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SUMMARY AND RECOMMENDATIONS

Nutritional management of children with cerebral palsy: a practical guide

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INTRODUCTION

In this supplement, we have gathered the evidence and best practices around the nutritional management of children with cerebral palsy (CP) to provide non-experts with a set of simple, practical suggestions to enable them to better manage these children's complex and challenging needs. Each article contains specifics regarding the nutritional assessment and/or management of these children.

Successes of neonatal intensive care and progress in supporting care have led to the emergence of a large group of children with CP at risk of undernutrition. The nutrition and growth deficits in these children are often under-recognised or considered to be of low priority. Undernutrition in children with CP can have various adverse consequences, including growth failure, decreased cerebral function, impaired immune function, reduced circulation time and diminished respiratory muscle strength. This is particularly compelling, given the evidence that poor growth in children with CP is linked not only with poor health and social participation[1] but also with increased mortality.[2] Attention to the nutritional status of children with CP should therefore be an indispensable part of their overall management.

FEEDING, NUTRITION AND GROWTH OF CHILDREN WITH CP

For a variety of reasons, largely due to impaired mobility and inadequate nutrition, children with CP grow differently than neurotypical children. As the level of motor impairment increases, the growth diverges more widely. Feeding and nutrition are intricately interwoven with growth and present some very specific challenges in this population. There is not yet a 'gold standard' for the management of feeding, growth and nutrition in children with CP; however, there is a growing body of evidence to support best practices. Our ability to understand, measure and intervene to optimize nutrition and growth of these children results from research efforts over the past 20 years.

Ideally, children with CP will be cared for in a multidisciplinary setting with access to a variety of subspecialists. In such a setting, a 'feeding team' should include experts in understanding the effect of medical conditions, measuring growth, managing nutrition and the mechanics of feeding and providing social support. At times, however, health care professionals find themselves either managing these children in isolation or leading a team that lacks experience with this population.

As in most of medicine, there is no 'one size fits all' approach, and so, we recommend asking the following general questions regarding the feeding, nutrition and growth of an individual child with CP to help guide decision making.

HAVE THE PSYCHOSOCIAL SUPPORT NEEDS OF THE CHILD, FAMILY AND CAREGIVERS BEEN ASSESSED?

The first step in growth and nutritional assessment is to consider the perspective of the child and their family. Feeding is a critical social component of a child's life, and the growth of the child can be viewed by parents/carers to be a reflection of their ability to nurture.

Structured support should be embedded within the care pathway and included in the care plan before and after interventions and periodically throughout the child's life. Professionals with appropriate training and understanding of the issues should be identified to ensure any emotional, practical and financial issues are addressed.

IS THE CHILD GROWING PROPERLY?

Anthropometric assessment is the cornerstone of evaluation of growth. However, measuring growth in a child with CP can be challenging, because measurement tools are not always available in the general pediatric clinic. Use of segmental measures is recommended as a reliable and valid method for obtaining an estimated height for children who cannot stand to obtain a reliable height. Equations are available to calculate height from ulnar length, knee height and tibial length in some age groups.[3–6] Weight should be obtained on a digital scale, and weight of clothing and undergarments should be considered. Wheelchair scales or weighing a child along with a parent and subtracting parental weights provide a reliable weight if a child cannot stand on a scale.

Providers caring for children use descriptive growth curves to assess whether a child is growing adequately. Although children with CP may be smaller and lighter with less muscle and bone mass than neurotypical children, there is not adequate evidence to support the use of curves specific for CP (these describe how a group of children grew rather than a prescription for how they should grow.) Most important is to follow a child over time and make sure he/she is growing along his/her own growth curve. For infants, it is recommended to assess growth every 1–3 months; for older children the frequency of assessment may vary depending on their nutritional and heath status.

Methods used to assess body composition such as body mass index or weight for height are not valid in children with CP as they do not take into account altered body composition.[7–9] This means that specialized tools may be necessary to truly assess body fat. Underwater weighing and dual-energy x-ray absorptiometry are not feasible in most centers as regular assessment tools, but when caring for a population of children with CP, it may be reasonable to invest in skinfold calipers or bioelectric impedance monitoring.

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Table 1. Key questions to ask parents for assessment of feeding/swallowing problems in children with cerebral palsy

Questions	*Red flags*
How long does it take to feed your child?	More than 30 min, on any regular basis
Are meal times stressful to child or parent?	Yes, if one or other, or both
Is your child gaining weight adequately?	Lack of weight gain over 2–3 months in young child, not just weight loss
Are there signs of respiratory problems?	Increased congestion at meal times, 'gurgly' voice, respiratory illnesses

Given a tendency to store fat centrally, reduced peripheral skinfolds may not necessarily mean low fat stores. Equations to calculate percentage body fat from multiple skinfolds have been developed and their validity is being evaluated in ongoing studies.[10]

SAFETY: IS FEEDING SAFE?

Many children with CP have some degree of oropharyngeal dysphagia, which may be more prominent with certain textures. Oral and pharyngeal problems in children with CP include reduced lip closure, poor tongue function, tongue thrust, exaggerated bite reflex, tactile hypersensitivity, delayed swallow initiation, reduced pharyngeal motility and drooling.

Four key questions should be asked to parents/caregivers in order to evaluate whether a child has feeding/swallowing problems and needs a more comprehensive feeding evaluation (see Table 1).

Providers may wish to refer for a swallow study if there is risk or history of aspiration or an unusual quality to the voice (breathy, husky and gurgly) that would suggest unsafe swallow. It is noteworthy, however, that there is no direct relationship between gag and swallowing ability.

Even with 'unsafe' swallow, most children can participate in non-nutritive oral stimulation and all children should be included in family meals where appropriate. Non-nutritive oral stimulation is important for the development of oral skills, and for pleasure. In tube-fed children, 'taste' sessions from 2–5 min, multiple times per day should be possible. A few drops of lemon juice or ice water given via spoon may help stimulate swallowing and give pleasure without increasing the risk for aspiration. It is rare that a child cannot take anything orally. However, it is important that children are not put at risk for aspiration.

Adequate positioning and physical support during meal times is important to ensure safe feeding. Many children with CP have their own customised seating and/or brace, but they may require additional body and head support to keep them stable and comfortable (avoiding hyperextension or flexion), and to ensure swallow safety.

Textures of food and thickness of fluids may need to be modified under the guidance of a specialised feeding therapist, to ensure airway safety, maximise eating efficiency and reduce fatigue during meal times. Problems with liquids are common and usually relate to a timing problem with delayed pharyngeal swallow initiation. Problems with thick smooth, lumpy or mashed foods relate to residue in the pharynx when pharyngeal motility is reduced. The bolus size can be manipulated for safety in some children. Small boluses are easier for many children than large ones, although the opposite may be true for some. Regular and thorough oral care is also vital for all children.

EFFICIENCY: IS FEEDING EFFICIENT FOR THE CHILD AND FOR THE FAMILY?

In general, an individual feeding session should not last longer than 30 min and caregivers should not be spending excessive amounts of time feeding (to the exclusion of other activities.) Some caregivers spend many hours a day trying to feed their disabled child and quality of life in parents of children with CP may be significantly impaired.[11]

Feeding should not be stressful for caregiver or child. Ideally, the child and family will find feeding to be pleasurable. With these conditions met, the child must still be growing properly and so must be taking in adequate nutrients to support growth.

FEEDING ROUTE: HOW SHOULD THE CHILD BE FED?

Total oral feeding is not a realistic goal for all children with CP but the aim should be to introduce some feeding that is physiologically possible and fits in with the social situation of the child and his/her family. Although most children with CP will be able to take (some) food orally, others will require alternative feeding routes because of dysphagia, extended feeding times and/or insufficient nutritional intake. Caregivers should be gradually introduced to the topic of alternative feeding methods, with sensitivity and careful exploration and support of caregiver's belief system regarding feeding.

Alternative feeding routes should be considered if the child has an unsafe swallow or if feeding is inefficient and/or insufficient. The decision to feed a child through an alternative enteral route (nasogastric, gastrostomy with or without anti-reflux procedure or post-pyloric feeding) should be considered with the input of the entire team including the family. Caregivers may experience an inability to feed their child 'normally' as a failure and should have ample and supported opportunities to explore feeding options.

NUTRITIONAL REQUIREMENTS: HOW MUCH DOES THE CHILD NEED?

Estimating the nutritional needs of a child with CP is not straightforward. Many children with CP have decreased energy requirements in comparison with neurotypical children, and these differences increase with increasing severity of motor impairment. Energy needs of children with severe CP who use a wheel chair for mobility have been reported to be between 60 and 70% of those of neurotypical children.[12–14] Participation in physical activity may increase the energy requirements of children with CP and needs to be considered when estimating energy needs.

There are a variety of methods to calculate energy requirements of children with CP, although none is perfect. We recommend choosing a method to calculate needs and use this as a starting point. Ongoing assessment and monitoring of weight gain and nutritional status is essential to avoid over- or underfeeding. If a child is growing along his/her growth curve, this should be considered successful. If a child is growing appropriately, growth should be monitored every 3–6 months, depending on the age of the child. If growth is faltering, more frequent monitoring may be necessary.

There is no evidence to suggest that protein needs of children with CP differ from those of typically developing populations and therefore recommendations for typically developing children can be used. For severely undernourished children with CP, additional protein and energy may be required to promote 'catch up' growth. An intake of 2.0 g/kg per day of protein and an additional 20% increase in energy intake should be sufficient in these instances.

Standard recommendations for micronutrients (vitamins, minerals and trace elements) should be followed with particular

attention to vitamin D, given the risk of deficiency due to medications and lack of sun exposure.

Once the energy, protein and micronutrient needs of the child have been identified, ideally a nutritionist (or a health care professional with good nutritional knowledge) should work with the family to optimize the dietary intake of the child, using oral or enteral tube feeds if needed.

NUTRITIONAL SUPPORT: WHAT SHOULD THE CHILD RECEIVE?

The type of nutritional support will depend on the nutritional status of the child, the child's ability to consume adequate quantities of food and fluids orally, and the risk of pulmonary aspiration. Where possible, first-line treatment should involve oral nutritional support, with the aim of increasing the energy, protein and micronutrient content of foods and fluids consumed.

If no improvement in nutritional status is seen after a suitable time period (1–3 months depending on the child's age and nutritional status), supplementation with oral nutritional supplements and/or enteral tube feeding should be considered. Numerous oral nutritional supplements (sip feeds) are available commercially including milk- or juice-based products, with and without fibres. Theses feeds have the benefit of significantly contributing to the intake of micronutrients (and potentially of fibre) as well as providing additional energy and protein. The appropriate length of time for a trial of oral nutritional support depends on the age and the nutritional status of the child. Initial follow-up in 1–3 months is usually sufficient; however, infants and those with a poorer nutritional status will need to be reviewed more frequently.[15]

If, despite oral nutritional support, weight gain continues to be inadequate, enteral tube feeding may need to be considered. Enteral tube feeding is indicated in children with CP who are unable to meet their nutritional needs orally, despite oral nutritional support; those with more severe undernutrition, and those with significant feeding and swallowing dysfunction (resulting in risk of pulmonary aspiration or prolonged and stressful oral feeding sessions).[15,16] It may be used as the sole source of nutrition for children with an unsafe swallow or to supplement oral intake. Enteral tube feeding can be administered as a bolus, intermittently or continuously, using an enteral feeding pump. A combination of overnight continuous feeds with boluses during the day may be required to provide sufficient nutrition for some children. The choice of access for enteral tube feeding will depend upon the anticipated duration of feeding and the clinical status of the child, and may include nasogastric, gastrostomy and post-pyloric feeding.

There are many commercial enteral feeds available including polymeric, semi-elemental and elemental formulas, tailored for different age groups. They vary in energy density, fibre content, macronutrient and micronutrient composition, osmolarity and packaging. For children with an increased energy requirement or fluid restriction, a high-energy formula may be useful. For children with lower-energy needs, a lower-energy formula can be used.[14] Feeds with dietary fibre have potential beneficial effects for the prevention of both diarrhoea and constipation.[17] Whey-based formulas may be beneficial in children with poor feed tolerance due to delayed gastric emptying.[18]

SUMMARY

In summary, providers caring for children with CP have a responsibility to assess, reassess and sometimes intervene to help each child maintain optimal growth over time. This requires frequent follow-up (at least every 3–6 months), broad knowledge, and an individualized approach that takes into account the specific needs of each child within his/her family. The child and family should enjoy a safe eating experience, the diet should be varied enough to provide sufficient macro and micronutrients as well as fibre and the child should not experience dehydration. A sensitive and thoughtful approach to all of these questions can guide practitioners with decision making regarding the feeding, nutrition and growth of these children with complex needs. A collaborative family-centered, longitudinal, 'big picture' approach lays the foundation for successful management.

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