treating can be dramatically reduced. Furthermore, variation in muscle tone and levels of activity both influence energy expenditure and calorie requirements.

#### Why averages aren't always helpful

Children burn calories in four ways: the basal metabolic rate; thermo-regulation; physical activity; and growth. Though averages are useful in regular pediatric nutrition, they are less helpful for children living with CP because their energy costs, growth and physical activity can vary so much.

#### An example – the 'cost' of movement

Take the energy cost of walking. When we compare children who can walk without restriction to children who use assistive devices, and again to children whose self mobility is severely

limited, the energy expenditure varies dramatically from 0.23 ml/kg/m to 0.44 to 2.17.<sup>2</sup>

### Other factors that affect energy needs

Children who are nutritionally compromised might also need extra energy for catch-up growth<sup>1</sup>. However, we need to be careful to monitor progress and BMI, as following Perendoscopic gastrostomy placement, up to one-fifth of patients may be overfed, becoming overweight which can lead to other problems.

### What about proteins and micronutrients?

The ESPGHAN WG can guide us here:

Recommendation 6a & 8: **DRI for protein and micronutrients in typically developing children** to estimate the appropriate intakes for children with NI.

Recommendation: 6b: **supplementary protein intake in clinical situations** – such as decubitus ulcers or in children with low calorie requirement, such as severely limited mobility.

Recommendation 4: children with NI have anthropometry at least every 6 months, with micronutrients checked annually.

### Nutritional support and feeding best practices

When it's safe, nutritionally sufficient and stress-free, oral feeding is best. However, always be mindful how long feeding takes – it shouldn't be more than 3 hours a day as it can get stressful for the child and the caregivers.

### See the big picture

Before taking the tube feeding route, pay careful attention to dental problems, general posture and orthopedic issues in NI patients, as these may contribute to feeding difficulties.

### Consider the feeding formula carefully

It's very important to choose the right formula diet<sup>3</sup>.

- **Standard** (1.0 kcal/mL) polymeric age-appropriate formula including fibre for NI children older than one year
- **High-energy density formula** (1.5 kcal/ml) containing fibre in cases of poor volume tolerance in NI children
- **Low-fat, low-calorie, high fibre, and micronutrient replete formula** for the maintenance of enteral tube feeding after nutritional rehabilitation in immobile NI children.

It is possible to maintain adequate nutritional status without excess body fat<sup>3</sup> even in children who are immobile, though be mindful that fibre intake is low even when supplemented.<sup>3</sup>

### Nutritional support in practice

Success starts with an adaptive approach. Family structures, the child's lifestyle and tolerance are all factors – you'll need to work with the family to work out what's right for them.

Use a combination of nocturnal continuous feeds with daytime bolus feeds in children with high-caloric needs or poor tolerance to volume.<sup>1</sup>

Explore modification of enteral nutrition such as the thickening of liquid enteral formulas, whey-based formulas in addition to therapeutic options of gastro oesophageal reflux disease.<sup>1</sup> It's also helpful to trial whey-based formulas if the child experiences gastroesophageal reflux, gagging or retching.<sup>4</sup>

### Moving to gastrostomy

Gastrostomy is the preferred way to provide intragastric access for long term tube feeding for children with CP – in fact, in a 2014 study, 53%<sup>4</sup> of procedures were performed on children with neuro-muscular diseases.

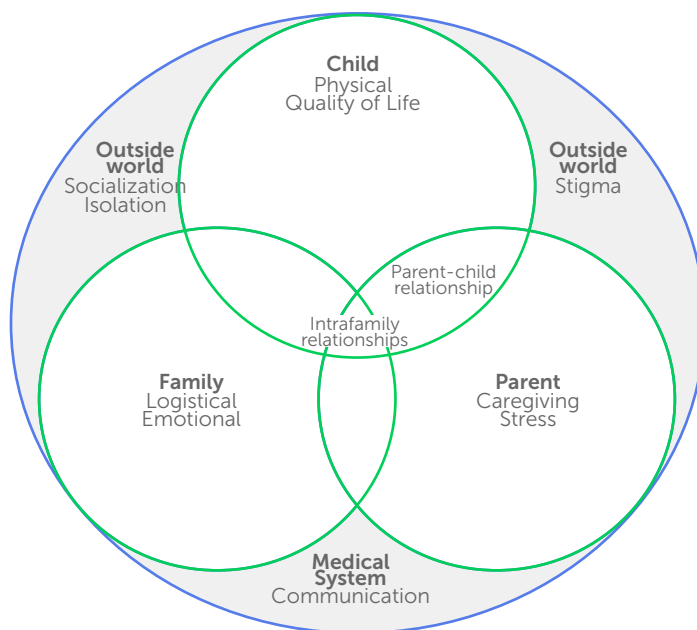
Compared to others within the study, the CP children were older<sup>4</sup> (7 ± 4 years vs 3 ± 2 years; p<0.05), with feeding difficulties being the main indication (82% vs 39%)<sup>4</sup>. At follow-up, mortality rate was higher (not due to EN), but the course of the neurological disease. It's also interesting to note that only 10% of the children could be weaned from EN<sup>4</sup>

What's more, PEG does not seem to worsen gastroesophageal reflux disease (GERD)<sup>5</sup>, or increase the need for surgery – though both do increase over time due to the course of the neurological disease.

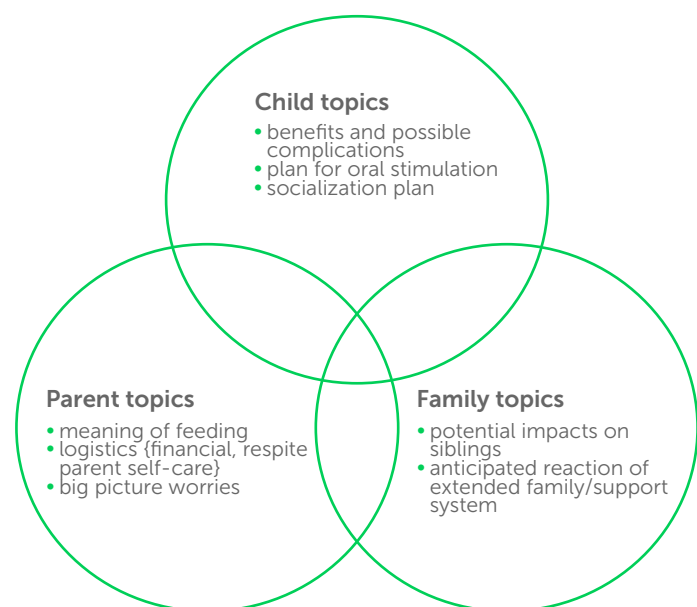
### Who makes the decision?

The choice to move toward gastrostomy isn't a decision for the clinical team alone; the child, the family and the caregivers all need to feel confident that the decision is right for them. There are a number of benefits and issues to discuss, which are well-covered by Nelson et al's 2015 diagrams:

### Conceptual diagram of themes.



### Issues to explore with families regarding G-tubes.



### In conclusion

EN is very important to improve the nutritional status of children affected by cerebral palsy. It may help to improve growth, and positively affects quality of life for families and perhaps children themselves. It probably provides a level of lung protection, and may decrease the risk of infection and hospitalisation. It may also decrease osteopenia<sup>7, 8, 9, 10, 11, 12</sup>

# The Impact Of Dietary Fibre In Enteral Nutrition



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Should malnutrition be considered normal in the treatment of children with neurodisability? Absolutely not – we need not and should not accept this – and there are many ways to ensure proper nutrition for all patients. A proven and highly effective method can be the addition of fibers for children who are nourished using Enteral Nutrition.

## Looking at the bigger picture

When it comes to improving both quality of life and clinical outcomes there is much we can do. Top-ten tips for managing nutritional issues and gastrointestinal symptoms in children with neurological impairment are suggested here.<sup>8</sup>

Today we will be discussing how we can support optimal nutrition – while reducing symptoms of digestive distress including diarrhea and constipation – by introducing additional fibre.

NI = Neurological impairment,  
GERD = gastroesophageal reflux disease,  
PPIs = proton pump inhibitors

Item/Focus	Tip/Action
1. Burden of NI	<ul style="list-style-type: none"> <li>Awareness of rising prevalence of NI-associated feeding difficulties and gastrointestinal symptoms</li> </ul>
2. Assessment of nutritional status	<ul style="list-style-type: none"> <li>Physical examination and nutritional status (see Tip 2)</li> </ul>
3. Definition of undernutrition	<ul style="list-style-type: none"> <li>Physical examination and nutritional status (see Tip 2)</li> </ul>
4. Nutritional needs	<ul style="list-style-type: none"> <li>Dietary reference intake for basal energy expenditure for typically-developing children, individualized according to motor function, muscle tone, and activity level</li> <li>Daily supplements in specific clinical conditions</li> </ul>
5. GERD	<ul style="list-style-type: none"> <li>Early assessment and treatment</li> <li>PPIs as the first line treatment</li> </ul>
6. Constipation	<ul style="list-style-type: none"> <li>Careful history, abdominal, perineal, and eventually digital rectal examination</li> <li>Osmotic agents (polyethylene glycol)</li> </ul>
7. Enteral nutrition	<ul style="list-style-type: none"> <li>Consider start before the development of undernutrition</li> </ul>
8. Enteral access and feeding regimen	<ul style="list-style-type: none"> <li>Gastrostomy as the preferred way for prolonged enteral tube feeding</li> <li>Post-pyloric feeding in case of contraindication to gastric feeding</li> </ul>
9. Enteral formula	<ul style="list-style-type: none"> <li>Choice of enteral formula based on patient's age, nutritional needs and enteral access</li> <li>Safety concerns about blenderized food</li> </ul>
10. Benefits of enteral tube feeding	<ul style="list-style-type: none"> <li>Long-term improvement of nutritional status, health-related quality of life</li> <li>Low rates of serious complications</li> </ul>

## First though, let's recap on the fundamentals of nutritional management for children who live with neurodisability.

### Enteral Tube Feeding (ETF) in children with CP

Enteral Tube Feeding (ETF) is a common and helpful way to support nutrition. In the long term, it is recommended in the ESPGHAN Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children with Neurological Impairment<sup>1</sup> "using a gastrostomy as the preferred way to provide intragastric access for long-term tube feeding in children with NI" – recommendation 23:

So we have the method – now what about the formula? We can make this decision by considering:

1. The child's age
2. The energy requirements of the child
3. The mode of enteral access
4. Tolerance

### Gastrointestinal symptoms during tube enteral feeding

Not all children will be wholly tolerant, and symptoms of gastrointestinal distress may occur, including:

- Ger-vomiting
- Constipation
- Aerophagia
- Delayed gastric emptying
- Diarrhea (ranging 6-60%<sup>14</sup>)

The prevalence of this last symptom may be attributed to a number of factors: contamination of the enteral formula; the fact that the risk of *Clostridium difficile* infection is threefold greater in patients with ETF; that intragastric infusion of enteral formula stimulates an abnormal secretion of fluid into the lumen of the ascending colon or that frequent prescription of antibiotics increases the risk of diarrhoea. The role of colonic microbiota is also an area of increasing interest.

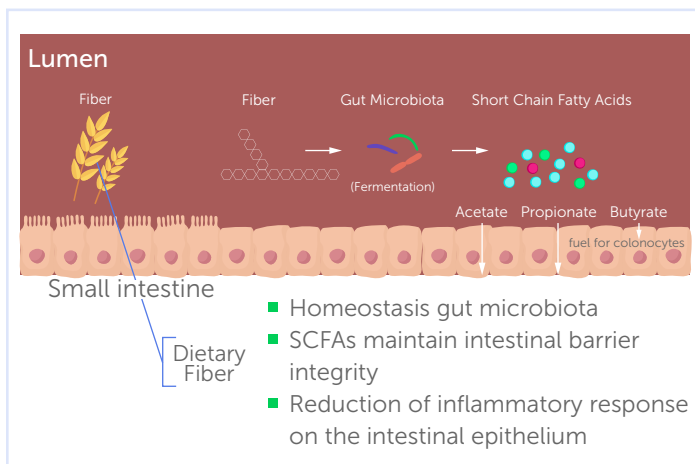
### Gut microbiota and artificial nutrition

There have been a number of studies investigating the gut microbiota of patients who are nourished using ETF. Schneider<sup>15</sup> suggests that these patients have lower concentrations of faecal aerobes and higher concentrations of anaerobes compared with healthy controls.

However, in an observational study of the usefulness of soluble dietary fibre in the treatment of diarrhoea during enteral nutrition<sup>16</sup> Nakao gave 20 EFT patients who were experiencing symptoms a supplement of 28g of galactomannan. Within 4 weeks of treatment, the diarrhoea resolved in all patients, with a reduction in the concentration of faecal anaerobes.

### Why is dietary fibre so important?

Fibre can help to support the microbiota, maintain intestinal barrier integrity, and reduce the inflammatory response in the intestinal epithelium.<sup>17</sup>



In a randomised, controlled, double blind study evaluating the effects of PHGG in enteral nutrition in medical and surgical patients, diarrhea and constipation were both significantly reduced in patients receiving fibre-supplemented formulas.<sup>18</sup>

Meanwhile, Whelan et al's 2005 study of the effects of enteral formula composition on the colonic microbiota<sup>19</sup> found that a FOS/fibre formula increased the bifidobacteria (p 0.004) and reduced the clostridia compared with the standard formula, the FOS/Fibre formula is matched with higher concentrations of total SCFA.

### So the results are clear, but how do we define and use fibre?

Dietary fibre is defined as a structural and storage polysaccharide found in plants that are non digested in the human gut. Sources of fibre in enteral formulas include soluble and insoluble.

- Soluble fibre includes Pectin and Guar, which is fermented by colonic bacteria providing fuel for the colonocytes.
- Insoluble fibre includes Soy Polysaccharide, which increases fecal weight and colonic peristalsis.

Fibre-containing feeds are recommended in the ESPEN Guidelines on Home Enteral Nutrition<sup>20</sup> for patients with diarrhea (recommendation 40) and constipation (recommendation 41).

The use of fibre is also supported in a number of systematic reviews, including Fibre and probiotic supplementation in enteral nutrition: A systematic review and meta-analysis. The authors found that the soluble fibre guar such as PHGG, is the most studied and tolerated.<sup>21</sup>

### What natural foods contain useful fibres? And how much should we use?

Natural fibre can be obtained by blending fruit and vegetables. Currently most of the available formula contain 3-6g of fibre per litre of formula. However, we believe that higher amount would fit better with patient needs.

### When you start with fibre in formula, should it be introduced gradually or immediately?

There isn't evidence to support this either way, but we've found that you can use fibre supplemented fibre immediately if symptoms like constipation or diarrhea are present.

## Conclusions

Fibre supplementation in EN has been shown to regulate bowel function and reduce both diarrhea and constipation. The addition of fibre increases proliferation of colonic microbiota, including bifidobacteria, and fermentation improves short chain fatty acids (SCFAs) production which enhances the absorption of water and sodium in the colon.

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