

Carol Rees Parrish, R.D., M.S., Series Editor

Nutritional Assessment and Intervention in Cerebral Palsy



Wendy Wittenbrook

Advances in medical care have resulted in a longer lifespan of individuals with cerebral palsy, with many surviving and thriving through adulthood. Individuals with cerebral palsy can have nutritional issues that may significantly impact their health, growth, and development. As children with cerebral palsy “age out” of the pediatric system, adult practitioners may be unfamiliar with the nutrition-related problems that can present in this challenging population. Medical issues, such as wounds, illness, or surgery, are typically the primary focus in the acute care setting. The ultimate goal in nutritional intervention should be to optimize health, fitness, growth, and function in individuals with cerebral palsy. Nutritional assessment, intervention, and monitoring of individuals with cerebral palsy are discussed in this article, along with special considerations.

INTRODUCTION

Individuals with cerebral palsy (CP) present unusual challenges to dietitians when presenting to an acute care setting. Short stature, scoliosis, and oral-motor difficulties are some of the unique characteristics to consider in nutritional assessment and intervention (see Table 1). Children with special health care needs (CSHCN) typically have a “Medical Home,” which is usually a pediatrician or family practice physician who provides routine pediatric care and care coordination of the multiple specialists the child sees (3). In adulthood, the family physician or internist usually contin-

ues this practice, or in some instances, the caregivers must coordinate the individual’s specialty care.

Caregivers usually have medical records containing assessments from an interdisciplinary team, which may include follow up recommendations and guidelines for monitoring nutritional status. If a registered dietitian has previously followed an individual, it can be very helpful to contact them for background information and recommendations. Individuals with CP may be unable to communicate; therefore, caregivers provide important information for a nutrition assessment.

In clinical practice, the Subjective Global Assessment technique (4) is not a good assessment tool for most individuals with disabilities, as the body habitus is not considered in this assessment. However, a phys-

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Wendy Wittenbrook, MA, RD, CSP, LD, Clinical Dietitian, Texas Scottish Rite Hospital for Children, Dallas, TX.

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Table 1.
Common Challenges seen in Individuals with Cerebral Palsy and Other Developmental Disabilities^{1,2}

<i>Parameter</i>	<i>Challenges</i>
Growth	• Underweight • Overweight • Short stature
Mobility	• Ambulatory • Nonambulatory • Power/manual wheelchair • Assistive devices
Dysphagia	• Oropharyngeal • Esophageal
Muscle tone	• Hypertonia • Hypotonia
Alternative/Complementary Medicine	• Side effects • Drug-nutrient interactions
Feeding	• Oral • Enteral • Parenteral
GI	• Gastroesophageal reflux • Dysmotility • Dumping syndrome • Malrotation • Diarrhea/constipation
Orthopaedic	• Contractures • Scoliosis • Dislocated hips • Osteopenia
Medications	• Drug-nutrient interactions • Side effects on muscle tone, bowels, appetite
Pulmonary status	• Effects on energy expenditure

ical assessment is important to identify signs and symptoms of dehydration and malnutrition. Tobin et al. (5) have summarized potential feeding and nutrition problems for a variety of developmental disorders. Although this resource focuses on CSHCN, it also provides information regarding oral motor problems typically seen in children and adults with special health

care needs. Please see references 1 and 2 for information on in-depth evaluation and Table 2 for additional practitioner resources.

NUTRITIONAL ASSESSMENT

ANTHROPOMETRICS: CLINIC VS ACUTE CARE

Stature Measurement

Short stature can result from an underlying diagnosis and/or nutritional stunting in childhood. Changes due to scoliosis, spasticity, contractures, and/or limb differences may even make the individual appear to “shrink” over time. Once maximum adult stature has been achieved, increasing energy and protein intake will not

Table 2.
Additional Resources for Dietitians

Professional Organizations

- American Academy of Cerebral Palsy and Developmental Medicine
- American Dietetic Association
 - Behavioral Health Nutrition Practice Group
 - Pediatric Nutrition Practice Group (Children with Special Health Care Needs Special Interest Group)

Government Organizations

- National Institute of Child Health and Human Development (NICHD), Division of Services for Children with Special Health Needs
- Department of Health and Human Services (state level)

Conferences

- Advances in Pediatric Nutrition
- American Academy of Cerebral Palsy and Developmental Medicine

Publications

(in addition to References at end of article)

- Cricco K and Holland M. Nutrition Assessment Guidelines for Children with Special Health Care Needs. *NUTRITION FOCUS Newsletter*. 2007; 22(3):1–11.
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increase stature. An accurate measurement of stature is necessary to determine an appropriate weight for height (also known as ideal body weight) and in calculating energy and protein needs for individuals with CP. Accuracy can be affected by contractures, scoliosis, or abnormally formed body structures.

In the clinic setting, practitioners use a variety of measurement techniques to assess stature. Canda has developed equations to estimate stature through the use of body segment lengths that may be used in adults with developmental disabilities (6). Knee height (1), upper arm length (1), recumbent length (7), or tibial length (8) are techniques used to estimate stature. Orthopaedic deformities and contractures make arm span and sitting height measurements difficult and impractical to obtain in individuals with CP. The use of a measuring tape to measure along the contours of a reclining individual is not accurate and should be avoided. Measurement techniques should be used consistently and follow a facility's protocol.

A stature measurement should be obtained on each acute admission for adults with CP, as changes in spasticity, scoliosis, and contractures may affect measurements. Children with CP should have a stature measurement upon hospital admission and monthly thereafter.

Weight

In individuals with CP, weight does not reflect the typical distribution of body fat and muscle; therefore, calculating body mass index (BMI) is not useful for estimating appropriate weight for height. Fat stores are typically depleted (9–11) and muscle stores are low compared to norms (9–10). These alterations in body composition should be considered when estimating energy needs. For example, if a hypometabolic individual has low muscle stores but high fat stores (as evidenced by skinfold measurements), increasing energy intake will not lead to muscle mass, as demonstrated by Ohata et al. (12).

An accurate weight may be difficult to obtain, particularly if bed, table, or wheelchair scales are not available. Standing scales may be used to weigh individuals who are able to bear weight. Here are a few considerations to remember when obtaining weights and patients with CP:

- A consistent scale should be used when obtaining weights.
- Outpatient weights should be obtained at least twice a year, and inpatient weights should be measured weekly.
- Scales must be zeroed out before each measurement.
- Individuals should be weighed in light clothing, with a dry diaper (if incontinent), and without shoes and braces.

Assessment of Stature and Weight

The Centers for Disease Control (CDC) growth charts (13) should be used for children and adults less than five feet tall and the Hamwi method (14) should be used for individuals over five feet tall to estimate the appropriate weight for height. Some practitioners use the 50th percentile BMI/age to determine the ideal body weight/appropriate weight for height; however, this assumes an accurate height and the typical distribution of fat and muscle. Disability-specific growth charts are available to assess “typical” growth of various syndromes, but small sample sizes, age ranges, and the lack of availability in an acute care setting tend to limit their use. When plotting individuals up to age 20 on the CDC growth charts, the goal is to have appropriate growth velocity and for the child to follow their growth curve, even when measurements are consistently below the 5th percentile.

Skinfold Measurements

Skinfold measurements are a quick and easy method to assess an individual's body habitus, and these techniques have been previously described in detail in references 1 and 2. The measurements may be interpreted using percentiles published by Frisancho (15), although these were based on a Caucasian population without disabilities. Although fat stores are usually low compared to norms in individuals with CP (9–11), severely disabled individuals tend to have more typical fat stores similar to nondisabled individuals (11).

A single skinfold measurement is not useful to estimate percentage of body fat in individuals with CP. Clinical practice has found serial skin fold measurements over time using the individual as their own control is the best use of these measurements. Triceps skin

fold measurements (TSF) less than 10th percentile have been validated as a reliable screening tool for depleted fat stores in this population (9), and, for these individuals, the appropriate (ideal) weight for height should be used for calculating energy and protein needs. Actual body weight may be used in individuals with TSF between the 25th and 90th percentile, and adjusted body weight may be used in obese individuals.

DETERMINING NUTRITIONAL REQUIREMENTS

Energy

Disability specific standards for estimating energy needs in children with CP are available, (2); however, they are often of limited use due to small sample size, limited age ranges studied and the necessity of an accurate stature measurement. For example, one formula used for CP is: 5–11 years old—14 kcal/cm if ambulatory; 11 kcal/cm if nonambulatory (16). Standards for adults with disabilities are not available. The typical use of prediction equations can overestimate energy needs in CSHCN by as much as 20% (17), and Vernon-Roberts et al. (18) have shown appropriate growth in children with CP with 75% of estimated energy needs via enteral feedings. No two individuals with cerebral palsy are alike; some individuals may be hypometabolic as a result of hypotonia, while others may be hypermetabolic related to increased muscle tone. The DRI equation for calculating energy needs (19) may be most useful in the acute setting, as it can be adjusted or “tailored” to meet a patient’s needs by adding in Physical Activity Coefficients. Adjustments may be made for higher energy needs, such as wound healing or postoperative healing. Energy needs may also be based on the energy intake of the typical diet, with adjustments made for current medical status. It is not uncommon to see a hypometabolic individual with CP who is able to maintain their weight on a very low calorie level. If an individual with CP is admitted to an acute care facility on a nutritional regimen that seems unusually low or high in calories based on a facility’s protocol equations, clinicians should resist the temptation to change it. Most likely, the individual has been followed regularly by a dietitian that is quite familiar with them, and this regimen may be the one that has worked out of many

months of trial and error. If the individual is doing well, they should remain on their preadmission nutritional regimen. The recommended changes based on a facility’s protocol may seem like a simple change to the inpatient staff; however, this may cause significant upset to the individual and family.

The effect of medications on energy expenditure is important to consider. For example, individuals with hypertonia that use medications such as Artane® (Trihexyphenidyl) or Lioresal® (Baclofen) to reduce muscle tone often have a reduction in their energy expenditure; therefore, weight should be closely monitored and energy intake adjusted to prevent undesirable weight changes. Antipsychotic medications, such as Risperdal® (Risperidone) have been noted to result in excessive weight gain resulting from the side effect of increased appetite.

Protein

Protein needs are estimated using the RDA/DRI and actual weight or appropriate weight for height (if <90% or >125% appropriate weight for height). There are no guidelines for estimating protein needs of individuals with disabilities under stress such as surgery. Protein intake has been increased up to 1.5–2 g/kg/day in clinical practice for presurgical/postsurgical planning and wound healing with normal renal status.

Estimating Fluid Requirements

Determining fluid needs is an important step in assessment, as many individuals with CP have fluid loss through sialorrhea or sweating, and are unable to con-

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Table 3.
Calculating Fluid Needs²⁰

<i>Weight</i>	<i>Calculation</i>
1–10 kg	100 mL/kg
10–20 kg	1000 mL + 50 mL/kg for each kg above 10 kg
>20 kg	1500 mL + 20 mL/kg for each kg above 20 kg

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sume adequate quantities of fluids and/or communicate thirst. Actual body weight is used to estimate fluid needs using the Holliday-Segar equation (Table 3). However, the calculated fluid needs may not be realistic; therefore, in clinical practice, a goal of 90% of “ideal” fluid intake is more feasible. The often used rule of thumb of 1 mL of fluid per 1 kilocalorie (21) may underestimate the fluid needs of individuals who are hypometabolic.

CONSIDERATION OF SPECIAL ISSUES

GI Issues

Gastrointestinal issues are prevalent in individuals with CP and should be considered during a nutrition assessment. The underlying neurologic impairment in cerebral palsy can affect the gastrointestinal system, most notably oral-motor function and motility (especially colonic, which typically results in constipation). The possibility of autoimmune diseases, such as celiac disease, food allergy, or eosinophilic esophagitis should also be considered.

Dysphagia/Oral Motor Dysfunction

Every individual with CP should be screened for dysphagia, for it commonly presents as a sequelae of the underlying damage to the central nervous system. Dysphagia in CP typically presents as a history of feeding difficulties, extended feeding times, malnutrition, and/or a history of aspiration pneumonia (22). More severe oral-motor dysfunction is seen with increased severity of the disability (23,24). Medications used to reduce muscle tone can also increase dysphagia risk (23). For example, severe dysphagia has resulted from Botox injections

of the salivary gland for sialorrhea treatment, as observed in clinical practice. See Table 4 for additional signs/symptoms of dysphagia in addition to obvious difficulty with oral feedings. As the population of individuals with CP ages, dysphagia can worsen or can present as a new diagnosis after a stroke or other central nervous system damage that occurs with aging (23). Screening for dysphagia should be done at each clinic visit, as well as when a patient presents to an acute care unit (23,24).

Constipation

Dysmotility, hypotonia, medications, and nonambulation contribute to constipation. Medications commonly used in this population that can cause constipation include Artane® (Trihexyphenidyl), Robinul® (Glycopyrrolate), Valium® (Diazepam), or narcotics. Veugelers et al. (25) found more than half of children with CP in their study had constipation. A higher incidence was seen in individuals with a more severe disability and those who took medications contributing to constipation. Despite laxative treatment, one-third of individuals were still constipated. Although the authors found increasing fluid and fiber intake had no significant effect (25), clinical practice has found increasing fluid intake to 90% of fluid needs can help manage constipation in CP. The DRI for fiber is typically used to determine fiber recommendations (19); however, this may not be realistic due to food choices in individuals with CP, although fiber supplements may be helpful. Ensuring adequate fluid intake prior to increasing fiber intake can help prevent additional problems with constipation. Adjusting fluid and/or fiber intake does not always improve constipation, and increasing fiber can sometimes worsen constipation; therefore, medical management is frequently required. Pain from constipation may be confused with pain in other areas, particularly hip pain. A kidney, ureters, and bladder (KUB) x-ray can be helpful to assess constipation to assist in decision making for medical management of constipation. A patient's normal stool habits should be noted and their typical bowel regimen continued while in the acute care unit unless contraindicated.

Dysmotility

Issues with dysmotility can present in several forms: dysphagia, gastroesophageal reflux disease (GERD),

Table 4.
Additional “Red Flags” for Dysphagia
in Cerebral Palsy²⁴

- Recurrent respiratory infections
- Constipation
- Hiatal hernia
- Gastroesophageal reflux disease
- Scoliosis
- Epilepsy

Table 5.
Risk factors for Low Bone Mineral Density in CP^{26,27}

- Feeding difficulties
- Medications: antiepileptics, birth control medications, glucocorticoids, magnesium/aluminum antacids
- Motor function/weight bearing status
- Poor nutritional status
- Prolonged immobilization
- Disordered puberty/growth retardation
- Low weight z-scores
- Calcium and vitamin D intake in diet

delayed gastric emptying and dumping syndrome (22). The diagnosis and treatment of these issues can make feedings more pleasurable and better tolerated in addition to promoting positive weight gain. Proton pump inhibitors such as Prilosec[®] and Prevacid[®] are often prescribed for treatment of GERD. Prokinetic drugs (Metoclopramide[®]) and positioning changes can be used to improve gastric motility. The feeding regimen can be changed by increasing or decreasing the infusion rate and/or formula volume to help promote gastric emptying and improve feeding tolerance. Sometimes, nighttime feedings may need to be changed to daytime feedings to assist with motility. Caregivers should always be involved in any discussions regarding changes in a feeding regimen, as they will be responsible for administering the feedings after discharge. A Nissen fundoplication or a conversion from gastrotomy to gastrojejunostomy can be done in more severe cases of GERD; however, a Nissen fundoplication does increase the risk of dumping syndrome.

Spinal Abnormalities

Neuromuscular scoliosis is present in many individuals with CP (7). Scoliosis progression can result in diminished gastric capacity, GERD, difficulty in positioning for feedings, and changes in motility that can cause early satiety, nausea, and vomiting. Pulmonary compromise related to scoliosis can also increase energy expenditure. Clinical practice has found previously undiagnosed malrotation and/or volvulus when individuals continue to have difficulty with feedings and weight gain. Individuals with CP who have postoperative weight loss are at risk of developing superior mesenteric artery syndrome (SMA) with the loss of the mesenteric fat pads.

Bone Health

Sheridan (26) recently reported more than 50% of adults with disabilities (including CP) had low bone mineral density (BMD). Table 5 lists risk factors for low BMD in individuals with CP. Clinicians should ensure adequate calcium and vitamin D intake, with supplementation as needed to meet the DRI for these nutrients (28). Vitamin D supplementation should be started when a deficiency is evident by assessing serum levels of 25(OH)-D. Shinchuk and Holick (29) recommend supplementation if 25(OH)-D levels are less than 30 ng/mL; however, the recent Institute of Medicine (IOM) report recommends supplementation only when 25(OH)-D levels are less than 20 ng/mL (28). 25(OH)-D levels should be checked every three months until levels are within normal range (30).

NUTRITION MANAGEMENT AND MONITORING

Once a safe feeding route has been decided, feedings may be started. The typical feeding pattern or schedule can be obtained from either caregivers or medical

Table 6.
Assessment of Feedings

- I. Usual feeding patterns
 - a. PO intake vs. enteral feedings
- II. Assess changes in intake/output
 - a. Feeding patterns, food selections, tolerance, stooling
- III. Assessment of safety and efficiency of usual feeding patterns/route
 - a. Growth trends in pediatrics, weight history in adults

Table 7.
Monitoring in the Acute Care Setting

<i>Parameter</i>	<i>Frequency</i>
Height	Upon admission (monthly in pediatrics)
Weight	Weekly
Skinfold measurements	Twice monthly
Laboratory measurements	Dependent on admission diagnosis, medications, treatment modalities
Oral intake/Enteral feedings	Monitor tolerance daily until stable/well tolerated; then per facility protocol

records. See Table 6 for feeding assessment questions. Adjustments may need to be made based on current medical status, such as postoperative status. Individuals that have been chronically undernourished can be at a higher risk of refeeding syndrome. In clinical practice, clinicians have noted increased energy expenditure resulting in growth failure or lack of weight gain with oral feeding due to the length of time and effort to eat. This should be considered when changing to enteral or parenteral feedings, which may reduce energy expenditure and result in rapid weight gain. Adjustments to increase energy intake by 10–15% with careful monitoring of weight and refeeding syn-

drome indicators in underweight or malnourished individuals has been well tolerated in clinical practice.

Supplementation to meet the DRI for vitamins and minerals may be required, particularly for hypometabolic individuals on low calorie diets or enteral feedings. Children who receive enteral feedings should be on a product that best meets their nutrient needs with minimal vitamin and mineral supplementation. This may result in a pediatric formula for a teenage individual, or a higher protein, 1 kcal/mL formula for a ten year old child undergoing complex spinal surgery. Table 7 has monitoring guidelines and Table 8 lists clinical pearls for use in individuals with developmental disabilities.

Table 8.
Nutrition Pearls for Individuals with Developmental Disabilities

1. A visual assessment is very important, consider what is “typical” for the diagnosis(es).
2. Consider all possible contributors to energy needs, including: mobility status, respiratory status, and muscle tone.
3. Screen for dysphagia to determine a safe feeding route.
4. Screen for motility issues, including GERD and constipation/diarrhea—“what goes in must come out”.
5. Assess drug/nutrient interactions, such as the effect of seizure medications and birth control medications on bone health.
6. Ensure adequate protein and micronutrient intake, especially in hypometabolic or hypocalorically-fed individuals.

CONCLUSION

The variable nature of CP, in addition to urgent medical issues, can present challenges to dietitians unfamiliar with this diagnosis. During a nutrition assessment, ensure accurate and consistent anthropometric measurements, appropriately determinate energy, protein, fluid and micronutrient needs, and consider dysmotility and spinal anomalies. Careful monitoring and adjustments to ensure optimal nutrient intake can help optimize health in individuals with CP.

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