

## Nutrition in neurologically impaired children



V Marchand; Canadian Paediatric Society, Nutrition and Gastroenterology Committee. Nutrition in neurologically impaired children. *Paediatr Child Health* 2009;14(6):395-401.

Malnutrition, either under- or overnutrition, is a common condition among neurologically impaired children. Energy needs are difficult to define in this heterogeneous population, and there is a lack of information on what normal growth should be in these children. Non-nutritional factors may influence growth, but nutritional factors such as insufficient caloric intake, excessive nutrient losses and abnormal energy metabolism also contribute to growth failure. Malnutrition is associated with significant morbidity, while nutritional rehabilitation improves overall health. Nutritional support should be an integral part of the management of neurologically impaired children, and should focus not only on improving nutritional status but also on improving quality of life for patients and their families. When considering nutritional intervention, oromotor dysfunction, gastroesophageal reflux and pulmonary aspiration must be addressed and a multidisciplinary team should be involved. Children at risk for nutrition-related problems should be identified early. An assessment of nutritional status should be performed at least yearly, and more frequently in infants and young children, or in children at risk for malnutrition. Oral intake should be optimized if safe, but enteral tube feedings should be initiated in children with oromotor dysfunction, leading to clinically significant aspiration, or in children unable to maintain an adequate nutritional status with oral intake. Nasogastric tube feeding should be used for short-term intervention, but if long-term nutritional intervention is required, a gastrostomy should be considered. Antireflux procedures should be reserved for children with significant gastroesophageal reflux. The patient's response to nutritional intervention should be carefully monitored to avoid excessive weight gain after initiation of enteral nutrition, and paediatric formulas should be used to avoid micronutrient deficiencies.

**Key Words:** *Cerebral palsy; Growth; Neurologically impaired; Nutrition*

Chronic diseases have a significant impact on nutritional status. In neurologically impaired (NI) patients, malnutrition negatively affects quality of life and is associated with increased health care use and impaired participation in various activities (1). Nutritional rehabilitation has been associated with improved overall health, improved peripheral circulation, healing of decubitus ulcers, decreased spasticity, decreased irritability and improved gastroesophageal reflux in patients with neurodevelopmental disabilities (2-5). A significant proportion of children with neurodevelopmental disabilities are undernourished (6-9). This state of malnutrition may have been once considered to be part of the disease, but there is now a better recognition of the

## L'alimentation des enfants ayant une déficience neurologique

La malnutrition, qu'il s'agisse de sous-alimentation ou de suralimentation, est courante chez les enfants ayant une déficience neurologique. Les besoins en énergie sont difficiles à définir au sein de cette population hétérogène. De plus, on manque d'information sur ce qui constitue la croissance normale chez ces enfants. Des facteurs non nutritionnels peuvent influencer sur la croissance, mais des facteurs nutritionnels, tels qu'un apport calorique insuffisant, des pertes excessives d'éléments nutritifs et un métabolisme énergétique anormal, contribuent également au retard de croissance de ces enfants. La malnutrition est liée à une importante morbidité, tandis que la réadaptation nutritionnelle améliore l'état de santé global. Le soutien nutritionnel doit faire partie intégrante de la prise en charge des enfants ayant une déficience nutritionnelle et viser non seulement à améliorer l'état nutritionnel, mais également la qualité de vie des patients et de leur famille. Au moment d'envisager une intervention nutritionnelle, il faut tenir compte du dysfonctionnement oromoteur, du reflux gastro-œsophagien et de l'aspiration pulmonaire, et une équipe multidisciplinaire doit se concerter. Il faut repérer rapidement les enfants vulnérables à des troubles nutritionnels et procéder à une évaluation de leur état nutritionnel au moins une fois par année, et plus souvent chez les nourrissons et les jeunes enfants ou chez les enfants qui risquent de souffrir de malnutrition. Il faut optimiser l'apport oral s'il est sécuritaire, mais entreprendre une alimentation entérale chez les enfants ayant un dysfonctionnement oromoteur qui provoque une aspiration marquée ou chez ceux qui sont incapables de maintenir un état nutritionnel suffisant au moyen de l'apport oral. Il faut réserver l'alimentation par sonde nasogastrique aux interventions à court terme, mais si une intervention nutritionnelle prolongée s'impose, il faut envisager la gastrostomie. Il faut réserver les mesures antireflux aux enfants présentant un reflux gastro-œsophagien considérable. Il faut surveiller étroitement la réponse du patient à l'intervention nutritionnelle afin d'éviter une prise de poids excessive après l'amorce de l'alimentation entérale, et privilégier les préparations pédiatriques afin d'éviter les carences en micronutriments.

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importance of nutrition in this population. Nutritional care of children with neurodevelopmental disabilities has improved with the advent of less invasive enteral access methods and better tolerated enteral formulas. We need to provide these often complicated patients with appropriate nutritional support by involving a multidisciplinary team of physicians, nurses, dietitians, speech and occupational therapists, and psychologists working to improve the child's and the family's quality of life.

### METHODS

Members of the Canadian Paediatric Society's Nutrition and Gastroenterology Committee, most of whom are

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involved in caring for children with neurodevelopmental disabilities, reviewed and interpreted the literature and developed the present position statement on the basis of their experience and research activity. It replaces the previous position statement published in 1994 (10).

### **NUTRITIONAL STATUS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITY**

Height, weight and weight-for-height of children with neurodevelopmental disabilities are significantly below standards, and other indicators of nutritional status, such as triceps skinfold thickness and mid-arm circumference, are also affected (3,6-9,11). While most children with cerebral palsy (CP) are undernourished, 8% to 14% are overweight (7).

### **PREDICTORS OF POOR NUTRITIONAL STATUS**

The incidence and the severity of malnutrition in NI children increases with the duration and the severity of neurological impairment (7,11,12). Growth of children with spastic quadriplegia is more severely affected, but children with diplegia or hemiplegia also have altered growth (7). The presence of oromotor dysfunction correlates with a greater risk of malnutrition (13-20). Physicians should identify severely affected patients with oromotor dysfunction and monitor them very closely because they are the ones most likely to require enteral nutrition support.

### **CAUSES OF MALNUTRITION**

#### **Inadequate intake**

The caloric intake of children with CP is lower than that of age-matched controls (21,22). Some patients are able to feed themselves independently but lack hand-mouth coordination and may, therefore, spill an excessive amount of food. These children may also eat more slowly than other members of the household or require more time to eat than is allowed by the school schedule. As a result, regular family or school mealtime may be too short for them to ingest a sufficient amount of food. Severely affected children are dependent on a caregiver at mealtime and are often unable to communicate hunger and satiety. The caregiver regulates their food intake. This may lead to underfeeding because it has been shown that the caregiver often overestimates the time spent feeding the child and also overestimates the child's caloric intake (22,23). Increasing caloric intake with tube feedings improves nutritional status in NI children (4,24-26).

#### **Increased losses**

Gastroesophageal reflux affects a significant proportion of children with CP (27,28). Frequent emesis and regurgitation may be a source of caloric loss. Reflux esophagitis may cause discomfort leading to food refusal and further decreasing food intake.

#### **Altered metabolism**

The resting energy expenditure is lower in children with CP than in controls matched for age and weight (22,29,30).

Children who are hypotonic and nonambulatory require few calories above the resting energy expenditure to thrive (31). However, children with increased muscle tone or with athetoid forms of CP may require an increased amount of calories (32). Children with mild to moderate diplegic or hemiplegic CP who can ambulate often require more calories to perform daily activities than their normal counterparts (33,34).

#### **Oromotor dysfunction**

Oromotor dysfunction affects up to 90% of patients with CP (23), and is a major contributor to malnutrition in NI children (13,14,16-20). Parents often report poor suck, breastfeeding difficulties, problems with the introduction of solid food and choking or coughing associated with feedings, even before the diagnosis of CP is made (21,23). Eighty per cent of these children have been fed nonorally at least once as infants (23). Children with oromotor dysfunction have a greater risk of malnutrition and often have lower weight, height and weight-for-height Z-scores than children with normal oromotor function (13,14,16-20). Inadequate sucking, dysfunctional swallowing, persistent extrusion reflex, drooling due to inadequate lip closure and reduced ability to chew make oral feeding difficult. Prolonged mealtimes, sometimes 3 h per day to 6 h per day, may not even be sufficient to compensate for the child's feeding inefficiency resulting in inadequate caloric intake (15,35).

### **NONNUTRITIONAL FACTORS AFFECTING GROWTH**

Although malnutrition plays a major role in linear growth failure, other factors may affect growth in the NI population because height Z-scores decrease with age independently of weight Z-scores (36). Neurological disease itself may affect linear growth because linear growth failure correlates with the severity of cognitive defect and with ambulatory status (7,11,36). In children with hemiplegia, the affected side is usually shorter and smaller than the nonaffected side, thus demonstrating the effect of the neurological disease on growth (36). Other non-nutritional factors affecting linear growth include specific syndromes, endocrine dysfunction, ethnicity, genetic potential and pubertal status.

### **NUTRITIONAL ASSESSMENT**

#### **Clinical observation**

**Nutritional history:** The child's nutritional history should review not only the type (purees, liquids and solid food) and the amount of food that the child eats, but the degree of dependency on a caregiver and the length of a typical meal. If the child is able to self-feed, the amount of spilling should be assessed. Signs of oromotor dysfunction such as drooling, persistent extrusion reflex, spilling and delayed swallowing, and symptoms of aspiration, such as choking and coughing, should be sought. Besides these functional considerations, the stress associated with meals and the quality of the interaction between the caregiver, the child and the family at

mealtime should be explored. Caring for NI children is very demanding and some children may be neglected.

Observation of a meal may be useful to determine the amount of food offered, spilled and ingested and to assess the parent-child interaction. Measuring oxygen saturation during a meal will detect desaturation that may result from aspiration (37).

**Medical history:** The medical history should include an assessment of gastroesophageal reflux symptoms such as emesis, regurgitation, pain or food refusal. The physician should also look for chronic respiratory problems, recurrent pneumonia and respiratory symptoms suggestive of chronic aspirations. Aspiration due to swallowing dysfunction usually presents with coughing or choking associated with meals. Reflux-related aspiration episodes are often accompanied by regurgitation of gastric contents or frank emesis. In many children, the two problems overlap. Aspiration may also be asymptomatic. Progressive fatigue toward the end of the meal may be suggestive of desaturation. Among other aspects of the medical history that should be investigated are recurrent infections, decubitus ulcers and constipation. A review of the child's medication is important because some drugs, particularly anticonvulsants such as valproic acid and topiramate, may affect appetite and, therefore, growth.

**Growth history:** Birth weight, length and head circumference and all previous weight, length and head circumference measurements should be obtained and plotted on a Centers for Disease Control and Prevention/National Center for Health Statistics (USA) growth chart. This will help determine whether there is a decrease in growth velocity. Midparental height may be useful to estimate growth potential.

**Physical examination:** The most important part of the physical examination is measurement of weight and length. They should be obtained with the proper technique on an adequately calibrated scale. The child should be wearing little or no clothing. Older children who are unable to stand may be weighed while held by a parent, and the difference should be calculated, or a wheelchair scale should be used. The supine length should be obtained in children younger than two years of age and in older children unable to stand. In children with skeletal deformities (scoliosis or contractures), alternative measures, such as lower leg length or upper arm length, may be obtained (38,39). References are available for these alternative measurements (39). Head circumference should also be obtained. Triceps skinfold thickness and mid-arm circumference are often helpful in assessing nutritional status and may even be more accurate than weight-for-height to detect malnutrition (40). Subscapular skinfold is often less affected than triceps skinfold in malnourished NI children (9).

The physical examination should detect signs of malnutrition such as decubitus ulcers and peripheral edema. Contractures, scoliosis, increased or decreased muscle tone as well as choreoathetoid movements should be assessed. Careful examination of the teeth and mouth are important because gingival hyperplasia and poor oral health may cause discomfort, interfering with oral intake. Auscultation

of the lungs may reveal signs of chronic aspiration. Examining for digital clubbing, and assessing oxygen saturation may be helpful. Abdominal examination and, if needed, a rectal examination, may reveal constipation.

### Investigation

Extensive bloodwork is usually not necessary. A complete blood count may help detect iron deficiency. Serum albumin may reflect nutritional status, but is not very reliable in this population (41). Electrolytes are usually normal. Phosphorus, calcium, alkaline phosphatase and vitamin D levels may be measured in patients with suspected osteoporosis and may be combined with a bone density scan.

For children with suspected oromotor dysfunction, a good clinical evaluation by an experienced clinician may be sufficient to detect fluid aspiration. A swallowing study using different food and liquid textures may be helpful to assess the efficiency and safety of the swallowing process, and may provide the physician with information regarding the child's risk for aspiration. The swallowing study can also guide recommendations with respect to position for feeds and possible texture restrictions. However, the reproducibility of the swallowing study may be questioned, and the clinician should also consider clinical symptoms of aspiration displayed by the child and be cautious about making decisions based solely on the swallowing study.

The diagnosis of gastroesophageal reflux is often made based on symptoms. An upper gastrointestinal series may be indicated to diagnose possible anatomical abnormalities, such as superior mesenteric artery syndrome, which is frequent in children with scoliosis or who have rapid weight loss. In children with chronic aspiration, a 24 h esophageal pH probe study may help determine whether aspiration is secondary to gastroesophageal reflux. A gastric emptying scan is useful in diagnosing delayed gastric emptying and possibly pulmonary aspiration of gastric content.

## PROBLEMS FREQUENTLY ENCOUNTERED IN THE NI POPULATION

### Gastroesophageal reflux

Gastroesophageal reflux affects a large portion of children with CP (27,28). Delayed gastric emptying may also be seen. Consequences of gastroesophageal reflux include emesis resulting in increased nutrient losses; reflux esophagitis, which may lead to food refusal; and pulmonary aspiration of gastric contents. Gastroesophageal reflux should be treated aggressively with proton pump inhibitors or H<sub>2</sub> blockers. Prokinetics may also be useful in some cases. Some children with severe gastroesophageal reflux that is unresponsive to medical therapy may require a surgical antireflux procedure (ARP). However, patients should be selected carefully because the NI population is known to have more complications after this type of surgery than the general population (42-45).

### Pulmonary aspiration

Pulmonary aspiration may be the result of swallowing dysfunction with aspiration of saliva and/or aspiration of gastric

**TABLE 1**  
**Calculating energy needs of neurologically impaired patients**

1. Krick method (32)
Kcal/day = (BMR × muscle tone factor × activity factor) + growth factor
BMR (kcal/day) = Body surface area (m <sup>2</sup> ) × standard metabolic rate (kcal/m <sup>2</sup> /h) × 24 h
Muscle tone factor: 0.9 if decreased, 1.0 if normal, 1.1 if increased
Activity factor: 1.15 if bedridden, 1.2 if dependant, 1.25 if crawling, 1.3 if ambulatory
Growth factor: 5 kcal/g of desired weight gain
2. Height-based method (73)
14.7 cal/cm in children without motor dysfunction
13.9 cal/cm in ambulatory patients with motor dysfunction
11.1 cal/cm in nonambulatory patients
3. Resting energy expenditure-based method (29)
1.1 × measured resting energy expenditure
<i>BMR Basal metabolic rate</i>

contents in patients with gastroesophageal reflux. It is important to differentiate between these two entities to treat the patient adequately.

Additionally, respiratory symptoms of viral origin and respiratory symptoms from aspiration may be difficult to differentiate. Community-acquired pneumonia in an NI child may be mistakenly diagnosed as 'aspiration pneumonia', leading to investigation and intervention that may not always be warranted.

### Osteoporosis

Osteopenia and osteoporosis are frequently encountered in the NI population (46,47). Among the factors contributing to this problem are reduced ambulation and weight-bearing activity, malnutrition, limited sun exposure and the use of anticonvulsant medication, which alters vitamin D metabolism (48-52). Dietary intake of vitamin D, phosphorus and calcium are insufficient in a significant proportion of these children (53,54). This may be exacerbated by using an adult type formula with a calorie-to-nutrient ratio that is inadequate for a growing child.

It may be difficult to evaluate bone mineral density in these patients because of skeletal deformities and the inability to stay still. While bone densitometry remains the gold standard, bone quantitative ultrasonography may be easier to perform in these children and may become a useful test in the future (55).

Pathological fractures may be very debilitating, and osteoporosis should be prevented with an adequate intake of dietary calcium, phosphorus and vitamin D. Biphosphonates have been used in these children with good results (56).

## NUTRITIONAL INTERVENTION

### Determine energy needs

Energy needs are difficult to define in this heterogeneous population. Most methods used to determine energy requirements tend to overestimate the needs of NI children (30,31). Energy requirements must be individualized to take into account mobility, muscle tone, activity level, altered

metabolism and growth. Indirect calorimetry may be used, but is not available everywhere. Different methods to calculate energy needs are summarized in Table 1. However, the best way to ensure adequate intake is to monitor weight gain in response to dietary therapy.

### Improve oral intake

The easiest and least invasive method to increase energy intake is to improve oral intake. Adequate positioning of the child during meals is very important. Oromotor skills may be improved with therapy, although results may be disappointing (57-59). Food consistency may be adjusted with thickening agents to provide the best consistency for the patient as determined by a swallowing study. Food caloric density may be increased with the help of a dietitian, by adding modular nutrients, modifying recipes or using high-calorie formulas. Oral intake can be maintained as long as there is no risk of aspiration, the child is growing well and the time required to feed the child remains within acceptable limits.

### Enteral nutrition

When oral intake is unsafe, insufficient or too time consuming, enteral nutrition should be initiated.

**Enteral access:** The type of enteral access will depend on the anticipated duration of enteral nutrition support as well as the clinical status of the child.

Nasogastric tubes are minimally invasive but are easily dislodged and have local complications (sinusitis, congestion, otitis and skin irritation). Generally, nasogastric feeds should only be used for short-term nutritional support (less than three months). They may be useful to use for a nutrition challenge to assess tolerance and efficacy.

For long-term enteral nutrition support (more than three months), a gastrostomy should be considered. Gastrostomies are more invasive, but are also more convenient and esthetically acceptable. The gastrostomy may be performed by open surgery, laparoscopic surgery, endoscopy (percutaneous endoscopic gastrostomy) or interventional radiology. The decision needs to take into account the institutional expertise and the need for a concomitant ARP. Children with symptoms of reflux who do not respond to medical therapy or with evidence of pulmonary aspiration caused by their reflux should undergo a surgical gastrostomy along with an ARP. In children without symptoms of reflux or with mild reflux responding well to medical treatment, a percutaneous approach, either endoscopic or radiological, may be used. There is no role for a prophylactic ARP (60-63). The choice between a gastrostomy with or without an ARP has to be carefully evaluated because the failure rate and the incidence of major complications following ARP are high in NI children (42-44,64,65). In difficult cases, it may be useful to attempt a trial of nasogastric feeds for one month to assess tolerance before making a decision. This is particularly true in patients for whom the indication of ARP is recurrent aspiration pneumonia because it is often difficult to differentiate aspiration from swallowing

dysfunction and aspiration from gastroesophageal reflux. Some children may develop gastroesophageal reflux after a gastrostomy. It is unclear whether this is a consequence of the change in volume, consistency and composition of the feeds or a consequence of the procedure. If this problem occurs, medical treatment with prokinetics and changes in the formula or in the rate and volume of feeds should be attempted before resorting to an ARP.

In some cases, patients may require jejunal feeds. Nasojejunal feeds should be used for short-term enteral nutrition in patients with gastroesophageal reflux or gastric dysmotility. Long-term gastrojejunal feeds should only be used in patients with reflux who are poor candidates for ARP. Gastrojejunal tubes often migrate back into the stomach and need to be repositioned under fluoroscopic guidance. In addition, these tubes tend to be of smaller calibre and are more likely to get obstructed. A jejunostomy may be an option in selected cases.

**Enteral formulas:** Before 12 months of age, an infant formula should be used. In patients with high-caloric needs or with poor tolerance to increased formula volume, the formula may be concentrated and/or modular nutrients, such as glucose polymer or lipids, may be added. The addition of modular nutrients should be made with the help of a dietitian to ensure that the final composition of the diet is adequate, and to avoid preparation errors. Casein hydrolysates and amino acid-based formulas may be used in selected patients.

After 12 months of age, a paediatric 1 kcal/mL formula is preferred. A 1.5 kcal/mL formula may be used with careful monitoring of hydration status. Fibre-containing formulas are often used to alleviate constipation. Adult formulas should be avoided because the calorie-to-nutrient ratio is inadequate for children. Their use may result in calcium, phosphorus and vitamin deficiency, especially in patients with low-caloric needs. Most children will tolerate a polymeric formula, but some children may require a semielemental or elemental formula (66).

**Feeding regimen:** The choice of feeding regimen will be based on the child's enteral access, activities, caloric needs and tolerance to feeds. In children with poor tolerance to gastric feeds, continuous feeds may be necessary. They may also be necessary for children with dumping syndrome. Continuous feeds should always be used when the child has a gastrojejunal tube. For ambulatory children who have scheduled daily activities, bolus feeds are preferred because they allow more freedom. A child with high-caloric needs or with poor tolerance to volume may benefit from a combination of daytime boluses and nocturnal continuous feeds.

**Monitor response to nutritional intervention:** NI children are often unable to communicate hunger and satiety. In tube-fed children, this may lead to overfeeding; some children become overweight after initiation of gastrostomy feedings (26). Because these children are often wheelchair bound and dependent on a caregiver for most of their transfers, it is important to avoid excessive

weight gain. These children often have a decreased lean body mass, and excess weight gain is mostly fat mass. In children younger than three years of age and in children with normal activity level, weight-for-height should be in the 50th percentile. For older children who are wheelchair bound but able to accomplish transfers, weight-for-height should be in the 25th percentile. For the bedridden patient, the 10th percentile may be sufficient (32).

## ETHICAL AND SOCIAL CONSIDERATIONS

Providing adequate nutrition should be a priority when taking care of NI children. The goal should be to improve their quality of life. Many NI children will ultimately need a gastrostomy. Although there is no randomized controlled trial comparing oral versus gastrostomy feedings in NI children, gastrostomies have been shown to improve nutritional status, to reduce the time spent feeding the child and to improve quality of life (24-26,59,67-71). For parents, however, a gastrostomy may be difficult to accept because they may see it as a failure on their part to feed their child adequately. The physician should respect the parents' wishes and the gastrostomy should be performed when the parents are ready, unless continuing oral feeds is compromising the child's health or nutritional status. Excellent communication and the support of the whole caregiving team are important (72).

## CONCLUSION

Malnutrition should not be considered normal in NI children. Nutritional intervention should be provided by a multidisciplinary team of professionals to ensure adequate growth, improve quality of life and optimize functional status. Early nutritional intervention, appropriate support and continuing follow-up are necessary to ensure success.

## RECOMMENDATIONS

- Nutritional support should be an integral part of the management of NI children.
- A multidisciplinary team should be involved in the nutritional care of NI children.
- Children at risk of nutrition-related problems should be identified early.
- Assessment of nutritional status should be performed at least annually in NI children, and more frequently in infants and young children or in children at risk.
- Oral intake should be optimized if safe for the child.
- Enteral tube feedings should be initiated in children with oromotor dysfunction leading to clinically significant aspiration or in children unable to maintain adequate nutritional status with oral intake.
- Nasogastric tube feeding should be used for short-term (less than three months) intervention.

- For the child requiring long-term nutritional intervention, a gastrostomy should be considered.
- ARPs should be reserved for children with significant gastroesophageal reflux.
- Response to nutritional intervention should be carefully monitored to avoid excessive weight gain after initiation of enteral nutrition.
- Paediatric formulas should be used to avoid micronutrient deficiencies.

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**ACKNOWLEDGEMENTS:** This position statement was reviewed by the Canadian Paediatric Society's Community Paediatrics and Psychosocial Paediatric Committees.

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