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Primary Care for the Special Needs Child

Nutrition and Growth

Start with accurate measurements:
- weight, length, head circumference
- record method used to insure consistency
- wheelchair does not obviate measurements!

Utilize standard growth charts
  plus “weight for height” chart (better for underweight than BMI chart)

Weight for height target for CP patients:
- < 3 years: 25-50th percentile.
- Older patients: above 10th percentile

Indications for gastrostomy feeds:
- Inadequate growth pattern
- Low weight for height
- Excessive time needed for oral feeds
  - May take 12-15 times longer to feed
  - Some children can initially maintain themselves on oral feeds, but need G-tube in second decade
- Choking/aspiration/swallowing dysfunction
  - 90% of CP pts have some oral/motor dysfunction
  - GERD common
- Delay in initiation of gastrostomy feedings may result in limited stomach capacity and lost potential for catch-up growth.

Mic-Key Button:
- Most used brand of LPGRD (low profile gastrostomy replacement device)
- Easier to replace than others
- Tubing attached at time of each feeding
- Easier to dress child. No pulling at tube

- Size: diameter (usually 12 or 14F) + stem length
- Bulb is inflated with 5 ml water through side port
- Button is rotated 360 degrees daily
- Flush if clogged (carbonated water, cranberry juice)
- May need Maalox, barrier cream, or skin barrier patch around edges if irritated
- Each button costs about $200
- Replace at least every 6 months
Initiating feeds:
  Surgical placement of tube, usually plus Nissen fundoplication

Feeds started at basal rate plus estimated “activity factor”, with adjustments based on closely followed weights.

Usual formula choice:
  <1 year: standard infant formulas
  1-10 years: (PediaSure, Nutren Jr., KinderCal) 30kcals/oz
  >10 years: may use adult products

Can start as continuous drip with pump; progress to bolus feeds, or combination.
Bolus done by gravity, syringe, or pump

Flush after each feeding with 15-30 ml water
  Patients need at least 8 oz water/day

### WHO BMR Calculation Method

<table>
<thead>
<tr>
<th>AGE (YRS)</th>
<th>BMR (kcal/d)</th>
<th>AGE (YRS)</th>
<th>BMR (kcal/d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 YRS</td>
<td>60.7 x wt - 54</td>
<td>0-3 YRS</td>
<td>61.0 x wt - 51</td>
</tr>
<tr>
<td>3-10 YRS</td>
<td>22.7 x wt + 495</td>
<td>3-10 YRS</td>
<td>22.5 x wt + 499</td>
</tr>
<tr>
<td>10-18 YRS</td>
<td>17.5 x wt + 651</td>
<td>10-18 YRS</td>
<td>12.2 x wt +746</td>
</tr>
<tr>
<td>18-30 YRS</td>
<td>15.3 x wt + 679</td>
<td>18-30 YRS</td>
<td>14.7 x wt + 496</td>
</tr>
</tbody>
</table>

(weight in kgs)

Caloric need /day = (BMR x muscle tone factor x activity factor) + growth factor

Muscle tone factor:
  0.9 decreased muscle tone
  1.0 normal muscle tone
  1.1 increased muscle tone

Activity factor:
  1.15 bedridden
  1.20 dependent (wheelchair)
  1.25 crawling
  1.30 ambulatory

Growth factor: 5 kcal per gram of desired weight
**Cortical Visual Impairment**

Problem is with the brain pathway, not the eye
Excellent article in *Pediatrics in Review* November 2009

Causes:
- Hypoxic/ ischemic brain injury  
  especially premature babies
- CNS infection  
  meningitis now less frequent
- Congenital CNS malformations  
  Lissencephaly, schizencephaly, holoprosencephaly
- Trauma  
  Abuse, Shaken Baby

Characteristics:
- Preference for red or yellow, sparkling object, moving object
- May have visual field preferences
- Slow response to object seen
- Doesn’t use vision to direct reach
- Turns away from object and explores by touch
- Light gazing; photophobia

**Handicapped parking Eligibility:**

Cannot walk 200 feet without stopping to rest
Cannot walk without use of assistive device
Lung disease (“forced respiratory and expiratory volume for 1 second is less than 1 liter” or oxygen tension less than 60)
Uses portable oxygen
Has Class III or IV heart disease
Severely limited in walking ability due to arthritic, neurological, orthopedic condition