Nutrition for Children with Special Health Care Needs

Module 3: Feeding Skills

Pre Test

This Pre Test contains 8 multiple-choice questions. It is intended to provide you with some information about material that might require particular attention.

QUESTION 1

Matthew is a 10-month old who is referred to you by his pediatrician. His weight-forage and length-for-age are between the 25th and 50th percentiles. Weight-for-length is at the 50th percentile. His mother describes his intake, reporting that he takes about 8 ounces of infant formula from a bottle every 3 hours. She says that she is not concerned about Matthew's nutritional status because he is growing well and the formula is nutritionally complete.

Do you have concerns about Matthew?

- a. No, because his growth pattern appears to be normal
- b. No, because his formula is meeting his nutrient needs
- c. Yes, because at age 10 months he should drink all of his formula from a cup
- d. Yes, because at age 10 months he should be eating solid foods *

Feedback: Although Matthew's growth pattern does seem to be appropriate, his feeding skills are not. The correct response is d. Yes, because at age 10 months, he should be eating solid foods. This will be covered in more detail in Section 1, Feeding Skills and Behaviors.

QUESTION 2

You learn that Matthew has developmental delay, including an immature gag reflex. Does this information change your concern about Matthew's food pattern?

- No, because even with developmental delay, a 10-month old should be eating some solid foods.
- No, because an immature gag reflex should not affect a child's ability to eat solid foods.
- c. Yes, because an immature gag reflex can interfere with a child's ability to eat solid foods. *
- d. Yes, because developmental delay will always prevent a child from eating solid foods.

Feedback:

- a. Developmental delay can contribute to difficulty with solid foods. The correct response is c. Yes, because an immature gag reflex can interfere with a child's ability to eat solid foods. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- b. The correct response is c. Yes, because an immature gag reflex can interfere with a child's ability to eat solid foods. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- c. That is correct.
- d. Although developmental delay might contribute to difficulty with solid foods, this is not always true. The correct response is c. Yes, because an immature gag

reflex can interfere with a child's ability to eat solid foods. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.

QUESTION 3

True or false: A child might have problems with eating if he has hypotonia that affects the muscles that control his shoulders and trunk but that does not affect his face.

- a. true *
- b. false

Feedback

- a. That is correct
- b. That is incorrect.

QUESTION 4

The correct response to the previous question was True. Why might a child with hypotonia that affects the muscles controlling the shoulders and trunk but not the face have problems with feeding?

- a. because the child probably cannot feed himself
- b. because the hypotonia might affect the child's ability to sit upright and positioning problems might impair eating *
- c. because the hypotonia is likey accompanied by hypertonia and a hyperactive gag reflex
- d. because the child probably requires adaptive equipment

Feedback:

- a. There is not enough information to determine whether or not the child can feed himself. The correct response is b. because the hypotonia might affect the child's ability to sit upright and positioning problems might impair eating. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- b. That is correct.
- c. Hypotonia is not necessarily accompanied by hypertonia, and a hyperactive gag reflex may or may not accompany hypertonia. The correct response is b. because the hypotonia might affect the child's ability to sit upright and positioning problems might impair eating. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- d. There is not enough information to determine whether or not the child requires adaptive equipment, and the use of adaptive equipment does not mean that an individual has a feeding problem. The correct response is b. because the hypotonia might affect the child's ability to sit upright and positioning problems might impair eating. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.

QUESTION 5

Which of the following is NOT an indication for tube feeding?

- a. inability to consume more than 80% of energy needs by mouth
- b. malnutrition, as evidenced by weight, stature, and lab values
- c. need for gut rest *
- d. repeated upper airway infections

Feedback:

- a. The inability to consume more than 80% of energy needs by mouth can be an indication for the use of tube feeding. The correct response is c. need for gut rest. This will be covered in more detail in Section 4, Management of Tube Feedings.
- b. Malnutrition can be an indication for the use of tube feeding. The correct response is c. need for gut rest. This will be covered in more detail in Section 4, Management of Tube Feedings.
- c. That is correct. Need for gut rest is not an indication for the use of tube feeding. This will be covered in more detail in Section 4, Management of Tube Feedings.
- d. Repeated upper airway infections can be an indication for tube feeding when they are a result of aspiration. The correct response is c. need for gut rest. This will be covered in more detail in Section 4, Management of Tube Feedings.

QUESTION 6

For a child who requires a non-oral enteral source of nutrition for a short period of time, which of the following is most appropriate?

- a. nasogastric tube *
- b. gastrostomy tube
- c. jejunostomy tube
- d. none of the above

Feedback:

- a. That is correct. This will be covered in more detail in Section 4, Management of Tube Feedings.
- b. The correct response is a nasogastric tube. Nasogastric tubes are most often used when non-oral enteral nutrition is required for a short period of time. This will be covered in more detail in Section 4, Management of Tube Feedings.
- c. The correct response is a. nasogastric tube. Nasogastric tubes are most often used when non-oral enteral nutrition is required for a short period of time. This will be covered in more detail in Section 4, Management of Tube Feedings.
- d. The correct response is a. nasogastric tube. Nasogastric tubes are most often used when non-oral enteral nutrition is required for a short period of time. This will be covered in more detail in Section 4, Management of Tube Feedings.

QUESTION 7

A 9-year old has malabsorption, receives tube feedings, but does not tolerate the standard pediatric formula. Which of the following is probably most appropriate?

- a. whole cow's milk and a multiple vitamin with minerals
- b. modular formula
- c. elemental infant formula

d. elemental pediatric formula *

Feedback:

- a. This preparation may not be nutritionally complete. The correct response is d. elemental pediatric formula. This will be covered in more detail in Section 4, Management of Tube Feedings.
- b. Modular formulas are not nutritionally complete and would not be used alone. The correct response is d. elemental pediatric formula. This will be covered in more detail in Section 4, Management of Tube Feedings.
- c. An infant formula is not likely to be appropriate for a 9-year old. The correct response is d. elemental pediatric formula. This will be covered in more detail in Section 4, Management of Tube Feedings.
- d. That is correct. This will be covered in more detail in Section 4, Management of Tube Feedings.

QUESTION 8

Which of the following conditions is often associated with a normal feeding pattern during infancy, but the development of feeding problems as children get older?

- a. Prader Willi syndrome
- b. Rett syndrome *
- c. cerebral palsy
- d. Down syndrome

Feedback:

- a. The correct response is b. Rett syndrome. Rett syndrome is a progressive disorder and is characterized by loss of skills (including feeding skills) as the condition progresses. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- b. That is correct. Rett syndrome is a progressive disorder and is characterized by loss of skills (including feeding skills) as the condition progresses. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- c. The correct response is b. Rett syndrome. Rett syndrome is a progressive disorder and is characterized by loss of skills (including feeding skills) as the condition progresses. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.
- d. The correct response is b. Rett syndrome. Rett syndrome is a progressive disorder and is characterized by loss of skills (including feeding skills) as the condition progresses. This will be covered in more detail in Section 3, Influence of Special Health Care Needs.

Introduction

After completing this module, you will have the skills and resources to:

- Understand typical feeding development and the assessment of feeding skills and behaviors
- Understand nutrition management of enteral (tube) feedings, including a basic understanding of equipment
- Identify appropriate routes of feeding for specific situations and appropriate formulas for specific situations
- Describe potential problems with feeding that are associated with children with special health care needs

Section 1: Feeding Skills and Behavior

In this section, the development of feeding skills and behavior are reviewed. The approximate age that typically-developing children obtain each of these skills is reviewed.

Understanding the progression of feeding skill development helps the clinician to make sound recommendations about the types of foods to offer and about intervention strategies.

The next screens describe typical development of oral-motor and feeding skills. (These are intended to provide general information only.) Each stage is discussed in terms of:

Age

The approximate age that a typically-developing child might acquire specific skills is given as a reference point. The age may or may not be appropriate for a child with special health care needs.

Reflexes

Many reflexes are present to equip an infant for sucking and swallowing, and, as an infant matures, these reflexes fade. If these "primitive" reflexes persist, they can prevent a young child from acquiring the skills needed to chew foods with increased textures.

Other reflexes are protective and do not "disappear" with development. These include the gag and cough reflexes. If these reflexes are impaired or "hypersensitive" because of a medical condition, a child's ability for oral intake may be impaired as well.

Oral-motor and self-feeding skills and behaviors

An infant or child's readiness for types and textures of foods is dependent upon his oral motor skills and ability to self-feed. Again, with an infant who is developing typically, these skills and abilities are generally acquired as the infant gets older. Many children with special health care needs gain these skills at later ages.

Positioning

The child's physical development and oral-motor skills determine the optimal position during feeding and eating. Improper positioning can prevent a child from eating or eating safely.

Appropriate foods

This section reviews types of foods or eating situations that are appropriate based on the skills and abilities described.

Age: 0-2 months

Reflexes

- Palmomental
- Gag
- Rooting
- Phasic bite

Oral-motor and self-feeding skills and behaviors

- Coordinated suck-swallow-breathe pattern
- Moving tongue forward and back
- Moving hand to mouth
- Expecting feedings at regular intervals

Positioning

Appropriate positioning at this stage can include:

- Supine, with the head slightly elevated
- Reclining at an angle of less than 45 degrees

Appropriate foods

• Breastmilk or infant formula

Age: 2-4 months

Reflexes

Palmomental and phasic bite decreasing

Oral-motor and self-feeding skills and behaviors

- Corners of lips start to become active in sucking
- Smacking lips
- Head control increasing
- Tongue protruding and mouth opening in anticipation of feeding
- Visually recognizing bottle
- Beginning to reach for objects

Positioning

- Appropriate positioning at this stage can include:
- Supported semi-sitting position, at an angle of 45-90 degrees

Appropriate foods

Breastmilk or infant formula

Age: 4-6 months

Reflexes

- Rooting diminishes
- Gag reflex now elicited farther back in mouth

Oral-motor and self-feeding skills and behaviors

- Voluntary sucking
- Showing an interest in food
- Up and down munching and biting
- Pursing and smacking lips
- Recognizing bottle
- Sitting unassisted
- Mouthing objects

Positioning

- Seat back at 90 degrees
- External support required for sitting
- Feet supported
- Hips flexed and trunk and head in midline

Appropriate foods

- Breastmilk or infant formula
- Soft, semi-solid, pureed foods from spoon (e.g., infant cereal, pureed fruits and vegetables)

The oral-motor and self-feeding skills exhibited at this stage indicate a readiness for the introduction of solid foods. For many infants, these skills are not developed until age 6 months.

Age: 6-8 months

Reflexes

Mature gag

Oral-motor and self-feeding skills and behaviors

- Munching continues
- Reaching for objects
- Tongue starting to shift laterally
- Beginning vertical chewing
- Holding bottle sometimes
- Closing lips around spoon
- Beginning to sip from a cup held by an adult
- Holding jaw closed while a soft piece of food is broken off

Positioning

- Seat back at 90 degrees
- External support required for sitting
- Feet supported
- Hips flexed and trunk and head in midline

Appropriate foods

- finger foods
- ground foods, soft semisolids
- breastmilk or infant formula

At this stage, the infant is indicating a readiness for finger-feeding large pieces of foods and for ground or mashed table foods.

Age: 8-10 months

Oral-motor and self-feeding skills and behaviors

- Transferring food laterally (from center to sides of mouth)
- Voluntarily biting on foods and objects

- Closing lips briefly on cup
- Finger-feeding more precisely, still primarily with palmar grasp
- Beginning to feed self with spoon
- Holding bottle

Positioning

- Seat back at 90 degrees
- External support required for sitting
- Feet supported
- Hips flexed and trunk and head in midline
- Highchair seatbelt used for safety, not support

Appropriate foods

- chopped or mashed table foods
- liquids (e.g., juice) from a cup
- finger foods
- breastmilk or infant formula
- ground foods, soft semisolids

At this stage, the infant is indicating a readiness for the introduction of liquids from a cup and for increased textures of solid foods to include more table foods. It is also appropriate to encourage an infant to feed himself with a spoon at this stage.

Age: 10-12 months

Oral-motor and self-feeding skills and behaviors

- Bringing spoon to mouth
- Beginning to pick up and hold cup
- Rotary chewing beginning
- Beginning to finger-feed with pincer grasp
- Closing lips when swallowing

Positioning

- Seat back at 90 degrees
- External support required for sitting (e.g., highchair)
- Feet supported
- Hips flexed and trunk and head in midline
- Highchair seatbelt used for safety, not support

Appropriate foods

- small finger foods
- liquids (e.g., juice) from a cup
- chopped or mashed table foods
- ground foods, soft semisolids
- breastmilk or infant formula

At this stage, foods with increased textures are introduced, including many foods from the family's table (e.g., well-cooked or mashed vegetables, soft fruits, tender meat).

12-18 months

Oral-motor and self-feeding skills/behaviors

• Continuing to develop self-feeding skills (e.g., picking up cup, finger-feeding with pincer grasp)

Positioning

- Seat back at 90 degrees
- External support may be required for sitting
- Feet supported
- Hips flexed and trunk and head in midline
- Highchair seatbelt used for safety, not support

Appropriate foods

- small finger foods
- soft table foods
- chopped or ground table foods
- liquids (e.g., milk or juice) from a cup

18-24 months

Oral-motor and self-feeding skills/behaviors

- Feeding self (with spilling)
- Finger-feeding discrete objects of food
- Placing food in spoon with free hand, then lifting spoon to mouth
- Using a controlled bite for hard foods (e.g., apple)
- Beginning to be able to lick food off the upper lip
- Holding cup well, spilling if too full
- Grasping spoon with a radial grasp
- Tongue clearing upper and lower lips
- Using a rotary motion for chewing

Appropriate foods

- small finger foods
- chopped table foods
- liquids (e.g., milk or juice) from a cup
- meat, some raw fruit and vegetables

During this stage, the child is ready for even more foods from the family's menu.

By the end of this stage, the child is ready to begin using a fork and to eat foods with more complex textures.

Preventing problems with choking

Young children (or older children with delayed feeding skills) are at an increased risk for choking on foods. For children 4 years and younger, the following should be avoided:

- hot dogs
- grapes

- raw vegetables
- popcorn
- nuts
- other round, hard foods that do not readily dissolve
- peanut butter

In addition, some feeding practices increase a child's risk for choking and should be avoided:

- "stuffing" too much food in mouth
- running while eating
- eating in the car

What is wrong with this picture?

Watch the clip, then identify the incorrect feeding practice.

The feeding practice in the clip was incorrect. What was inappropriate?

- a. the infant should be in a highchair
- b. solid foods are inappropriate at this stage
- c. solid foods of a thicker consistency should be offered
- d. solid foods should be offered before the bottle is offered

The correct response is b. solid foods are inappropriate at this stage.

What is wrong with this picture?

Watch the clip, then identify the incorrect feeding practice.

In the clip, the caregiver ignored some of the infant's feeding cues. Which cues did she ignore?

- a. he was full and finished with the meal
- b. he did not like the food she was offering
- c. he was ready to feed some foods to himself
- d. he was distracted by the environment and needed to be "calmed"

The correct response is c. he was ready to feed some foods to himself.

Section 2: Assessment of Feeding Skills

Observation of a meal or snack can often provide the most valuable information about a child's feeding skills. When an actual observation is not possible, a detailed interview can be conducted.

Problems (or potential problems) with feeding may be identified by monitoring:

- Positioning during feeding
- Length of time of the feeding
- Amount of food offered
- Amount of food consumed
- Amount of liquid offered (and consumed)
- Eating utensils used
- Signs of hunger or satiety
- Rate of eating and drinking
- Manner in which food is refused
- Interaction between child and caregiver/feeder

The following questions may be useful for assessing a child's feeding skills:

- What types of foods does your child eat?
 - Describe the texture
 - Describe the consistency
 - How many times does your child eat each day?
- Do you have concerns about your child's feeding skills?
 - Does your child feed himself? With fingers? With utensils?
 - Does your child have problems chewing or swallowing? Gagging or choking?
 - Are there specific foods or textures that your child has difficulty with?
 - Does your child choke while eating? If so, how often does this happen?
- Can your child clearly communicate hunger and thirst?
- How does your child respond when food is offered?

Asking a caregiver about a child's feeding history can also provide useful information:

- When were solid foods introduced?
- What types of solid foods were introduced?
- When did your child learn to drink from a cup?
- What was your child's reaction to solids? To finger-feeding? To utensils? To the cup?

When a problem with feeding or eating is suspected, referral to a practitioner (e.g., occupational, speech, or physical therapist) with experience with feeding problems and children with special health care needs is warranted.

If a problem is identified during this assessment, interventions are developed. Interventions can include:

- Proper positioning
- Therapy to improve oral-motor skills
- Modification of food types or textures (for example, thickened liquids)

- Adaptive feeding utensils (for example, a weighted spoon may help a child with motor problems to feed herself)
- Specialized feeding techniques

For a child with identified feeding problems, coordination between the RD and feeding therapist is critical...to ensure that the foods that are offered meet the child's nutrient needs and are safe for the child to consume.

The *Bright Futures: Nutrition* materials include questions that can health care providers can ask, to get information about a child's feeding skills. See the Resource section for more information.

Section 3: Influence of Special Health Care Needs

Many problems associated with specific conditions can contribute to problems with eating. This section reviews some of these issues and describes potential feeding problems that can result. When these feeding problems are suspected, a feeding evaluation by a therapist is indicated.

This page describes the following problems:

- Hypertonia
- Hypotonia
- Hypersensitivity
- Developmental immaturity
- Gastroesophageal reflux
- Other oral-motor problems

Hypertonia

Hypertonia, common among children with neuromuscular disorders, can cause a number of problems related to feeding and eating:

- Lip retraction –lips are pulled away from the midline in a tight "smile," often as an object nears the face
- Tongue thrust –the tongue is forcefully extended, often in response to an oral stimulus
- Jaw thrust -the lower jaw opens forcefully
- Tonic bite reflex -the mouth clenches involuntarily with oral stimulation (especially touch to the teeth and gums); it can be difficult for the child to release
- Problems with positioning

Hypotonia

Hypotonia, or low muscle tone, can lead to feeding-related problems:

- Poor jaw and lip closure, interfering with chewing and swallowing
- Problems with positioning
- Drooling

Hypersensitivity

Hypersensitivity, or sensory defensiveness, can interfere with eating and feeding:

- Exaggerated bite reflex
- Hyperactive gag reflex
- Aversions to different textures

Developmental immaturity

Developmental immaturity may be accompanied by retention of reflexes including tongue thrust, bite reflex, and rooting reflex. In addition, the gag reflex may be immature, preventing a child from consuming solid foods.

Gastroesophageal reflux

Gastroesophageal reflux (GER) is the regurgitation of stomach contents into the esophagus, often resulting from a weak esophageal sphincter. GER can be common among children with neuromuscular disorders. GER can lead to problems with feeding:

Aspiration can result, making oral intake unsafe

 Feeding aversions can result because of the pain and discomfort associated with being fed

Other oral-motor problems

Other oral-motor problems include:

- Tongue retraction –tongue is pulled back in mouth and may obstruct the airway
- Jaw retraction –lower jaw is pulled back involuntarily
- Jaw clenching jaw is tightly closed, involuntarily
- Nasal regurgitation –food or liquid moves into the lower sinus and nose during swallowing and may come out of the nose

The next several pages review some of the contributors to feeding problems related to specific conditions.

- Cerebral palsy
- Cleft lip and cleft palate
- Down syndrome (trisomy 21)
- Prader-Willi syndrome
- Rett syndrome

Cerebral palsy

Description

Cerebral palsy (CP) involves chronic, nonprogressive central nervous system (CNS) dysfunction leading to problems with tone and movement. Children with CP make up a very heterogeneous group. Depending on the original insult, this diagnosis has many clinical manifestations, from very mild to very severe neurological involvement. Children with cerebral palsy may or may not be ambulatory and may or may not have mental retardation.

Potential feeding problems can include:

- Tongue thrust and incoordination
- Lip retraction
- Tonic bite reflex
- Problems with suck/swallow
- Hypotonia affecting the mouth
- Hypotonia interfering with proper positioning

Cleft lip and cleft palate

Description

Cleft lip and cleft palates are birth defects. Cleft lip is a fissure (or fissures) in the upper lip. Cleft palate is a cleft (or clefts) in the palate. The two may or may not occur together. Usually, surgery is performed to correct the clefts. Repair of a cleft lip is usually done within the first few months of life, and cleft palate repair is typically done later.

Children with cleft lip and/or cleft palate are generally followed by a team of specialists at a craniofacial center.

Potential feeding problems can include

- Infants ability to suck effectively can be impaired (special techniques are often used to make breastfeeding possible, or specialized bottles and nipples are suggested)
- Impaired coordination of chewing and swallowing solid foods

Down syndrome (trisomy 21)

Description

Down syndrome is caused by an "extra" 21st chromosome. Children with Down syndrome often have mental retardation, cardiac defects, and hypotonia (decreased muscle tone). Duodenal atresia (blockage of the intestine) may be present. Oral problems can include oral hypotonia, small oral cavity causing tongue protrusion, and delayed and/or abnormal tooth eruption.

Potential feeding problems can include:

- Tongue control, problems with tongue protrusion, tongue thrust
- Endurance during feeding because of cardiac problems (primarily for infants)
- Oral-motor problems

Children who have had numerous medical procedures, especially around the mouth and head may develop aversions to oral stimuli. For these children, a feeding team with a behavioral component is almost always necessary to a successful oral intake. This may also be the case for children who have had problems with reflux.

Prader-Willi syndrome

Description

Prader-Willi syndrome is a genetic disorder caused by partial deletion of chromosome 15 (paternal) or disomy (maternal). Children with Prader-Willi syndrome have mental retardation and abnormal food-related behaviors. Prader-Willi syndrome is characterized by feeding problems during infancy, and hyperphagia in childhood and adolescence, often resulting in obesity.

Potential feeding problems can include:

- Hypotonia as an infant
- Weak suck as an infant

Rett syndrome

Description

Rett syndrome is a neurodevelopmental disorder that occurs in females. Typically, infancy is normal, but progressive deterioration occurs after infancy, with seizures and microcephaly. Problems with growth can be present, as well as oral-motor problems.

Potential feeding problems can include

- Problems with lip closure and excessive drooling
- Loss of feeding skills as condition progresses

Other conditions

Other conditions that can have associated feeding problems:

- Craniofacial anomalies, where anatomical problems interfere with eating and feeding
- Developmental delay, where oral-motor or self-feeding skills are impaired
- Muscular dystrophy, where oral-motor problems or other reasons for problems with self-feeding exist
- Williams syndrome, where abnormal tooth development and other oral-motor problems exist
- Neurodevelopmental conditions that impair mechanical aspects of eating (e.g., Arnold-Chiari malformation associated with myelomeningocele can interfere with swallowing)

Hypertonia and thus, problems with gagging can be common among children with which of the following disorders?

- a. cerebral palsy
- b. Prader-Willi syndrome
- c. Down syndrome
- d. cleft lip and palate

The correct answer is a. cerebral palsy. Prader-Willi and Down syndromes are more often associated with hypotonia than hypertonia. Hypertonia is not generally associated with cleft lip and palate.

Problems with chewing and swallowing can be caused by a number of factors. Which of the following is NOT a factor that contributes to problems with chewing and/or swallowing?

- a. hypotonia
- b. developmental immaturity
- c. immature gag reflex
- d. rooting reflex

The correct response is d. rooting reflex. Hypotonia and developmental immaturity can contribute to problems with chewing and swallowing.

Section 4: Management of Tube Feedings

For some children, an oral intake is not adequate to meet nutrient needs. Sometimes, a child cannot eat safely. Other times, a child cannot consume enough because of increased needs, oral-motor problems, or fatigue. The nutrient needs of these children are often met with non-oral enteral feedings (tube feedings).

Sometimes, tube feedings are used for short periods of time (e.g., after surgery or recovery from an acute illness).

Tube feedings are also needed long-term (e.g., because of oral-motor problems or risk of aspiration because of swallowing difficulties).

Indications for tube feeding can include:

- Inability to consume more than 80% of energy or 90% of fluid needs by mouth
- Malnutrition (e.g., as evidenced by serum albumin, skinfold measurements, weight, stature)
- Repeated upper airway infections (indicating aspiration)
- History of gastroesophageal reflux that cannot be managed with medications

Management of tube feedings involves a team of health care professionals with experience with tube feeding and children with special health care needs. Coordination between the child's family, primary care physician, the physician who placed the tube, a registered dietitian, and the home infusion company is critical.

This section reviews some basic information about tube feeding and presents some tools for assessment.

Types of Tube Feeding

Nasogastric tube feeding

A tube that is placed through the nose into the stomach is called a nasogastric tube. When tube feeding is required for short periods of time, this type of tube is sometimes used.

Gastrostomy tube feeding

Gastrostomy tubes go through an opening from the abdomen to the stomach. They can be placed surgically or through percutaneous endoscopy. This type of tube feeding is generally used with individuals who will need the tube to meet nutrient and/or fluid needs long-term. The gastrostomy tube is generally larger than the nasogastric tube, and thus, use of a more viscous formula is possible.

Jejunal tube feeding

Jejunostomy tubes deliver formula to the jejunum. They can be placed in the jejunum through an opening in the abdomen or placed in the stomach and passed through the pyloric sphincter into the jejunum. Like the gastrostomy, a jejunal tube can also be placed surgically or through percutaneous endoscopy. This modality is used by individuals who cannot use their upper GI tract or for whom aspiration is a problem. Typically, continuous drip feedings are required, and the use of semi-elemental or elemental formulas may be necessary because the stomach is being bypassed.

Administration of Tube Feeding

Bolus feeding

The use of a "bolus feeding pattern" is more similar to an oral eating pattern than the use of "continuous drip." A specified amount of formula is given several times during the day.

For example, a child's prescription may be for 120 mL formula every 3 hours. The formula may be administered with an infusion pump, or by "gravity drip."

Continuous drip feeding

A continuous drip regimen provides formula at a defined rate (usually slower) for a longer amount of time than a bolus pattern.

For example, an infant may receive 20 mL formula per hour for 20 hours each day.

In other cases, continuous drip feeding is used at night and either oral feedings or bolus tube feedings are given during the day.

For example, a child may receive 30 mL formula per hour for 8 hours at night and eat a regular food pattern during the day.

Typically, an infusion pump is used to deliver the formula.

Formulas Used in Tube Feedings

A variety of tube feeding formulas is available. This page summarizes some of the types of formulas that are typically used.

- Commercial formulas for infants
 - Formulas for premature infants
 - Standard infant formulas
 - Protein hydrolysate infant formulas
 - Elemental infant formulas
- Commercial formulas for children
 - Standard formulas
 - Elemental formulas
 - Specialized formulas
- Home-prepared formulas for children
- Commercially- available modular components

COMMERICAL FORMULAS FOR INFANTS

The formulas described in this section are "complete" formulas, providing carbohydrate, fat, and protein, as well as vitamins and minerals.

Formulas for premature infants

Formulas for premature infants are available. These formulas are more energy-dense than a standard infant formula, and have more protein, electrolytes, minerals, and vitamins. Most formulas are appropriate for infants weighing 1800 grams or less, and thus, it is not common for many infants using these formulas to be seen in a community setting.

A few formulas are available for premature infants weighing up to 2000-2500 grams. These formulas are more energy-dense and have more vitamins and minerals than standard infant formula.

Both formulas for premature infants and "post-discharge" formulas should be suggested and monitored by a physician and RD familiar with the specialized needs of preterm infants.

Standard infant formulas

Standard infant formulas provide 20 kilocalories per ounce and generally approximate the nutrient composition of breastmilk. Standard infant formulas are made from cow's milk protein (casein and whey) or soy, lactose (sometimes corn syrup solids), and a variety of vegetable oils. Standard infant formulas are appropriate for most infants who receive formula.

Protein hydrolysate infant formulas

For infants who have protein malabsorption problems, formulas with small peptides and amino acids are available. The fatty acid compositions of several of these formulas are also modified to include medium chain triglycerides.

Elemental infant formulas

Amino acid-based formulas are available for infants who have cow's milk protein or multiple food protein intolerance and cannot tolerate hydrolysate formulas.

COMMERCIAL FORMULAS FOR CHILDREN

The formulas described in this section are "complete" formulas, providing carbohydrate, fat, and protein, as well as vitamins and minerals.

Standard formulas

Standard formulas contain intact protein (usually from casein, whey, or soy) and can contain fiber. In general, they are appropriate for children between 1 and 10 years of age and have a variety of osmolalities.

Elemental formulas

Elemental formulas are peptide-based formulas, with simple carbohydrates and, typically, fat as medium-chain triglycerides and essential fatty acids. These formulas are appropriate for children with problems with malabsorption who do not tolerate a standard formula or for children with allergies to soy protein or casein.

Specialized formulas

Formulas are available for children with specific nutrient needs (e.g., metabolic or renal disorders). The use of these formulas should be monitored by a team familiar with the specific condition.

HOME-PREPARED FORMULAS FOR CHILDREN

Some families prefer to prepare formulas from food at home because this allows the child to eat the same foods as the rest of the family. Home-prepared formulas can present a number of complications, including problems with tube clogging because of viscosity of formula. Careful attention to the nutrient composition (energy, protein, vitamins, minerals, fluid) is necessary, especially if the same foods are always used, and supplements may be needed to meet micronutrient needs. More information

about the use of home-prepared formulas is referenced in the <u>For More Information</u> section.

COMMERCIALLY-AVAILABLE MODULAR COMPONENTS

Products to add specific nutrients to formulas are also available. Modular products can include:

- Protein and amino acid preparations
- Carbohydrate
- Fat as medium chain triglycerides
- Vitamin and mineral supplements

Assessment

The following list of questions can be used during the nutrition assessment interview to identify the child's tube feeding regimen. Recommendations for changes can be made to the team that manages the child's tube feeding.

- What products are used?
- What is the feeding schedule?
 - o bolus feedings: how many mL or ounces per feeding?
 - o drip feedings: what is the rate? how long is the pump on?
- What times are feedings?
- How much water is used to flush the tube?
- Does your child seem comfortable after each feeding?
- How do you tell if your child is hungry?
- Does the feeding schedule fit the family and school routine? How often do you deviate from the schedule?

The following questions for caregivers can be used to identify some problems associated with the tube feeding:

- Are there problems with the gastrostomy site?
- Does your child have constipation or diarrhea or problems with vomiting?
- What are the instructions if the tube needs to be replaced?
- Do you have problems getting the formula?
- Do you sometimes have to turn the pump off at night?
- Who else can feed your child?

Medication

Many families use the feeding tube as a means to deliver medications as well as formula. Some tubes have separate "ports" for administering medications. It is critical that whichever port is used, the tube be "flushed" to prevent clogging.

If medications are given at the same time as feedings, it is important to ensure that the formula and medications are compatible. Some medications are less effective when given with food or formula. Other medications may interact with the formula, causing a "clog."

Complications

Common problems associated with tube feeding can include:

- Leakage
- Skin irritation
- Granulation tissue

· Tube blockage

Medical attention should be sought when:

- Tube comes out and will not go back in easily
- Tube cannot be flushed
- Bleeding through or around the tube
- Thick drainage, redness, tenderness, skin breakdown around the tube
- Excessive leakage around the tube
- Child has persistent vomiting, diarrhea or constipation
- Child's temperature is > 101 F or 38.5 C

Transition to Oral Feeding

The transition from tube to oral feeding can be difficult, especially when a tube feeding has been used for an extended period of time. Often, the efforts of a feeding team are necessary, with collaboration between a pediatrician, registered dietitian, and feeding therapist.

Which of the following is NOT a common complication of tube feeding?

- a. leakage
- b. skin irritation
- c. dehydration
- d. granulation tissue

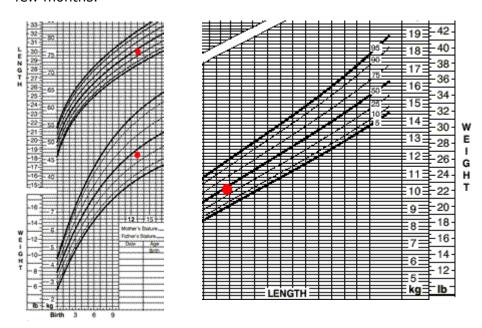
The correct response is c. dehydration. Leakage, skin irritation, and granulation tissue are all common complications that should be addressed, however, dehydration is NOT a common complication of tube feeding.

Section 5: Making Clinical Decisions

This section "walks" you through the decision-making process. Two examples of children with feeding problems are presented.

Scenario 1

Nicholas is a 13-month old with developmental delay. His pediatrician is concerned because he does not eat solid food. He does not have reflux, but his parents feel he may have problems with swallowing. His measurements appear to be within normal limits, and his parents report that his growth pattern has not changed over the past few months.



You ask his family about his feeding history, and his parents report that he used to eat solids (they were introduced when Nicholas was about 4 or 5 months old), but he quickly stopped eating them.

Now, he takes a standard infant formula, in amounts that provide adequate amounts of energy, protein, fluid, and micronutrients. Nicholas's family continues to offer solid foods to him; he will play with the foods, but will not eat them.

Is it appropriate to expect Nicholas to eat solid foods at age 13 months?

- a. Yes
- b. No, because Nicholas has developmental delay
- c. No, because Nicholas may have difficulties with swallowing
- d. There is not enough information

The correct response is d. There is not enough information. Although it is appropriate to expect most 13-month old children to eat solid foods, there is insufficient information to conclude that Nicholas should be eating solid foods. If Nicholas's developmental delay has led to oral-motor problems (or difficulty swallowing), and

his skills are below the 4-6-month old level, then solid foods are inappropriate. However, this information was not presented.

You present your concerns to Nicholas's parents:

If Nicholas does have a swallowing problem, this should be addressed.

 You contact his primary care physician, and a referral for a feeding evaluation is scheduled with a local therapist. This evaluation will include a videofluoroscopic swallowing study (VFSS), which is a radiologic procedure to evaluate the swallowing mechanism.

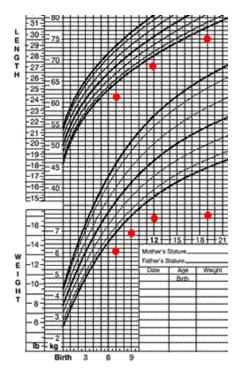
While infants and children develop feeding skills at different ages, it is appropriate to expect a 13-month old (who can safely consume solids) to eat solid foods.

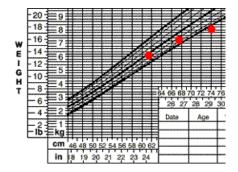
- First, the safety of an oral intake for Nicholas should be determined.
- Then, if no physical barriers to eating solid foods are identified, a referral to a feeding team is probably needed.
- You provide his family with some information about the development of feeding skills, and also suggest a referral to a feeding team.

Scenario 2

Frank is a 19-month old with developmental delay, but no significant oral-motor problems. His rate of weight gain has slowed over the past few months.

You are asked to evaluate his nutritional status and make recommendations to improve his weight gain.





Frank's mother describes his food pattern.

He is taking about 15-18 ounces of infant formula that is concentrated to 30 kilocalories per ounce each day and eating some solid foods. Mom says that mealtime is a "battle" and that the family usually has to force Frank to eat.

His family adds foods like heavy cream to the solid foods he is offered, to increase the energy density.

Mom says that Frank has recently started to refuse to open his mouth very wide, making it difficult for him to take large volumes. A week or so ago, he began refusing all solid foods, but his intake is slowly increasing again.

Frank's mother says that he has been seen by a feeding therapist, who was working on increasing his intake of solid foods. The family felt that Frank was not making much progress, so discontinued the therapy.

You calculate Frank's estimated energy intake and review his medical record.

- Weight gain has slowed; weight-for-age and weight-for-length are less than the 5th percentile
- Energy intake is about 70% estimated needs for age; fluid intake is about 50-70% of estimated needs
- Serum albumin indicates protein deficiency
- Frank has had problems with feeding since age 7 months

Does Frank's history support recommendation of evaluation for a feeding tube?

- a. No, more feeding therapy should be pursued.
- b. Yes, a feeding tube will alleviate the need for oral feeding and feeding therapy.
- c. Yes, a feeding tube along with continued feeding therapy may be beneficial.
- d. Yes, a feeding tube is warranted and should be placed immediately.

The correct response is c. Yes, a feeding tube, along with continued feeding therapy may be beneficial. While more feeding therapy is an appropriate recommendation, Frank's history is consistent with the guidelines for use of a feeding tube presented in this module, and a feeding tube may make it less critical that Frank's overall oral intake meet his nutrient needs for a period of time. The decision to place a feeding tube is a complex one that must be considered carefully. Thus, this recommendation does not necessarily mean that a feeding tube should be placed, but further assessment is warranted.

Frank's physician has also suggested the use of a feeding tube to Frank's family, and the decision is made to place a gastrostomy tube. Frank does not have any problems with malabsorption and is 20 months old when the tube is placed.

His family currently makes his formula as follows: each bottle contains 6 ounces standard infant formula, 4 Tablespoons heavy cream, and 1 ounce standard pediatric formula (30 kilocalories per ounce).

What is an appropriate formula for Frank?

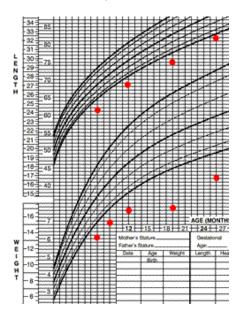
- a. continue with the current formula
- b. elemental formula
- c. standard infant formula
- d. standard pediatric formula

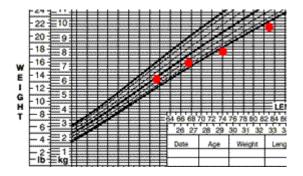
The correct response is d. standard pediatric formula. Frank is over 1 year of age and does not have any physical conditions (e.g., malabsorption) that require the use of a specialized formula.

A standard pediatric formula is prescribed for Frank. A combination of nighttime continuous drip and daytime bolus feedings is used.

A referral to another feeding team is made, and Frank is receiving feeding therapy.

Frank returns to see you at age 26 $\frac{1}{2}$ months. His length-for-age is still below the 5th percentile, but his rate of weight gain has increased. Weight-for-length remains below the 5th percentile.





Frank's mother is pleased with the progress he has made with feeding therapy. He still has weeks where he refuses to eat, but the family is reassured that his nutrient needs are met with the tube feeding.

His current tube feeding regimen is 65 mL per hour for 11 hours at night and three 120 mL bolus feedings during the day.

His mother has begun making all of his formula at home using this recipe: 4 Tablespoons peanut butter, 1 raw egg, $\frac{1}{2}$ avocado, 1 cup standard pediatric formula, $\frac{1}{4}$ cup buttermilk.

What is your primary concern at this visit?

a. weight-for-length remains below the 5th percentile

- b. Frank is still refusing to eat solid foods
- c. Frank's tube feeding schedule should be adjusted
- d. Frank's tube feeding formula is inappropriate

The correct response is d. Frank's tube feeding formula is inappropriate. The use of a raw egg is dangerous, and the nutrient composition of the home-blended formula may not meet Frank's needs. Although his refusal to eat solid foods is a concern, his feeding skills are being addressed at feeding therapy.

You explain your concerns about the home blended formula to Frank's mother:

- The nutrient composition may not meet Frank's nutrient needs
- Food safety use of a raw egg
- Inappropriate nutrient composition –e.g., energy, protein, vitamins, minerals, fluid
- Need for supplements to meet micronutrient needs
- Problems with tube clogging because of viscosity of formula

Frank's parents would like to use the home-prepared formula, if possible. You tell them that you will work with them to see if a blenderized formula is possible.

You calculate Frank's intake based on the blenderized formula, and it is adequate for fluid, energy, protein, calcium, iron, and other vitamins and minerals. Mom reports that they have not had problems with tube clogging. The decision is made that Frank's family will use either the blenderized recipe or a standard pediatric recipe.

Post Test

QUESTION 1

Children with Prader-Willi syndrome often have the following problems with feeding:

- a. large, protruding tongue
- b. cleft lip and/or palate
- c. hypotonia that makes oral intake difficult throughout infancy and childhood
- d. weak suck as infants *

QUESTION 2

True or False: Problems with gastroesophageal reflux (GER) can lead to long-term feeding problems even when GER is treated.

- a. true *
- b. false

QUESTION 3

The correct response to the previous question was a. true. Why might problems with GER lead to long-term feeding problems, even when the GER is treated?

- a. because of the risk of aspiration associated with GER
- b. because of feeding aversions that can result from conditions such as GER *
- c. because of the irreversible damage to the intestinal mucosa caused by GER
- d. because there is no effective treatment for GER

QUESTION 4

Which of the following tube-feeding problems is an indication to seek immediate medical attention?

- a. bleeding through or around the tube *
- b. granulation tissue
- c. child indicates he is still hungry after tube feeding
- d. none of the above

QUESTION 5

A 2-year old who was born preterm has feeding problems that include aversions to oral stimulation. She receives tube feedings to supplement her limited oral intake. Based on the information above, which formula is probably most appropriate?

- a. post-discharge preterm formula
- b. standard infant formula

- c. standard pediatric formula *
- d. elemental pediatric formula

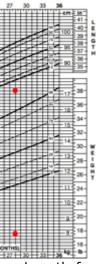
QUESTION 6

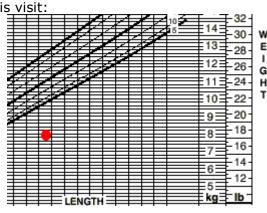
Terry is a 28-month old with cerebral palsy. He has hypotonia, and his wheelchair has straps to help him sit upright. Terry has GER that is being treated, but still has some episodes of vomiting. He receives speech therapy, primarily for oral-motor skills. He eats some solid foods, but his parents say that he was eating more one year ago. He also takes about 8-9 3-ounce bottles during the day, a mixture of a standard pediatric formula and goat's milk that is thickened with rice cereal.

Which of the following factors is probably NOT an indicator that a problem with feeding or eating may exist?

- a. hypotonia
- b. GER
- c. thickened formula
- d. use of goat's milk *

Terry's growth charts at this visit:





- Length-for-age (top) and weight-for-age (bottom) are below the 5th percentile
- Weight-for-length is below the 5th percentile

His feeding therapist does not feel that Terry's oral intake will increase significantly in the next few months. A VFSS was done and indicated that Terry does not have problems with swallowing or aspiration.

Terry has had "the flu" 3 times over the past few months. His parents are becoming increasingly frustrated with the amount of time they spend feeding Terry, and they worry that his younger brother is not receiving enough attention.

Terry's family, and the health care providers involved in Terry's care are concerned that his problems with feeding are compromising his growth and over all health. They decide that a feeding tube is necessary.

QUESTION 7

Which type of feeding tube is most appropriate for Terry?

- a. nasogastric tube
- b. gastric feeding tube (gastrostomy) *
- c. jejunal feeding tube (jejunostomy)
- d. none of the above

QUESTION 8

Placement of a gastrostomy tube is planned, and you are consulted to recommend a tube feeding formula. Which formula is most appropriate for Terry?

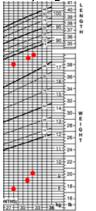
- a. continue with current formula (standard pediatric, goat's milk, rice cereal)
- b. elemental infant formula
- c. standard pediatric formula *
- d. elemental pediatric formula

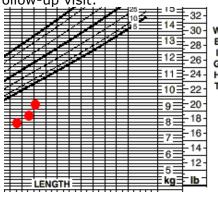
The gastrostomy tube is placed, and a feeding regimen is established. Terry receives a drip feeding of a standard pediatric formula at night (35 mL per hour for 8 hours), and is offered food and formula orally during the day. Terry's family offers food at 2 specified mealtimes, using recommendations provided by the feeding therapist. He is offered 6 ounces of formula from a bottle, and is tube-fed what he doesn't drink. His family is comfortable with this plan.

The feeding plan is adjusted as Terry grows and as his acceptance of solid foods increases. After 16 months, his rate of growth has increased. His growth charts are on the next slide.

Terry's oral intake has increased as well, and is meeting about 50% of his estimated energy needs. At age 3 years, 8 months, he is enrolled at a developmental preschool, where he receives feeding therapy.

Terry's growth charts at the follow-up visit:





- Length-for-age (top) and weight-for-age (bottom) are closer to the 5th percentiles
- Weight-for-length is closer to the 5th percentile

For More Information About Feeding Skills, Behaviors and Assessment of Feeding Skills

Questions about food patterns and feeding skills. This tables outlines questions that may be useful in assessing food patterns and feeding skills. It is available for download in pdf format.

Nutrition Questionnaires for Infants, Children, and Adolescents. Appendices A, B, and C in Holt K, Wooldridge N, Story M, eds. 2011 *Bright Futures in Practice: Nutrition* (3rd ed.). American Academy of Pediatrics. Questionnaires, along with quidelines for interpreting answers to the questionnaires are included.

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Oral-motor Feeding Problems. Glass RP. Oral-motor feeding problems. In: Yang Y, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2010. This chapter reviews many of the medications (and the medication-nutrient interactions that may be present) commonly used in the treatment of children with special health care needs. The publication can be downloaded from the WA DOH website: http://here.doh.wa.gov/materials/nutrition-interventions

Pre-Feeding Skills: A comprehensive resource for feeding development.

Morris SE and Klein MD. *Pre-Feeding Skills: A comprehensive resource for feeding development*. Therapy Skill Builders, 2000. This revision of the 1987 book includes information about normal feeding development and factors that influence feeding. Assessment and treatment are discussed. (ISBN: 076-1674-071) Available from Harcourt Assessment http://www.pearsonclinical.com/therapy/products/100000580/pre-feeding-skills-second-edition-a-comprehensive-resource-for-mealtime-development.html

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Feeding Infants: A guide for use in the Child Nutrition Programs. United States Department of Agriculture Food and Nutrition Service. *Feeding Infants: A guide for use in the Child Nutrition Programs*. USDA FNS-258. 2002. The 105-page guide includes information on infant development, nutrition for infants, breastfeeding and formula feeding, preventing tooth decay, feeding solid foods, drinking from a

cup and choking prevention. This guide was distributed to child care centers, sponsors of CACFP homes, and state agencies, and is available in electronic format at: http://www.fns.usda.gov/tn/Resources/feeding_infants.html.

How to Get Your Kid to Eat...But Not Too Much. Satter E. *How to Get Your Kid to Eat...But Not Too Much*. Bull Publishing. 1987. This book is written for parents and discusses the impact of child development and parent-child relationships on feeding dynamics from infancy to adolescence. It is available at bookstores, or directly from the publisher: Bull Publishing, http://www.bullpub.com.

Child of Mine, Feeding with Love and Good Sense. Satter E. *Child of Mine, Feeding with Love and Good Sense*. Bull Publishing. 2000. This is a nutrition and feeding reference book for parents of children under 4 years of age. It is available at bookstores, or directly from the publisher: Bull Publishing, http://www.bullpub.com.

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Eating/Feeding Problems of Children: The Team Approach. Cloud HH, Bergman J. Eating/feeding problems of children: the team approach. *Nutrition Focus*, 2004; 19(6). This issue reviews problems related to feeding eating in terms of assessment and intervention. To order, visit http://depts.washington.edu/chdd/ucedd/ctu 5/nutritionnews 5.html.

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