

Nutrition Focus

for children with
special health care needs



Volume 28, No. 2

March/April 2013

Feeding the Child with Very Low Energy Needs

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EDITOR'S NOTE

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Neurologic impairments, whether associated with a congenital disorder or due to a traumatic event, can influence the nutritional requirements of children with special health care needs. In some cases the nutrition issues are present due to medical complications and severe disabilities, including seizures, gastrointestinal disturbances such as gastroesophageal reflux (GER), vomiting, or constipation; oral-motor dysfunction, severe intellectual disabilities, hypotonia, minimal physical movement, poor head control, and developmental delays.

Some children, such as those with athetoid cerebral palsy, or those with pulmonary and cardiac conditions, require a very high intake of energy (kilocalories) due to increased muscle tone and respiratory rates and a high level of involuntary movements. Many resources are available to aid in the nutrition management for children with high energy needs. For other children, metabolic rate and activity level are very low compared to children of a comparable age and size. Thus, their energy needs are reduced, but there is little documented information available for assessing children with low energy requirements.

For any child with special health needs a coordinated team approach provides for communication and the most effective care. This team includes parents or caregivers and other professionals who work with the individual child. The team should include a registered dietitian (RD), who has experience working with families who have children with special needs. The RD assesses the unique requirements of a child with very low energy requirements.

This NUTRITION FOCUS edition will review issues related to energy and nutrient needs for children requiring a very low level of kilocalories. Two case studies will be presented to illustrate the discussion.

Editor's note - In this issue we will use the term energy to indicate kilocalories.

ETIOLOGY

Causes for decreased energy needs may include genetic defects, birth trauma, progressive degenerative neurologic disorders, complications of metabolic disorders and severe injury. Table 1 (on page 2) outlines possible etiologies for a child who may require less energy intake.

Static encephalopathy, seizure disorders, and microcephaly can result from many conditions or traumatic events. Similar brain injuries can occur in children of any age, due to accidents such as near-drowning or head trauma.

Some disorders are seen at birth, such as lissencephaly (abnormal brain tissue growth), or mitochondrial oxidative disorders (defect in the cells ability to make energy for growth). Others are sometimes identified during infancy from known genetic causes. There can be instances when a diagnosis is not found.

Neurologic impairments also may result from an acute single traumatic event in utero or at birth. These include birth asphyxia or intravascular hemorrhage of prematurity. In these cases irreversible brain damage occurs due to reduced blood flow leading to lack of oxygen for brain tissue.

In situations in which blood glucose drops too low (if a baby is not fed for extended period of time), brain development and function may also be impaired.

Some disorders, such as Batten disease, may present at older ages, with progressive loss of developmental skills and motor function. These children have normal development until the onset of the disorder. Developmental milestones and skills are lost as the condition progresses. Children with Batten disease have a defect which causes accumulation of a fatty substance in the brain, destroying brain cells. There are four different types, which can present at infancy, toddler age, school age, and adolescence. Symptoms may begin with seizures and movement difficulty. As the disease progresses, brain atrophy and microcephaly can develop. Many other conditions and disorders may also lead to a decreased level for energy intake but are beyond the discussion of this article.

GROWTH AND BODY COMPOSITION

Altered body composition associated with Down syndrome, Prader-Willi syndrome, cerebral palsy, and spina bifida may decrease energy needs.¹ Children with these diagnoses usually have hypotonia (with the exception of children with spastic cerebral palsy who may have increased needs), delays in motor development, or limited mobility, resulting in low lean body mass.² Studies have shown these children to have significantly higher body fatness than typical children. Their metabolic rate both at rest and during activity may be lower than children with a similar body mass index (BMI). For further reading on the nutrition management for Down syndrome and Prader-Willi syndrome, please refer to RESOURCES 1 and 2.

Linear growth is often impaired but weight gain tends to continue in this population of children with low energy needs. Providing levels of energy intake considered normal for age and body weight can lead to overweight and obesity. Excess weight can complicate medical conditions such as respiratory distress. Lifting and positioning heavy children during daily care can become difficult. In one instance, parents reported nurses would no longer continue their services, as their child had gained too much weight.

Many children with special health care needs, including those with very low energy requirements, experience growth patterns that are different from their peers. Although specialized growth charts for specific diagnoses are available, practitioners should recognize their limitations and interpret with caution. Specialized growth charts should be used together with the World Health Organization (WHO) growth chart for infants birth to 24 months, and the Centers for Disease Control (CDC) growth charts for children aged 2 years to 20 years for accurate assessment. For additional information about the use of specialized growth charts please see RESOURCE 3. Individual assessments for

Table 1 – Conditions which may require a decreased energy intake

- Down syndrome
- Prader-Willi syndrome
- Cerebral palsy
- Spina bifida
- Birth asphyxia
- Mitochondria oxidative disorders
- Static encephalopathy
- Intravascular hemorrhage
- Severe hypoglycemia
- Batten disease
- Intravascular hemorrhage
- Lissencephaly
- Intractable seizures
- Near-drowning
- Head trauma

Table 2 – Growth Guidelines for the Child Requiring a Very Low Energy Intake

- Maintain an ideal weight-for-length (for infants and toddlers birth to 24 months) or BMI (for children and youth 2 years to 20 years) of 25th percentile (acceptable range - 10th to 50th percentile)
- Underweight - catch-up to minimum weight-for-length or BMI of 10th percentile
- Overweight - when weight-for-length exceeds the 75th percentile, reduce calories to slow weight gain. Weight loss is not usually recommended unless the child is severely obese and the obesity is a threat to the child's health.

growth and weight gain are essential with trends evaluated over time. Table 2 lists the goals for growth in a child who requires a very low energy intake.

Length/Height

Children who require a low energy intake are often shorter (clinical observation), despite receiving adequate nourishment. If the condition occurs at birth, the infant's growth may plot within normal limits on a growth chart, but then lose velocity depending on the underlying condition. In addition, the effect of the condition or event on the central nervous system may also influence the child's growth potential. Growth may be adequate if the child's rate of growth is maintained, and weight for length or body mass index (BMI) is between the 10th-50th percentiles.

Weight

In early infancy the child may experience poor weight gain or failure to thrive due to poor feeding, chronic vomiting, and recurrent infections, such as pneumonia. Energy and nutrient requirements should be estimated for catch-up

weight gain. If catch-up weight is achieved without subsequent gains in height or head circumference, then the child's overall growth pattern may be affected by the underlying condition.

FEEDING ISSUES AND COMPLICATIONS

Oral Motor Issues

Oral motor dysfunction and gastrointestinal problems can interfere with adequate nourishment. See Table 3 for a list of concerns.

Infants may present with poor suck and swallow. Parents or caregivers may spend hours trying to feed their child. Formula intake may be insufficient despite feeding times of one hour or greater. Progression to solid foods may be limited to pureed consistencies. Also, chewing and swallowing of textured food may be ineffective and unsafe.

Other children may never achieve oral and/or self-feeding skills, or feeding skills may be lost, as with Batten disease. They may start choking and gagging when eating and later lose the ability to chew. Eventually, adequate oral-motor function may be lost completely, requiring a gastrostomy tube placement.

When feeding issues are present, a feeding evaluation and video fluoroscopy swallowing study (VFSS) is warranted to assess the difficulties and the safety of intake of liquid and solid foods. If the child has had recurrent upper respiratory infections, the possible aspiration of food into the lungs must be considered and may be determined during the VFSS. Regardless of the child's prognosis, if it is unsafe for the child to eat because of aspiration or if the child is undernourished, a discussion of the placement of a feeding tube is needed between the family and the health care team. For additional information regarding VFSS please see RESOURCE 4.

Medical Issues

Feedings may also become more difficult when conditions worsen, such as uncontrolled seizures. Children with intractable or poorly controlled seizures are often on more than one medication to control seizures. A nasogastric feeding tube can be placed for adequate nutrition, until the issue of seizure control is resolved and/or medications are changed.

Side effects of medications can also cause lethargy, difficulty swallowing and chewing food, and GER, all of which exacerbate poor eating. Many of these side effects may resolve with decreasing or changing medications. RESOURCE 5 provides information regarding side effects for selected medications <http://here.doh.wa.gov/materials/nutrition-interventions/?searchterm=nutrition%20interventions>.

Gastrointestinal symptoms (GER, vomiting and/or constipation) can also occur from underlying conditions and/or medications. GER and vomiting can occur during or after Nutrition Focus Vol. 28 #2

feeding. Modifications in feeding can aid in reducing vomiting or GER. If the child is bottle fed, thickening formula is sometimes recommended. Smaller, more frequent feeds may also help. Children receiving gastrostomy tube feedings may benefit from a reduction in the rate formula is offered through the use of drip feeds. Drip feeds can be given either by gravity or by using a feeding pump.

Medications are also used to reduce acid in the stomach and increase stomach emptying if the GER/vomiting becomes a chronic condition. If untreated, these conditions can cause esophagitis (inflammation of esophageal tissue) and in severe cases, stomach or esophageal bleeding. Aspiration can occur, resulting in pneumonia. Surgical procedures (i.e., Nissen fundoplication), or a jejunostomy feeding tube may be considered in extreme cases of GER, if medications are not effective.

Constipation is a common problem. Chronic constipation may contribute to GER and vomiting if a good bowel program is not maintained. Factors contributing to constipation include:

- low muscle tone
- non-ambulation
- minimal movement
- inadequate fluid intake
- lack of solid food intake and/or fiber intake
- medications

A nutrition assessment is an important part of any bowel program and includes a review of food and fluid intake. Adequate fiber (from food or as a component of a formula), and appropriate levels of fluids, including water and juices, such as prune or pear nectar, can be recommended. The contribution of energy from these foods/fluids needs to be calculated based on the child's overall plan. For some children the management of severe chronic constipation may require a prescription for stool softeners or suppositories from the health care provider.

Table 3 – Oral Motor Difficulties Which Can Affect a Child's Food Intake

- Inability to suck
- Inability to chew
- Tongue thrust
- Discoordinated tongue movement
- Difficulty swallowing
- Gagging
- Choking
- Lack of progression to increasing textures

GUIDELINES FOR ESTIMATING NUTRIENT REQUIREMENTS

Energy Needs

With the exception of infants, estimation of energy needs is based on calories per length/height instead of calories per weight. The use of weight tends to over-estimate energy requirements in children with low-energy needs, as many have reduced muscle tissue. However, an infant's energy needs are higher, as a greater percentage of growth is lean body tissue (i.e., heart, lung, liver, etc.).

Table 4 provides a guide to energy recommendations for a child with very low needs. The energy recommendations listed here are provided as a guide. More specific information may be available in condition-specific literature.^{3,4,5,6} Each child needs an individual nutrition assessment by the RD experienced with children who have special needs, especially those with very low energy requirements that impact their overall nutrient intake. Initially, the lower level of energy may be a starting point unless catch-up growth is an issue.

Once an energy level is determined, close monitoring will be needed to assess the child's growth and weight gain. The selection of one setting to do monthly weight and length/height checks provides for consistent measurement technique and equipment. The family may choose a site convenient and close to them. The site may be the primary care provider, an early intervention center, a WIC clinic, or the school. Another option may be home visits by a nurse or therapist who has access to the proper equipment.

Ongoing weight monitoring is important, as adjustments in energy recommendations are necessary once the child achieves an appropriate weight and rate of gain. If

Table 4 – Energy Recommendations for the Child Requiring a Very Low Energy Intake	
NOTE: kcal/kg body weight = kilocalories per kilogram of body weight kcal/cm body height = kilocalories per centimeter height	
Infants (based on weight)	Birth-6 months of age: <ul style="list-style-type: none"> • 70-100 kcal/kg
	6-12 months of age: <ul style="list-style-type: none"> • 50-80 kcal/kg Estimated energy needs for catch-up growth <ul style="list-style-type: none"> • 110-130 kcal/kg
Children (based on height)	Lower energy needs <ul style="list-style-type: none"> • 7-9 kcal/cm
	Moderate energy needs <ul style="list-style-type: none"> • 9-11 kcal/cm
	High energy needs <ul style="list-style-type: none"> • 12-15 kcal/cm

Table 5 – Fluid Needs for Children	
Calculate fluid needs for the first 10 kg or 22 lbs as noted.	
Weight	Water
0-10 kg (22 lbs)	100 mL/kg (45 mL/lb)
Calculate the first 10 kg or 22 lbs as noted above. Then add additional fluid for additional weight using these guidelines for the next 10 kg or 22 lbs.	
10-20 kg (22-44 lbs)	+ 50 mL/kg (24 mL/lb)
For children weighing more than 20 kg or 44 lbs first calculate fluid using the guidelines above. Then add additional fluid for weight greater than 20 kg or 44 lbs.	
>20 kg (>44 lbs)	+ 20 mL/kg (9 mL/lb)
Example – Child weighs 24 kg:	
1st 10 kg	= 1000 mL fluid (10 x 100)
2nd 10 kg	= 500 mL fluid (10 x 50)
4 additional kg	= 80 mL fluid (4 x 20)
Total fluid needs	= 1000 + 500 + 80 = 1580 mL fluid
30 mL = 1 ounce; 1 kg = 2.2 lb.	

close monitoring has not been established, weight gain can exceed the ideal, with weight for length or BMI moving above the 95th percentile (See Case Study 2).

If weight increases too rapidly, determine if the gain is due to the current energy guidelines before decreasing the intake recommendations. Confirm the child's intake, the use of extra food/formula, and if applicable how the formula is prepared. For a child who receives a tube feeding, ask what is being used to flush the tube (e.g., is Pedialyte being used instead of water and supplying not only extra electrolytes but also extra energy), and whether extra tube feeding is being given when the caregiver thinks the child might be hungry. The child should also be assessed for fluid retention.

Protein Requirements

There are no clinical studies that support different protein requirements for children with low energy needs.^{7,8} The Dietary Reference Intake (DRI) for age should be used to determine protein needs.

Fluid Needs

Fluids should be based on maintenance needs and increased for additional losses from excessive drooling, increased sweating, or constipation. For extra fluid losses, add an additional 5-10% above maintenance levels. Watch for signs of dehydration if the child has excessive losses from vomiting, drooling or sweating.

If the child receives a reduced volume of formula or food to meet his lower energy needs, careful attention to the water content of the formula/food is needed. An individual

child may need more fluids than one would expect since the contribution from formula/food is lower than typical. See Table 5 on page 4 for a guide to fluid needs of children.

Children with very low energy needs may not meet their electrolyte needs through formula or food. The RD should monitor trends in electrolytes. It may be necessary to meet electrolyte needs with an electrolyte rich beverage such as Pedialyte, or by adding table salt and salt substitute to formula or food. Remember to include energy contributions from Pedialyte when developing the recommended intake.

Vitamins, Minerals and Trace Elements

The child's intake for other nutrients should meet 100% of the DRI for vitamins, minerals and trace elements based on the child's age.⁷ Generally, pediatric formulas are designed for children ages 1-10 years of age. They provide 30 kcal/ounce (1 kcal/mL) and meet 100 percent of the DRI for vitamins, minerals and trace elements at a volume of 1000 mL (about 33 ounces). Pediatric formulas are lower in protein than adult products to reflect a child's lower needs. Formulas for adults meet the DRI at a higher volume (1500-1800 mL), with higher protein content. Adult formulas may be used for older children and teenagers who need lower energy needs.

Recently a new formula has been introduced for children with lower energy needs. Nestle Compleat Pediatric Reduced Calories is an enteral formula that provides 18 kcal/ounce (0.6 kcal/mL) and meets the RDA at a volume of 1000 mL.

Low energy diets may not provide adequate levels of protein, vitamins, minerals and trace elements. To achieve the proper amounts of all nutrients, modular components, such as protein, vitamins and minerals, can be mixed with the formula or given as a "medication." A formula should be selected which best meets all of the child's energy and nutrient needs, to reduce the number of supplements and modular components. However, some children may have such a low energy need that these supplements and components become necessary. A complete dietary assessment by the pediatric RD is needed to determine if supplementation is needed and how much of each nutrient is required. The availability, cost, and ease of using these products must be considered for each family. Additional supplementation can be given if <90% of RDA is being met with the current intake. Table 6 lists some guidelines for supplementation.

Children with low energy needs may also be taking seizure medications which impact bone health. Consider measuring serum vitamin D level (25-OH vitamin D) and supplement as necessary. The vitamin D DRI for children is 600 International Units (IU) per day. However children living in certain parts of the U.S. may require intakes above this to achieve an adequate serum vitamin D level.

SUMMARY

Children with severe brain injury and neurologic impairment may have several issues which can affect nutrition. Often a gastrostomy feeding tube may be needed for

Table 6 - Guidelines for Supplements for Low Energy Diets

Vitamin-Mineral Supplement - Use a complete vitamin-mineral supplement. NanoVM® (Solace Nutrition) and Phlexy Vits® (Nutricia) are more complete than typical pediatric vitamin-mineral supplements, but can also be costly. Adult Centrum® in reduced doses has also been used by practitioners. Tablets or capsules can be crushed and dissolved in water and given with food or through the feeding tube.

Calcium - If additional calcium is needed then several choices are available.

1. Neocalglucon® - a liquid calcium supplement; 5 ml = 115 mg calcium. In some states Medicaid may pay for this if the use is justified.
2. Regular strength Tums® (200 mg of elemental calcium per tablet) can be crushed and dissolved with water for calcium replacement. Editor's Note - Dissolve 12 regular strength TUMS® in four ounces (120 cc) of water. Store in refrigeration. Shake prior to use. 20 cc of this mixture equals 400 mg of calcium.

Phosphorous - Neutraphos® for phosphorous replacement (this is a powdered product with 250 mg of phosphorous per packet)

Note - calcium and phosphorous supplements must be given separately to prevent these supplements from precipitating and clogging feeding tubes.

Magnesium - Magnesium can be found in 50- 250 mg tablets.

Vitamin D - Check serum 25-OH vitamin D levels to assess need for additional supplementation. Most pediatric multivitamins do not meet the updated recommended dietary allowance (RDA) of 600 IU/day. Vitamin D supplements are available in softgel, capsule, tablet, and liquid form. They also commonly come combined with calcium.

Protein - Protein supplements, such as Beneprotein® (Nestle), Protifar (Nutricia), or nonfat powdered milk can be added to pureed foods or tube feeding formulas if protein is too low. Note: Beneprotein is contraindicated for children under 1 year of age, and nonfat powdered milk is not recommended for infants due to high renal solute load. Some adjustment will be needed for the energy that the protein supplement provides.

adequate nourishment, if it is unsafe for a child to eat, or if they are unable to eat orally. Over-feeding these children is a common occurrence if a follow-up schedule/monitoring is not incorporated in the care plan. Establishing weight goals with frequent monitoring of weight helps reduce the risk of chronic under or overfeeding.

Reducing calories from the child's food intake or formula also limits protein and other nutrients. Additional supplementation is often required for adequate nutrition. A pediatric RD can assess the needs for the very unique requirements of child requiring a very low energy intake. There is no ideal prescription for these children; each is an individual that must be evaluated based on their own growth and development.

CASE STUDIES

Case 1

Brandon was born with lissencephaly, seizures, prenatal onset of encephalopathy, and microcephaly from unknown causes. He was first seen by a pediatric RD when he was five months of age. His parents had concerns about his poor weight gain over the past month and Brandon's progressive difficulty with feeding and tolerance to feeds.

Brandon was usually fed every three hours with three to four ounces of a standard infant soy formula. Earlier feedings had lasted about 45 minutes with periods of poor nipping and vomiting both during and after feedings. Currently feedings were about 1 1/2 hours in length with four ounces consumed. Brandon's parents fed him every 5 hours as Brandon was difficult to rouse from sleep. He continued to vomit after feeds.

An initial recommendation was made to thicken formula with rice cereal (one tablespoon rice cereal for every 2 oz formula). Brandon was given different seizure medications at this time. An appointment for a feeding evaluation and VFSS were scheduled. (See RESOURCE 4 for a NUTRITION FOCUS article which discusses GER, possible interventions and VFSS).

At the two week follow-up appointment Brandon was drinking four to four and one-half ounces of formula every three hours. Vomiting/spit-up had decreased with the thickened feeds. Brandon had gained 1.8 kg (four ounces per day) during the two week period. His parents noted that Brandon seemed hungry and was sometimes given a bottle more frequently than every three hours. The length of feeding time had decreased back to one hour. The RD recommended the use of 3-3 1/2 ounces per feeding to slow the rate of Brandon's weight gain.

Also during this visit a VFSS was conducted, indicating severe dysphasia, with frank aspiration of formula after feeding. Long term problems of chronic aspiration were discussed by the physician and Brandon's parents. The use of a gastrostomy feeding tube was recommended and the

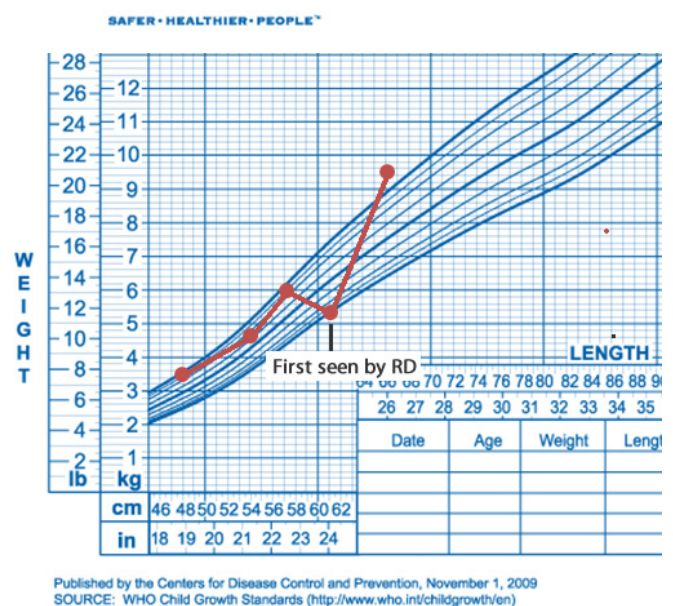
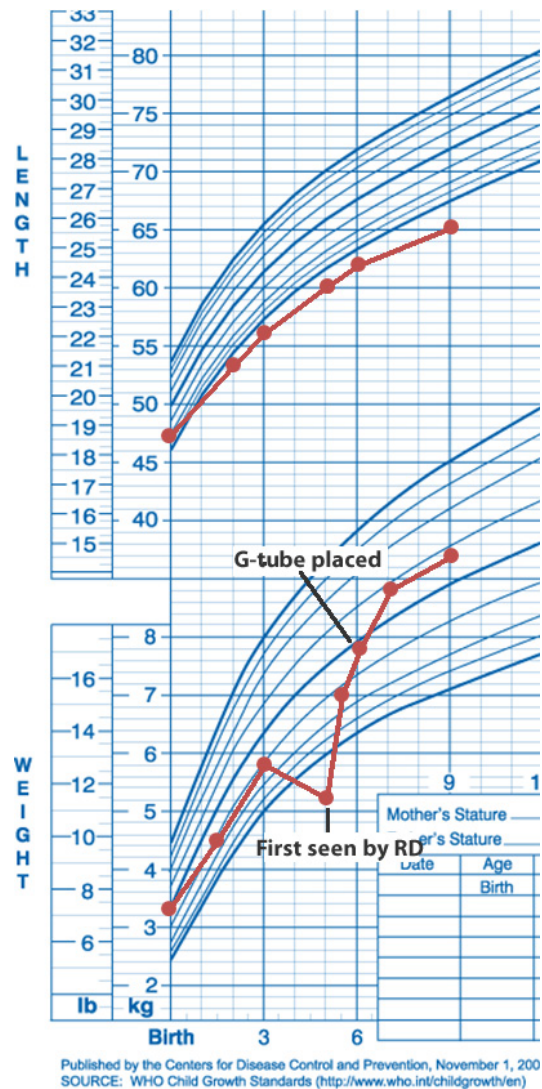


Figure 1. Brandon's growth charts. Top: Weight-for-age and length-for-age, Bottom: Weight-for-length

parents agreed to this placement. A nasogastric feeding tube was placed at the clinic until surgery for the gastrostomy tube. To reduce vomiting episodes, the feeding schedule was changed to 2-2 1/2 ounce bolus feedings every three hours during the day with a night drip feeding over a ten hour period.

At a follow-up visit one month after gastrostomy was placed, Brandon had continued to gain weight at an excess rate (1 kg in one month) despite his decreased formula intake. Brandon's weight was greater than 130% of expected for stature. (See Brandon's growth chart on page xxx).

His formula volume was reduced further and monthly weight checks were recommended. His parents were given a goal weight for each month. If Brandon was over or under this weight, parents were to call. Additional formula changes would be given over the phone.

Comment

This case illustrates how rapidly Brandon gained weight. Frequent weight checks were essential for determining appropriate energy level. Early intervention with the RD helped with management of feeding issues, formula tolerance, and prevented excess weight gain.

Case 2

Editor's note - Raymond's early growth was plotted on the CDC Birth to 36 month growth charts available at that time (Figure 2). With the introduction of the WHO growth charts for children Birth to 24 months NUTRITION FOCUS has decided to plot information on those charts for selected cases so that readers can compare the charts and understand how changes in weight may appear (Figure 3). The reader must also remember that the WHO charts were derived from healthy, breast fed babies. We use the WHO and CDC charts for children with special health care needs. Careful evaluation of growth patterns and, for some children, more frequent monitoring due to their individual concerns is required.

Raymond is a 9-year old boy with prenatal encephalopathy, microcephaly, cerebral palsy, seizure disorder, significant hypotonia, intellectual disabilities and developmental delays. Raymond has had ongoing nutrition concerns and is seen by a pediatric RD once or twice per year.

As an infant, Raymond had difficulty with bottle feeding, due to a poor suck and frequent spit-up after feeds. He only gained 0.8 kg (1.7 lb) between 7 and 21 months of age although his weight and weight/length were both >95th percentile at 7 months of age. (See Raymond's growth charts on pages 8 and 9.)

Raymond was able to maintain slow growth at an average energy intake of approximately 50 kcal/kg. At 27 months of age, Raymond was hospitalized for pneumonia. During this illness, he had difficulty bottle feeding, leading to a significant weight loss of 2.5 kg (5 lb) over a 2

month period. A nasogastric (NG) feeding tube was placed to supplement bottle feeds. The NG feeds were poorly tolerated, (three ounces of diluted PediaSure[®] were given every 3 1/2 hours). To reduce episodes of vomiting the NG tube feedings were changed to continuous drip at a rate of 35 mL/hr to reduce episodes of vomiting. At this time Raymond's energy intake was estimated, considering infection and weight loss, to be 10 kcal/cm of length.

The physicians were concerned with possible aspiration pneumonia due to swallowing difficulties and GE reflux. Therefore, a VFSS was done at 32 months of age, which showed aspiration with all liquids, but not pureed food.

A gastrostomy tube was placed at 33 months of age. Raymond showed rapid weight gain with an intake of 6 kcal/cm. He received 2.5 cans of PediaSure[®] and 4 ounces of pureed foods per day. In addition to the formula and food, Raymond was daily given 3 tablespoons of Casec[®] (a protein supplement by Mead Johnson which is no longer in production), calcium (2 Tums[®]), phosphorous (2 packets), and a liquid multivitamin-mineral supplements. By 38 months of age Raymond's BMI was at the 95th percentile.

Editor's note - By 38 months of age Raymond's growth was plotted on the CDC charts for 2-20 year olds. The growth charts at this age are based on children measured using a standing height. Due to Raymond's development a length measurement was required. This is appropriate for children with special health care needs. However, on the 2-18 year old growth chart, a note should be made stating that the data is from a length measurement.

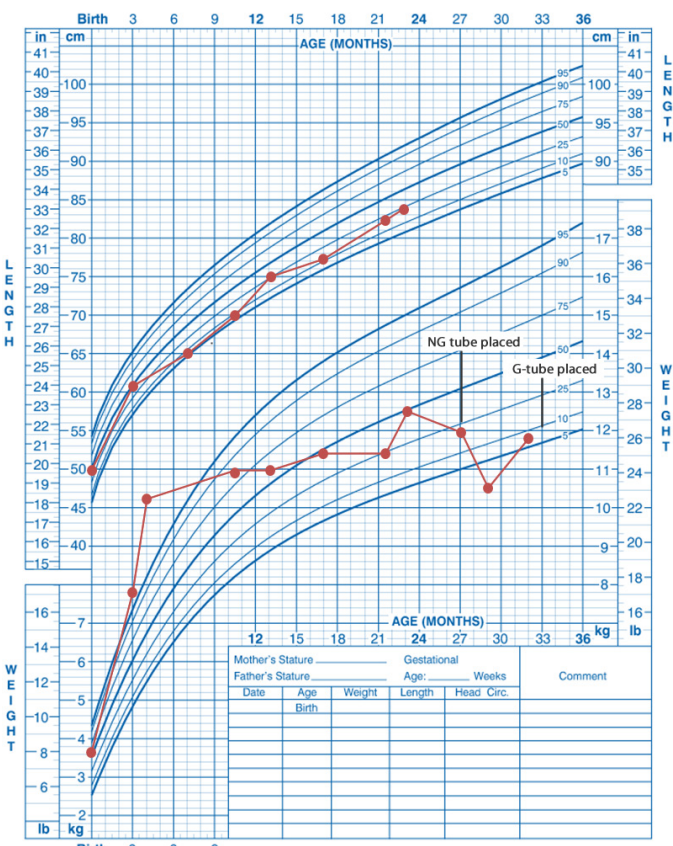
At 4 years, 10 months of age, Raymond developed diarrhea and lost weight. He was hospitalized with pancreatitis (a side effect from the seizure medication, Depekane). Treatment required bowel rest and total parenteral nutrition. His energy needs, considering increased stress from the illness, were estimated to be 9-10 kcal/kg and he regained 3 kg.

Once the pancreatitis resolved, Raymond was transitioned to Tolorex[®] (an elemental formula, low in fat, with predigested protein) through his G-tube. At this time his energy intake was reassessed to be 6 kcal/cm. At the end of three months time when there was no reoccurrence of pancreatitis, Raymond was transitioned back to PediaSure[®]. All of the supplements listed earlier had been continued.

Both growth and weight gain continued with a BMI >95th percentile. At age 6 years, during the nutrition consultation the RD decreased Raymond's energy to 4 kcal/cm to slow his weight gain. This resulted in daily use of 1 3/4 cans PediaSure[®]. Adjustments were made in supplements to maintain 100% RDA for vitamins, minerals and trace elements. Protein intake was 1 g/kg body weight.

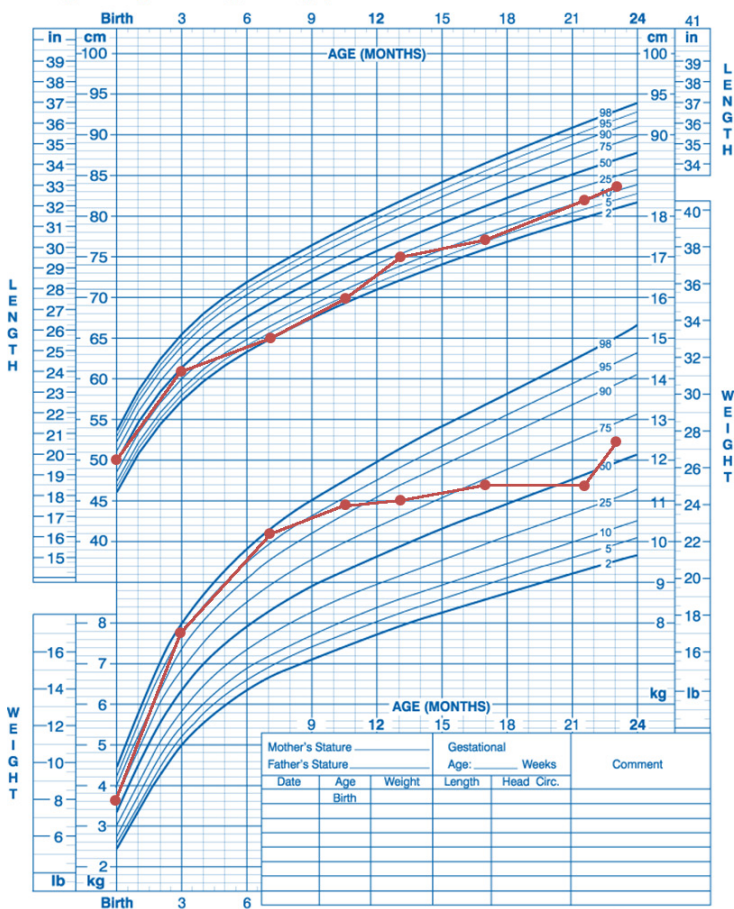
Raymond continued with this regimen for the next 3 years which resulted in a slower weight gain. At age 9

Birth to 36 months: Boys
 Length-for-age and Weight-for-age percentiles

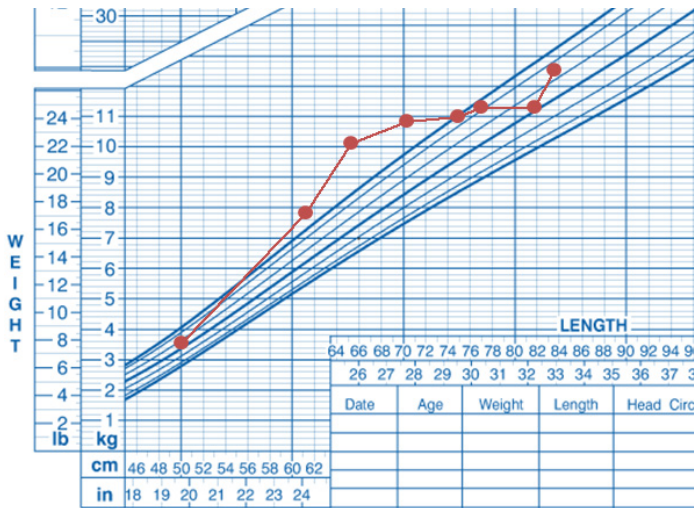


Published May 30, 2000 (modified 4/20/01).
 SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>

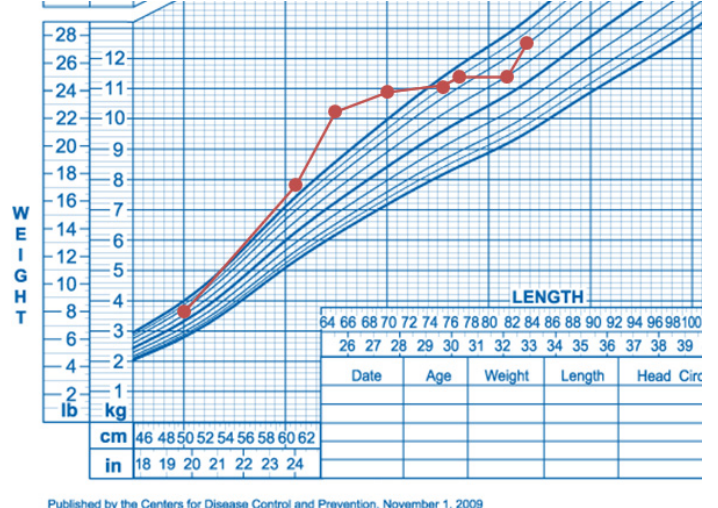
Birth to 24 months: Boys
 Length-for-age and Weight-for-age percentiles



Published by the Centers for Disease Control and Prevention, November 1, 2009
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)



Published May 30, 2000 (modified 10/16/00).
 SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>



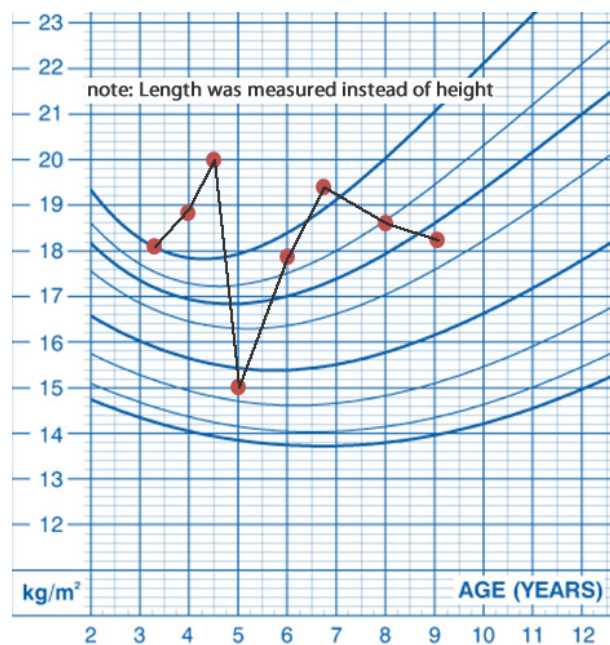
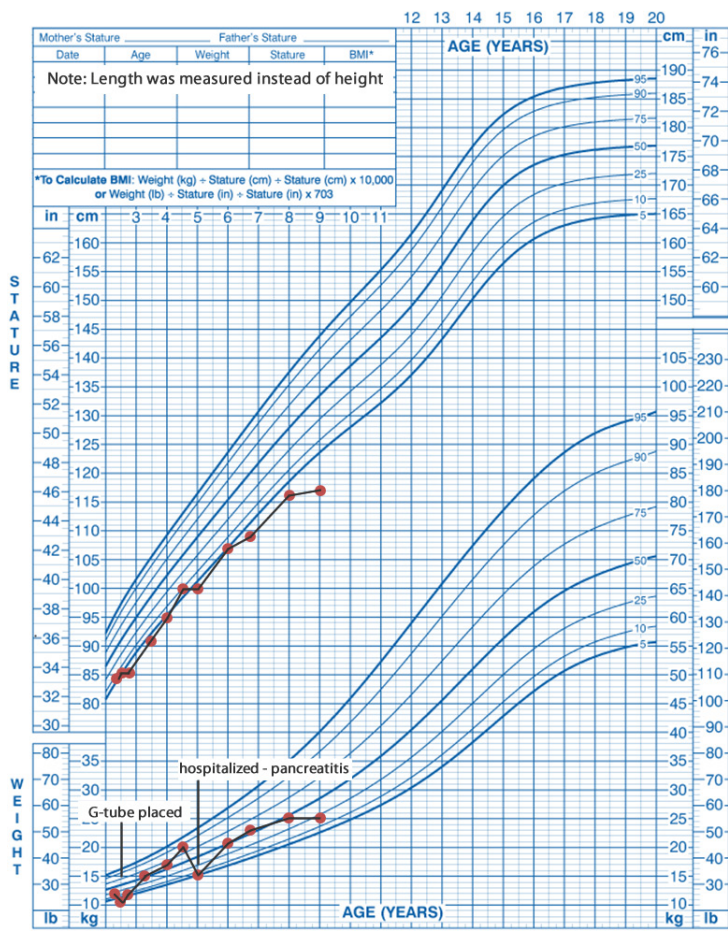
Published by the Centers for Disease Control and Prevention, November 1, 2009
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)

Figure 2. Raymond's growth plotted on CDC (0-36 month) charts. Top: Weight-for-age and length-for-age, Bottom: Weight-for-length

Figure 3. Raymond's growth plotted on WHO (0-24 month) charts. Top: Weight-for-age and length-for-age, Bottom: Weight-for-length

2 to 20 years: Boys
Stature-for-age and Weight-for-age percentiles

NAME _____ RECORD # _____



Published May 30, 2000 (modified 10/16/00).
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>

Figure 4. Raymond's growth plotted on CDC (2-20 year) charts. Left: Weight-for-age and stature-for-age, Right: BMI-for-age

years, Raymond had not gained weight for the past year and this resulted in slowing of height growth. Therefore at the nutrition visit the RD increased Raymond's intake by 30 kcal/day (1 oz PediaSure®). In 3 months a weight and length check was recommended to monitor growth and weight gain.

Comment

This case describes the continued role of the pediatric RD with a child who has a variety of special needs. The RD was involved early with this child and his family. With this early intervention his intake could be modified to prevent continued weight gain while at the same time insuring an adequate nutrient intake. Over the years, as Raymond experienced changes in his growth, development and health, many adjustments were required for his energy and nutrient intake. Raymond continues to need monitoring by the RD and other members of the team.

Editor's note – The newer product for children with lower energy needs had not been introduced at the time Raymond may have benefitted from its use. This product could be a consideration for Raymond at this time based on a current nutrition assessment.

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NUTRITION FOCUS is published online six times per year by the Nutrition Section at the Center on Human Development and Disability, University of Washington.

Subscription Rate and payment - Annual subscription rate is \$45.00 and must be prepaid to the University of Washington. Credit card payments can be made online. Or, mail your payment (payable to the University of Washington – US Funds), name, complete address and phone number to the editor. Some printed back issues are available, and online archives are available to all current subscribers.

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1. Which of the following is NOT a condition that is commonly associated with decreased energy needs:
 - a. Hypotonia
 - b. Birth asphyxia
 - c. Athetoid cerebral palsy
 - d. Static encephalopathy
2. Which of the following WOULD contribute to decreased energy needs:
 - a. High respiratory rate
 - b. Increased muscle tone
 - c. Neurologic impairment
 - d. Gastroesophageal reflux (GER)
3. True or false: A condition may affect linear growth potential; in this case, lower weight gain is appropriate.
 - a. True. Growth may be adequate if the child's rate of growth is maintained and weight-for-length or BMI is between the 10th and 50th percentiles
 - b. True. Decrease in growth velocity is appropriate for children with low energy needs
 - c. False. However, caregivers may wish to slow their child's weight gain for ease of care
 - d. False. Low rates of weight gain will impair linear growth
4. If a feeding issue is present or suspected, which of the following is an appropriate action for an RD to take:
 - a. Determine how the issue is affecting nutrient intake; if the child is still able to consume adequate energy/protein, no intervention is necessary
 - b. Refer for a feeding evaluation, which may include a VFSS, depending on identified or suspected issue
 - c. Refer for nasogastric or gastrostomy tube placement
 - d. If skills have been stable (i.e., no loss in skills), no intervention is necessary
5. Intractable seizures can be associated with low energy needs for all of the following reasons EXCEPT:
 - a. Neurologic effects of the seizure disorder
 - b. Side effects of medications can cause lethargy
 - c. Energy expenditure is decreased during seizures
 - d. None of the above, seizures are always associated with increased energy needs
6. Constipation can be associated with many conditions that cause decreased energy needs. For some children, constipation management may require medication. The reasons for this include:
 - a. Low energy needs are always associated with bowel hypotonia
 - b. Most children with low energy needs have fluid restrictions, so adequate fluid to prevent constipation is difficult
 - c. The contribution of energy from foods/fluids commonly used to manage constipation (e.g., fruit nectars, high fiber foods) may be too high
 - d. None of the above; medications should be avoided if at all possible
7. Which of the following statements about fluid and electrolyte needs is true:
 - a. Children with low energy needs require less fluid than children with typical energy needs
 - b. Children with very low energy needs may not meet their fluid and electrolyte needs through fluid or food
 - c. Children with very low energy needs require supplemental electrolytes, e.g., from additional table salt or Pedialyte
 - d. Extra fluid losses (e.g., drooling, increased sweating) generally require an increase of about 50% above maintenance fluid needs
8. Frequent monitoring of children with very low energy needs is important because:
 - a. This helps to assure job security for RDs
 - b. It is important to identify problems with feeding
 - c. Nutrient deficiencies can develop quickly and must be addressed immediately
 - d. Small changes to nutrient intake and/or energy expenditure can lead to rapid weight changes
9. For the child with very low energy needs, the article recommends that vitamin and mineral intake:
 - a. Meet 75% of the DRI
 - b. Meet 100% of the DRI
 - c. Meet 150% of the DRI
 - d. Be evaluated on a case-by-case basis
10. In general, the recommended protein intake for a child with very low energy needs:
 - a. Is higher than typical
 - b. Is lower than typical
 - c. Is unchanged from the DRI
 - d. Depends on individual factors, so generalizations cannot be made