NOTICE TO THE READER

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GASTROINTESTINAL SYSTEM OUTLINE

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GASTROINTESTINAL SYSTEM

Why Assess the Gastrointestinal system?

The gastrointestinal (GI) system fuels the body, through the processes of ingestion, digestion, absorption, and removes body wastes, through the process of elimination. Problems in the gastrointestinal (GI) tract can have far-reaching metabolic implications for your children. For example, dental caries or periodontal disease may affect a nutritionally deficient child’s ability to eat, exacerbating his nutritional problems and prolonging his recovery. Vomiting and diarrhea, if untreated, may cause acid-base imbalance. Bleeding from the gastrointestinal (GI) tract may result in severe anemia.

Comprehensive assessment of the gastrointestinal system (GI) requires examination of the following areas: oral examination is a simple assessment procedure, which is often overlooked as part of the gastrointestinal (GI) assessment. Yet, you may be the first to detect an oral lesion, dehydration, thrush, or problems with cavities of the teeth, and be able to refer your child for early diagnosis and treatment. Secondly, mastering abdominal assessment presents a real challenge. The abdomen contains most of the gastrointestinal (GI) system: the lower end of the esophagus, the entire stomach, and the small and large intestines. It also contains parts of other body systems - the urinary, reproductive, cardiovascular, nervous, and blood forming and immune systems. In fact, only the respiratory system lies completely outside the abdomen - yet a distended abdomen certainly affects breathing. You can see then, how you may encounter many abdominal signs and symptoms during an assessment, and the implications they might have. Differentiating among so many possible signs and symptoms is a challenge. Lastly, a rectal examination needs to be considered. Detection of hemorrhoids, redness or irritation and checking for an impaction can be important to report to your Doctor.

Gastrointestinal (GI) assessment helps you sort out abdominal complaints and shed light on your child’s problem. Information gained through a gastrointestinal (GI) assessment can also help you monitor your child’s therapy, allowing you to identify any adverse developments and provide a database for your assessment with possibly your other children.
Reviewing Anatomy & Physiology

Mouth
The mouth has many vital functions. The tongue, teeth, and lips modify sound for speech. The mouth also initiates the digestive process and salivary lubrication through chewing, tearing and grinding of food with the teeth, and the decompensation of starches. It then delivers food to the digestive tract through swallowing. Its mucous membranes serve as a physical defense; its salivary secretions serve as an antimicrobial defense. Finally, the mouth is the medium for sensory response to taste.

Esophagus
The esophagus is a muscular tube that propels food from the pharynx to the stomach’s cardiac sphincter. Approximately 9” long, the esophagus extends from the 6th cervical to the 11th thoracic vertebrae.

Diaphragm
This domed muscle/tendon sheet separates the thoracic and abdominal cavities. The phrenic nerve, which starts in the neck, through the thorax, along the heart muscle, supplies innervation to the stomach. The diaphragm raises and lowers with respirations.

Abdomen
The abdomen extends from the diaphragm to the pelvis. Besides gastrointestinal organs (GI), it contains the kidneys and ureters, the suprarenal glands, and the blood vessels, nerves, and lymphatic systems. The abdominal contents are partially protected by the lower ribs, the lumbar vertebrae and the iliac bones. The rest of the abdominal walls consist largely of muscles and tendons.

Stomach
The stomach is roughly J-shaped. It lies under the diaphragm, to the left of and partially under the liver, to the right of the spleen, and in front of the pancreas. The stomach secretes gastric juices containing hydrochloric acid and enzymes. Together, with the stomach’s churning motion, these juices break food down into semisolid chyme. Serving as a reservoir, the stomach regulates the passage of chyme into the duodenum. (Hydrochloric acid kills most of the microbes in food). The stomach’s gastric mucosa can absorb small amounts of water, glucose, and certain drugs.
Small Intestine
The small intestine is approximately 21 feet long: the duodenum measures about 1 foot; the jejunum about 8 feet; and the ileum, the remaining 12 feet. Highly mobile and quite active, the small intestine coils and loops through much of the abdominal cavity and part of the pelvic cavity. The duodenum is a horseshoe-shaped organ, opening to the left, entering into the jejunum in the left upper abdominal quadrant, and the ileum lies in the right lower quadrant. The small intestine is where absorption and digestion largely takes place, where millions of villi (which transports fluids and nutrients) increase the surface area and controls the absorption of carbohydrates, fat and protein, then joins the large intestine.

Large Intestine
The large intestine consists of the cecum, the ascending, transverse, descending, and sigmoid colons, and the rectum. Its primary functions are to absorb water and store feces (stool). The rectum eventually excretes feces. The ascending colon starts along the right side of the abdomen. It bends to the left just in front of the right kidney. The transverse colon runs across the abdominal cavity, usually paralleling the stomach’s lower border. This portion of the colon is quite mobile, commonly occupying the lower quadrants of the abdominal cavity when the cavity is full. It meets the descending colon just in front of the left kidney. It runs down the left side of the abdominal cavity to the sigmoid (s-shaped fashion) colon to the rectum, which descends and bends along the back of the pelvic cavity, following the curve of the sacrum.

Peristalsis
Peristalsis is an involuntary process that propels food in waves through the esophagus, the stomach, and the intestines. Controlled mostly by vagus nerves, a peristaltic wave can travel the length of an organ or it can be a short, local reflex. Peristalsis can also result from the pressure of food or gas within the gastrointestinal (GI) tract. Peristaltic waves in the stomach tend to mix its contents and move them into the duodenum. Waves occur at the rate of three per minute, and usually two or three waves are in progress at any one time throughout the gastrointestinal (GI) tract. The waves in the small intestine are usually short and localized; they enhance absorption by bringing food into contact as they move food through the intestine. In the large intestine, peristaltic waves do progress, propelling food and gas toward the rectum, usually at the rate of \( \frac{\frac{1}{2}}{1} \) per minute. Three or four times a day, much more powerful contractions move larger masses of waste material. Peristalsis also keeps bacteria moving along the walls of the large intestine, preventing the accumulation of harmful organisms. By moving gas toward the rectum, peristalsis helps prevent distention and pain.
Accessory Organs
Accessory gastrointestinal (GI) organs (those that assist the digestive process, but are not part of the gastrointestinal (GI) system) are the liver, gallbladder, and pancreas. The liver, one of the largest organs in the body, lies under the thoracic cage, in the upper right abdominal quadrant. It has many vital functions. It figures prominently in the metabolism of carbohydrates, producing and storing glycogen and metabolizing galactose. The liver breaks down fat and converts fatty acids into small molecules that can be oxidized. And lastly, the liver secretes bile and detoxifies harmful substances in plasma, forms Vitamin A and stores other essential nutrients (Vitamin K, D, B12 and iron). The gallbladder lies just underneath the right lobe of the liver. About the size and shape of a small pear, it stores bile until it is discharged into the biliary duct system, which empties into the duodenum to aid digestion. The pancreas lies horizontally behind the stomach. Its head is attached to the duodenum; its tail reaches the spleen. The pancreas serves as an endocrine gland, producing pancreatic juices that travel to the duodenum for use in digestion. It also performs endocrine functions, releasing insulin and glycogen into circulation.

Autonomic Nerves of the Abdomen
The autonomic nerves of the abdomen consist of the thoracic and lumbar (sympathetic division) and the vagus and pelvic nerves (parasympathetic division). Sympathetic impulses slow activity in the gastrointestinal (GI) tract, inhibit secretions, and contract sphincters. Parasympathetic impulses stimulate gastrointestinal (GI) activity and secretions, and relax sphincters.

Blood Supply to the Abdomen
The abdominal aorta enters the abdomen at the level of the twelfth thoracic (ribs) vertebrae. After coursing slightly to the left of the vertebral column, it divides into the common iliac arteries at the fourth lumbar vertebrae, which supply the rest of the abdominal organs. It then becomes part of the femoral arteries (right and left) and supplies the lower extremities with blood supply.

Peritoneum
The peritoneum is a continuous serous membrane, which is lined with mesothelium (a layer of tissue) and is a covering for the organs in the abdominal cavity. It serves as a protective lining for each abdominal organ.

Abdominal Musculature
The abdominal wall consists of three pairs of sheet-like muscles (external and internal obliques and the transverse abdominis) and a pair of band-like muscles (rectus abdominis).
ANATOMY OF THE GASTROINTESTINAL TRACT (GI)
Collecting Appropriate History Data

Biographical Data
Besides serving to identify your child, biographical data, particularly age and sex, may indicate that your child runs a greater risk of having certain gastrointestinal disorders.

Chief Complaint - the most common chief complaints associated with gastrointestinal disorders are pain, dysphagia, nausea, vomiting, diarrhea, and constipation. Ask your child to elaborate on his chief complaints.

History of Present Illness
- Pain - What does the pain feel like? What symptoms accompany the pain? Fever, malaise, nausea, vomiting, warmth, redness, and swelling (such as in the mouth) may indicate viral infection or inflammation of the gastrointestinal (GI) tract. If your child has painful mouth ulcerations, ask if he notices any relation between exacerbation (reappearance of the symptoms once they have lessened) of symptoms and stress, food, change of seasons, or other factors. Ulcers are sometimes associated with these factors. Do you have heartburn or dyspepsia (a vague feeling of gastric discomfort felt after eating)? These conditions usually occur after eating certain spicy foods that produce excess acid in the stomach; dyspepsia may also occur with hiatal hernia or as a side effect of certain medications such as Salicylates (Aspirin). If your child has abdominal pain, ask him about the relationship of the pain to meals. Peptic ulcer pain usually occurs about 2 hours after meals or whenever the stomach is empty; it may wake your child at night. Has your child's bowel elimination patterns changed recently? When did your child have his last bowel movement? Can you pass flatus (gas)? Does your abdomen feel distended (swollen or tight)? Your child's answers may give clues to inflammatory or obstructive bowel disorders. Do you have rectal discomfort? This type of pain can indicate local problems, such as pain from a large, hard stool that has torn the mucosa, inflammation from infections or pain associated with hemorrhoids
- Dysphagia (difficulty in swallowing) - When, during swallowing, do you feel discomfort? Does it occur between your mouth and esophagus? In the esophagus? Between the esophagus and stomach? Asking your child to point to the area of discomfort is important, because certain disorders affect specific points in the swallowing process. Does the dysphagia result from ingesting solid food, or both solids and liquids? Did you have symptoms of reflux prior to the onset of dysphagia? Dysphagia usually results from mechanical obstruction or loss of motor coordination. Neurological disease
• Nausea and Vomiting – Do you feel nauseated before you vomit? Is the vomiting projectile (which means that vomiting is forceful and uncontrollable across the room)? Projectile vomiting often indicates central nervous system disorders. Does the vomitus have an unusual odor? A fecal odor (smelling like stool), for example, usually indicates a small bowel obstruction. Have you been emotionally upset recently? Have you vomited blood? Hematemesis (bloody vomit) may reflect a gastrointestinal (GI) disorder, such as severe esophagitis, stomach ulcers, or disorders outside the gastrointestinal (GI) system, such as anticoagulant toxicity

• Diarrhea – Ask about the frequency and consistency of your child’s bowel movements. Have you been under emotional stress lately? Psychogenic factors may affect bowel motility. What particular foods did you eat before the diarrhea’s onset? Food poisoning (such as from custard-filled pastries and processed meats contaminated with staphylococci) may cause diarrhea, usually accompanied by abdominal cramping and vomiting. Fever, tenesmus (spasmodic contraction of the rectal sphincter with pain and persistent desire to empty the bowel with involuntary, ineffectual straining efforts), and cramping pain associated with diarrhea usually indicates an infection, most commonly viral. Is the stool bloody? This may be due to hemorrhoids. Does the stool smell foul, bulky and greasy? This suggests a fat malabsorption problem. Passage of mucous suggests irritable colon. Do periods of diarrhea alternate with periods of constipation? This combination may be associated with irritable colon or diverticulitis

• Constipation – How would you describe the size, character, and frequency of your child’s bowel movements? Many children mistakenly claim to have constipation, so always ask this type of question to determine if constipation exists. What is your child’s typical daily diet like? The absence of fiber in the diet or inadequate fluid intake may lead to constipation. Laxative abuse, decreased physical activity, and emotional stress may also produce this symptom. Does your child experience cramping abdominal pain and distention related to the constipation? These symptoms suggest mechanical obstruction, such as from a stricture (closing of the diameter of the bowel). Find out if the problem is acute – in which case, it is more likely to have an organic cause – or chronic, which is commonly caused by a functional problem

Past History
Explore the following relevant areas when talking to your child about the history of the problem.

• Gastrointestinal (GI) disorders – long-term gastrointestinal (GI) conditions such as ulcers, reflux, hiatal hernia, nausea and vomiting
Neurological disorders – certain conditions of the brain may cause gastrointestinal (GI) disorders. For example – these conditions can impair movement of the tongue, the uvula (the small flap in the back of the throat), the larynx (voice box), or the pharynx (passageway for the respiratory and digestive tracts and changes shape to allow the formation of various vowel sounds), which can lead to drooling, dysarthria, and difficulty chewing or swallowing.

Other major disorders – gastrointestinal signs (GI) and symptoms may also result from pathologic conditions in other body systems – for example – scoliosis which can affect a child's breathing if the diaphragm is involved or motor impairment, which can lead to constipation due to inactivity.

Previous abdominal surgery or trauma – even such a relatively simple procedure as oral surgery may cause infection or bleeding. Previous surgery may cause adhesions, which can lead to scar tissue and pain.

Allergies – allergic reactions to certain foods and medications can produce a variety of gastrointestinal (GI) complaints, such as pain, nausea, and diarrhea. Check especially to see if your child is hypersensitive to penicillin, sulfonamides, or local anesthetics, which can lead to severe allergic symptoms affecting gastrointestinal (GI) mucous membranes. Also, ask your child about hypersensitivity to toothpastes or mouthwashes, which may cause symptoms on contact.

Chronic laxative use – laxatives including mineral oil and stool softeners, affect intestinal motility, habitual use of laxatives may cause constipation (from insensitive defecatory reflexes).

Medications – anti-infectives and many other drugs can produce various gastrointestinal (GI) side effects, such as oral ulceration, nausea, vomiting, diarrhea, or constipation.

Family History
Ask your child or parents if anyone in the family has ever had gastrointestinal problems. A family history of gastrointestinal (GI) disorders may predispose certain disorders for your child.

Psychological History
To review your child's psychological history, question him first about how his chief complaint is disturbing him. Emotional problems can contribute significantly to gastrointestinal (GI) symptoms – for example: pain, dyspepsia, nausea, anorexia, gluttony (over indulgence), or more idiosyncratic tendencies, such as cheek biting (which you will see as multiple areas of reddened, missing tissue or bleeding).
Other Things to Explore - Activities of Daily Living (ADL)

- Oral hygiene - ask your child to describe his oral hygiene routine for a typical day - note if he mentions using a toothbrush or dental floss
- Eating habits - frequent in between meal snacking on sugar-rich foods may predispose your child to dental caries. Excessive consumption of very hot or very spicy foods may lead to stomatitis
- General - ask if there has been a recent fever, weight loss, anorexia, fatigue or weakness. Record weights periodically
- Skin - generalized jaundice and pruritus (itching) may result from liver involvement. Pruritus around the anal (rectum) region may be caused by local infections, or by specific dermatologic disorders, such as psoriasis
- Eye - ask about eye pain and photophobia (abnormal sensitivity to light)
- Respiratory - dyspnea (shortness of breath) may result from scoliosis due to the degree of the curvature. We are finding that a larger than expected number of children with Batten Disease suffer from some degree of scoliosis
- Urinary - abdominal pain may be a symptom of urinary disorders
- Musculoskeletal - contractures (abnormal, usually permanent positions of the hands and feet due to the muscle fibers shortening due to inactivity) may develop due to inactivity and is common toward the end of Batten Disease seen in our children
- Psychological - anxiety, depression, and other emotional disturbances commonly accompany gastrointestinal (GI) disorders

Conducting a Quick Physical Examination

Physical examination can be done very quickly with a “head to toe” assessment.

- Mouth - have a flashlight - look into the mouth for sores, redness, white spots in the tonsil area, white coating on the tongue, ask if your child's throat hurts when swallowing, look for blackened teeth that may be decayed, check out the gums - are they reddened or swollen, excessive salivation, dryness or bleeding of the mouth, and also check for any unusual mouth odor
- Neck - check the neck to see if there is any obvious swelling of glands on either side, and if there is pain or tenderness when palpating the gland area
- Respiratory - unbutton or lift up your child's shirt to watch his breathing - shortness of breath, gasping, rapid breathing, breathing equal on both sides (does the chest rise and fall equally)
- Abdomen - check for any abdominal distention, does it appear symmetrical - does one side look swollen or larger than the other. If you have a stethoscope, listen for “bowel sounds” - which should be little gurgles heard every 3-5 seconds, which denotes movement in the stomach and intestines of
• Rectal - ask about any diarrhea, constipation, rectal pain, hemorrhoids, itching or bleeding with bowel movements
• Legs - check lower extremities for any swelling of the feet or ankles or swelling of the hands or face
• Skin - with each step - look at the skin, starting with the neck, abdomen, back, and legs for redness, swelling, rashes, scratching from itching, sores, dryness/perspiration and color of the skin

**Considering Specific Diagnoses or Problems**

The following topics can be specific problems of the gastrointestinal system (GI). They are mentioned because of symptoms seen in "normal" children as well as some of them are indicative with Batten Disease. Also, a lot of these symptoms or problems we as adults will see in our lives, so I have included them for us as well.

**Anorexia**

Anorexia by definition means lack or loss of appetite, resulting in the inability to eat. The condition may result from poorly prepared food or unattractive surroundings, unfavorable company, or psychological causes. It can be a result of specific factors such as anxiety, chronic pain, poor oral hygiene, increased blood temperature due to hot weather or fever, alterations in taste or smell, or drug therapy.

You need to be aware of recent weight loss and be exact in the number of pounds your child has lost. In children, anorexia commonly accompanies many illnesses, but usually resolves promptly. Anorexia and/or malnutrition usually arises gradually and is accompanied by the following:

- Hair - dull, dry, thin, fine, straight, and easily plucked; areas of lighter or darker spots and hair loss
- Face - generalized swelling; dark areas on cheeks and under eyes; lumpy or flaky skin around the nose and mouth; enlarged parotid glands (a salivary gland which lies just in front of the external ear)
- Eyes - dull appearance; dry and either pale or red membranes; triangular shiny gray spots on conjunctivae (the mucous membrane lining the inner surfaces of the eyelids and the anterior part of the sclera - the white part of the eye); red and fissured eyelid corners; bloodshot ring around cornea
- Lips - red and swollen, especially at corners, are there certain tastes and smells that nauseate your child and cause loss of appetite?
- Tongue – swollen, purple and raw-looking with sores or abnormal protrusions on the tongue
- Teeth – missing, or emerging abnormally; visible cavities or dark spots; spongy, often bleeding gums that may interfere with chewing
- Neck – swollen thyroid glans; is there pain when he swallows?
- Skin – dry, flaky, swollen and dark with lighter or darker spots, some resembling bruises; tight and drawn, with poor skin turgor
- Nails – spoon-shaped, brittle, and ridged
- Musculoskeletal – muscle wasting; knock-knee or bowlegs; bumps on ribs; swollen joints; musculoskeletal hemorrhages
- Cardiovascular system – heart rate above 100 beats per minute; dysrhythmias (irregular heart rhythm); elevated blood pressure
- Abdomen – enlarged liver and spleen; is their vomiting or diarrhea after meals? Is there a history of stomach or bowel problems, which can interfere with the ability to digest, absorb or metabolize nutrients? Are there any changes in bowel habits?
- Reproduction – amenorrhea (no menstrual periods for girls)
- Nervous system – irritability, confusion, paresthesias (abnormal sensations such as numbness, tingling or prickling in hands and feet); loss of proprioception; decreased ankle and knee reflexes
- Psychological factors – Does your child know what is causing the lack of appetite? Has there been problems at home or school, a death in the family?

What can we do as parents for our children?

- When do you get concerned if your child appears to have a lack of appetite? If your child has not eaten much for 7-10 days, you need to be looking for an alternative method of nutrition, sometimes, adding products like ensure may be helpful to maintain nutrition. If your child is an infant or toddler, you will need to call your Doctor before then. If you notice specific symptoms of dehydration, decrease in urinary output, fever to name several, you will have to notify your Doctor as soon as possible.

- Make sure that the cause of the lack of appetite is not due to another reason or illness, or is it the disease process (of Batten Disease) that is causing the symptoms – drug therapy, gastritis, constipation to list several. It has been noted that children with Batten Disease at times (usually due to medications such as anticonvulsants or when our children begin having more increased swallowing problems, they are almost afraid to eat due to the coughing and choking) will have periodic episodes when their appetite decreases, but then it will increase again to a more normal appetite over 1-2 weeks. If their appetite does not increase, consult your Physician.
Does your child have any swallowing difficulties? Children with Batten Disease will at some point during the illness develop swallowing problems. Many parents will go to a feeding clinic or see a speech pathologist when they notice the first symptoms of problems and usually a swallowing study will follow and alternatives to eating certain foods may need to be changed.

Offer small frequent meals that look appealing and his favorite foods, but nutritious.

Also offer supplemental liquids such as ensure or milkshakes – high in calories.

Continue to include exercises or some form of activity in the daily routine, whether it may be with a bath, passive range of motion (where you need to initiate exercises), or active range of motion (if your child is able to do some activities on his own).

Weigh your child on a regular basis and record, once a week, every 2 weeks, or monthly.

Consider talking to a nutritionist/or start multi vitamins to supplement his daily intake of essential vitamins.

Keep a daily log of how your child is eating, what time of day he eats better, what foods he seems to eat more of and any problems that may become apparent.

Weight Loss or Gain

Weight loss can reflect decreased food intake, increased metabolic requirements, or a combination of the two. As well as the things mentioned above in anorexia, specific medical causes that may cause weight loss could include the following:

- Crohn’s disease - with chronic cramping, abdominal pain and bowel movements.
- Depression - which may be difficult to detect in children - may see insomnia/hypersomnia (extreme drowsiness or sleep - more than normal), apathy (an absence or suppression of emotion or feelings), or fatigue.
- Diabetes - which is uncommon for children with Batten Disease.
- Gastroenteritis - (flu) malabsorption and dehydration - may be acute with viral infections or reactions, or gradual in parasitic infections.
- Stomatitis - inflammation of the oral mucosa, (usually red, sore, swollen, and ulcerated) due to decreased eating.
- Ulcerative colitis - weight loss is seen in the late stages of this disorder with the multiple stools (usually diarrhea); possibly bleeding, pus, or mucous in the stool, along with cramping abdominal pain; nausea and vomiting may also be present.
- Batten Disease - weight loss can be very sudden in Batten Disease - it is not uncommon for a child (especially Juvenile Batten) to go from 130 pounds to 75 pounds over just a few months period of time usually due to swallowing difficulties and not eating an adequate number of calories.
Weight gain occurs when ingested calories exceed body requirements for energy, causing increased adipose (fat) tissue to be stored. Some of the primary causes of weight gain may be overeating, emotional factors – most commonly, anxiety, guilt, depression, and social factors. It can also be caused from specific drug therapy, which causes overeating, when activity levels slow, family history of obesity, or is it age specific (growth spurt)?

**Medical causes of weight gain include the following:**
- Diabetes
- Thyroid disorders
- Adrenal gland disorders
- Increased insulin secretion
- Kidney disorders
- Cardiac disorders when the heart does not circulate properly, edema (swelling) may occur, therefore, the weight gain is fluid retention
- Poor eating habits
- Heredity

What can we do as parents for our children?
Refer to anorexia for weight loss and what we can do for our kids. As far as overeating, we can do the following for our children:
- Prepare well balanced meals
- Have healthy snacks available
- Limit chips, pop, and sweets
- Record weight on a regular schedule
- Give a multi vitamin to assure essential vitamins
- Encourage daily exercises or activities
- Keep a daily log of your child’s intake (as much as possible)
- Discourage fad diets

**Diet**
Children's appetites naturally vary from day to day, especially in response to their patterns of growth. Because each child is an individual, each has a unique growth pattern as well as unique caloric requirements to support their growth. Appetite is the inner voice that helps determine the amount of food a healthy child must eat to grow normally. Sometimes, a decrease in appetite is a tip-off to the parent of a child with special needs that something is not going well. But, while any significant decreases in appetite should be discussed with your Doctor or health care team, keep in mind that after the first year of your child’s life, decreases in appetite are a normal and predictable part of a child’s development. Other factors can influence appetite as well. The health of your child depends a great deal on the food they eat. Their diet has a big impact on their energy level, alertness, physical development, emotional moods, and appearance. By giving children the right kinds
of food, you help their bodies “work” better and grow to their maximum potential. Foods are made up of various nutrients. Each nutrient gives the body energy and helps the body grow. The most nutritious foods are those that provide the best building blocks while giving energy. Children will receive well-balanced meals and the necessary nutrients when you plan and serve meals that include food from the “basic 4” food groups which are: fruits and vegetables, milk and milk products, meat and meat equivalents (fish, eggs, and poultry), bread and bread alternatives (cereal and grains). Foods serve several purposes within the body: energy – they provide the “fuel” the body burns, growth – the building of new cells and body tissue, and maintain body functions – they keep organs and body processes working.

Some children also have allergies to certain foods. Two big ones are peanut butter and milk. Be sure you keep a list of food allergies for your child. **Lactose intolerance** is the inability to digest significant amounts of lactose, the predominant sugar in milk. This inability results from a shortage of the enzyme lactase, which is normally produced by the cells that line the small intestine. Lactase breaks down milk sugar into simpler forms that can be absorbed into the bloodstream. When there is not enough lactose to digest the amount of lactose consumed, the results although not usually dangerous, may be very distressing. Some degree of lactose intolerance develops in most people after the age of 5. But for reasons that are not entirely understood, it is usually more pronounced among Blacks, Asians, Orientals, and South Americans. And in a few cases, complete lactose intolerance is present from birth. Secondary lactose intolerance may occur in children or adults with malnutrition.

Few children require a diet that is totally free of lactose – most can tolerate some milk as long as it is carefully spaced throughout the day. In addition, many children are able to consume cheese and yogurt, in which the lactose is broken down by the active cultures. Symptoms may include nausea, cramps, bloating, gas, and diarrhea, which begin about 30 minutes to 2 hours after eating or drinking foods containing lactose. The severity of symptoms varies depending on the amount of lactose each individual can tolerate. After about the age of 2 years, the body begins to produce less lactase. Today many lactose alternatives are available in the grocery stores. Foods to avoid if lactose intolerance is a problem are milk and milk products (including cheese, buttermilk and yogurt), baked goods made with milk, sausages that contain milk products, creamy sauces and gravies, processed foods that contain lactose, chocolate, caramel, cocoa mixes, nondairy creamers, vitamins, medications, instant potatoes and frozen french fries. You will need to monitor your child’s intake of calcium and riboflavin, both are usually supplied by milk. Provide dietary supplements, if ordered. Also, assess your child’s diet to be sure he is taking in sufficient protein and calories. Make sure you read food labels to detect the presence of milk, milk solids, whey, lactose and casein. Suggest
substituting water or fruit juices for milk in recipes. Explain, if you eat out, avoid sauces, gravies and breading. And also, if symptoms improve, small amounts of dairy products can be added at one meal and then progress further as long as they are tolerated (for example - if you want to add cottage cheese - check with different brands because the amount of lactose varies widely in cottage cheese).

Fiber-modified diet makes up a crucial part of the diet and yet it is completely indigestible. Its benefits are primarily mechanical in nature: it promotes peristalsis, reduces intestinal transit time, and increases stool volume and weight. A high-fiber diet can help prevent diverticulitis by distending the colon and relieving pressure on the intestinal wall. It can help treat obesity by decreasing caloric density and promoting a feeling of fullness. Water-soluble fibers, such as pectin, can lower cholesterol levels and prevent coronary heart disease. Although dietary fiber is usually beneficial, it may need to be altered for children who suffer from indigestion, gastric reflux, or diarrhea - but remember, low fiber diets lack sufficient vitamins and minerals.

Sources of high fiber include:
- Breads and baked goods made from 100% whole wheat or rye flour instead of white flour
- Granola
- Oatmeal
- Unpeeled apples and other fruits
- Raw and leafy vegetables such as carrots and lettuce
- Coarsely ground bran can be added to muffins, cereals, or breads as a further fiber supplement

If on a high-fiber diet:
- Have female children to increase calcium intake to prevent osteoporosis
- Drink at least two glasses of milk a day and to eat cheese and yogurt
- If trying to lose weight, drink skim milk and low-fat cheeses
- Eat plenty of iron-rich foods, such as liver
- To increase zinc intake, recommend meat, nuts, beans, wheat germ and cheese

Sources of low fiber include:
- Soft, mild foods
- Excludes raw vegetables and fruits, nuts, seeds, coarse breads and strong seasonings
- Fried foods and fats are limited (they increase gastric reflux)
- Milk and milk products
- Cook meats and vegetables until they are quite tender
Remind all children/adults on a fiber-modified diet to schedule follow-up appointments to evaluate their progress and assess their nutritional status.

**Protein-modified diets**
Protein – the raw material for building cells and regulating bodily functions – is normally supplied in abundance by a well balanced diet. But a high protein diet may be necessary for those with increased body-building needs, such as growing children. A high protein diet can benefit children with increased tissue breakdown or with nitrogen depletion caused by stress or increased secretions of thyroid hormones. And it is often used with children who suffer protein loss due to immobilization, dietary deficiency, infection, or chronic disease.

Sources of high protein include:
- Eat plenty of carbohydrates so the body does not burn protein for fuel.
- Eat more meats, cheese, nuts, milk products, eggs
- Divide proteins as equally as possible throughout the day for better absorption
- Can add nonfat dry milk to regular milk and casseroles to increase their protein content
- Increase protein and calorie consumption gradually
- Weigh weekly – your child can gain weight rather quickly, feel stronger, resistance to infection increases and wounds heal more quickly
- Return for frequent checkups and evaluations

Sources of low protein include:
- If a low-protein diet is recommended, try a vegetarian cookbook
- Limit the amount of protein as ordered by your Doctor
- Usually not seen in children with Batten Disease
- Be sure your child eats enough protein to meet energy requirements
- Weigh your child weekly for possible weight loss
- Signs of protein deficiency include: weakness, decreased resistance to infection, low hemoglobin (blood count) levels, low albumin levels (check for edema - swelling) a sign of albumin deficiency)

Briefly, I would like to explain the understanding of Vitamins and Minerals supplements. Most people know that vitamins are essential for growth and development. But how they are stored can greatly influence their intended effects. And how they act depend on your child’s condition, his need for medications and other factors. Some points to remember when giving supplements.

- Vitamin C – usually no problems, give amounts as directed by your nutritionist or Doctor
Vitamin B1 (Thiamine) - B vitamins act together so an excess of one can cause an increased need for others. If given in shot form (IM - intramuscular), rotate sites to reduce discomfort

Vitamin B2 (Riboflavin) - before Riboflavin can be absorbed, it must be combined with Phosphorus (give with dairy products). Riboflavin supplements are also sensitive to light so keep them in an opaque container, do not give Riboflavin with alkaline substances (such as Maalox, Mylanta)

Vitamin B3 (Niacin) - do not give to children with peptic ulcers, low blood pressure, or any form of bleeding. Begin therapy with small doses and gradually increase to appropriate dose prescribed by your Doctor. Administer Niacin supplements with food to reduce upset stomach and to avoid taking with hot beverages because of increased vasodilatation (dilation of arteries). Use timed-release Niacin to avoid or limit symptoms of tingling, itching, headache, or a sensation of warmth, especially around the neck, head and ears. And also caution against exposure to bright sunlight

Vitamin B6 (Pyridoxine) - need for increased doses may be seen if your child is taking Penicillin

Vitamin B12 (Cyanocobalamin) - protect B12 from light and heat, watch Potassium levels - may need to give extra doses of Potassium

Vitamin A - may be contraindicated in malabsorption conditions, do not give Carotene with Mineral Oil - it can impair Vitamin absorption, adequate Vitamin A absorption requires suitable protein intake, bile, and concurrent recommended daily allowances of Zinc and Vitamin E, absorption is fastest and most complete with water preparations, intermediate with emulsions (a system using small droplets of the drug) and slowest with suspensions (a system where the drug is dispersed but not dissolved until stirred or shaken), carefully evaluate from giving extra doses of Vitamin A if foods are fortified with Vitamin A to avoid self mega-dosing, liquid preparations are available if necessary for gastrointestinal or jejunostomy tube (GT/JT) administration - can be mixed with cereals or fruit juices, protect from light and heat, record eating and bowel habits

Vitamin D - monitor eating and bowel habits: dry mouth, nausea, vomiting, metallic taste, and constipation may be toxic symptoms, if high doses are used, monitor blood and urine levels of Calcium, Potassium and Urea - doses of 60,000 units/day may cause increase Calcium, this Vitamin is fat-soluble - talk to your Doctor before increasing dose on your own, restrict intake of Magnesium containing Antacids

Vitamin E - use cautiously with: Aluminum containing Antacids which can decrease absorption of fat-soluble Vitamins, Iron supplements, and Vitamin A, water preparations are more completely absorbed in the gastrointestinal (GI) tract than other forms, adequate bile is essential for absorption, Vitamin E may protect other Vitamins against oxidation
- Folic Acid – if your child has a sore mouth or tongue, provide soft bland foods or liquids, protect Folic Acid from light and heat
- Vitamin K – be careful if any source of bleeding is noted – may have coagulation problems

Understanding Mineral supplements – minerals help build bone and soft tissue and form hair, nails and skin. They serve other purposes, too. Iron and Copper, for instance, promote synthesis of hemoglobin (blood count) and red blood cells (RBCs). Other Minerals help regulate muscle contraction and relaxation, blood-clotting, and acid-base balance. When administering a Mineral supplement, keep in mind these important considerations.

- Calcium – do not give Calcium with dairy products, bran cereal, spinach, rhubarb, or steroids to prevent impaired absorption, take 1 hour after meals to reduce gastrointestinal (GI) upset, monitor blood and urine Calcium levels
- Potassium – use cautiously if children are taking Atropine, may cause gastrointestinal (GI) ulcers, monitor intake and output to check kidney function, take immediately after meals to prevent gastrointestinal (GI) upset
- Phosphorous – watch for signs of tetany (muscle spasms, paresthesias around the mouth and in the extremities, abdominal pain, hair loss, or heart irregularities) from insufficient Calcium or excessive Phosphorous
- Sodium – (salt) use cautiously in children with heart failure, impaired kidney function or edema (swelling), monitor blood electrolyte levels frequently since imbalances can occur during therapy, check intake and output daily since excessive Sodium (salt) can cause fluid retention, weigh your child daily
- Oral Iron – use cautiously in peptic ulcers, flu, ulcerative colitis or in long-term therapy, gastrointestinal (GI) upset is related to the dose - take in between meals since food may decrease absorption, however, if your child experiences nausea, may give with food, enteric-coated products reduce gastrointestinal (GI) upset, but they may also reduce Iron absorption, advice to take Iron supplements at least 2 hours after eating dairy products, eggs, coffee, tea, or whole grain bread or cereals since these foods interfere with absorption. Iron is available in liquid form - dilute it with juice (preferably orange juice or water, but not in milk or with antacids), if you are giving Iron in tablet form - take with orange juice to promote absorption, Iron can be toxic - symptoms would include vomiting, upper abdominal pain, pallor, cyanosis, diarrhea and drowsiness, do not double up on doses if a dose is missed, stools may be black because of unabsorbed Iron, check for constipation and record the color and amount of stool - try to prevent
- Magnesium - monitor levels during therapy, most precautions are with intravenous (IV) route of administration
- Copper and Zinc - monitor blood levels during therapy, take Zinc with meals but not with dairy products because it can decrease absorption

Do your children argue about what to eat for breakfast? Maybe you want them to eat eggs and toast with their milk and juice, but they want something else. By looking at a food chart, you see that there are many possible substitutes. Children can receive the nutrition they need by eating something else. Think of other breakfast ideas that your children may prefer. Your idea of a good breakfast may not be a peanut butter and banana sandwich, but if your children like it, remember that protein, fruit, and grain provided here substitute for other breakfast foods they may not be fond of. You are respecting their tastes and at the same time, providing them with good nutrition. Some foods lose Vitamins when they are cooked for a long time. Try the following ideas to help save nutrients: steam fresh vegetables instead of cooking them directly in water and cook them for a short time; eat raw vegetables in salads or with dips; use water from cooked vegetables (the water contains nutrients) in soup broth or gravy; cook frozen vegetables while frozen (do not thaw ahead of time); cover and refrigerate juices (Vitamin C is lost by exposure to the air and heat).

Feeding a child who has a Visual Impairment is more like than unlike feeding a sighted child. All children want to be active participants in the mealtime process. All children find ways to let you know that they want more, or that they want to eat faster or more slowly. All children want to smell, touch, and play with foods. Vision is one way sighted children get themselves ready to take a bite of food. Children with visual impairments may need your help to learn other ways to prepare for eating. Here are a few ideas that may be helpful:

- Try it! Have someone feed you while being blind folded. What was it like? Did you find yourself noticing things you had not noticed before? Did you trust the feeder? Were you fed too fast or too slow? Did you know what was coming next? Was the spoon too big or too little? How did you take control of the situation?
- Keep a mealtime routine - the sounds of pots and pans in the kitchen, the smell of food, the time of day - all are clues that let your child know a meal is being prepared, also washing your child's hands or putting him in his chair
- Talk with your child about the foods to be eaten, naming and describing them. Also let him know when the spoon is coming
• Active participation - pay close attention to what your child is telling you with words, sounds, and body language. Let your child help in feeding as much as possible
• Who controls the pace - let your child handle this one. Let him know that the spoon is coming, bring it his lower lip, then let him open his mouth to let you know he is ready
• Touch preference - temperature changes may seem more dramatic if your child is not warned that the temperature of the food is coming and is different from the last mouthful
• Texture changes - may be more difficult for your child - let him know if it is smooth, lumpy, or a meat, for example

Encourage children to eat or try new foods by eating with your children - your attitudes affect theirs; have your children help prepare the meal; avoid forcing the issue - it tastes better when you want to eat it; serve your meal in small portions; offer a variety of foods when your children are young; serve foods as “finger foods” so they can feel textures; and ask your child what foods they like.

Many diseases begin or are passed along in the food preparation process. Keeping your kitchen, foodstuffs, and utensils in a sanitary condition to prevent the outbreak or spread of disease is a necessary health precaution. Be sure you follow simple rules: food must be in sound condition, unspoiled, and safe for human consumption; if you have any doubts, throw the food away; all milk and milk products, eggs, meat, poultry, fish, and other food items which can spoil in a refrigerator that is not kept below 45 F degrees; use silverware and utensils that are easily cleaned and that are free of breaks, cracks, and chips where food particles could lodge; always wash your hands and your children’s hands in soap and water before preparing food or working in the food preparation area; and the unused portion of formula, breast milk, or infant food remaining in the container cannot be reheated or served a second time.

Allow your child/children to help you prepare meals in the kitchen. Children can learn many concepts as they help in the kitchen. The kitchen is also a place to help them with muscle development, coordination, and social skills.

Children:
• Gain in muscle development and coordination as they pour juice and milk, wash fruits and vegetables, spread peanut butter, stir ingredients in a bowl, cut foods such as bananas, cheese, apples, grate cheese, peel hard-boiled eggs, or use a hand beater
• Build self-confidence as they realize they can produce something valuable that is used by others, complete jobs usually done by grown-ups, enjoy what
• Learn math concepts as they count the number of eggs, spoonfuls, etc., cut foods into halves, quarters, etc., set the table (placing one cup, plate, etc. at each chair), use the terms "more" and "less", "bigger" and "smaller", measure cups and teaspoons

• Develop language skills as they listen to sounds in the kitchen, use new vocabulary words (sift, chop, blend, stir, etc.), practice talking and building sentences, or follow directions from you or a recipe

• Improve social development as they learn about foods from other cultures, learn that males and females can enjoy work in the kitchen, and cooperate and work together

• Learn science concepts as they learn that water can be liquid, solid, or gas, discover that fruits and vegetables have seeds, understand the relationship between certain foods and what is made from those (fruits and juices, milk and yogurt, etc)

• Improve their use of senses by comparing tastes (sour, bitter, sweet, salty), touching textures (prickly pineapple, smooth apple, bumpy cauliflower), noticing smells (from spices and cooking foods), listening for sounds (crunching carrots, whirling blender), seeing colors, and comparing sizes and shapes

To summarize, you want to have a relaxed meal or snack time to help you and your child’s day go more smoothly. You do not want to look forward to arguing with your children over food and eating habits. Serve foods that look attractive, colorful, and nutritious, have children learn something about nutrition or what are “good foods” so when you are not around they will naturally choose foods that are good for them, let children choose and serve themselves so they start to build up this sense of how much they can eat and what foods they need, let your children help prepare the meals so they have a more positive attitude about meals, and serve smaller portions and then give them seconds if they ask for them.

*Ketogenic Diet* - when medications fail to control a child’s seizures, your Doctor may recommend a special high fat, low carbohydrate, restricted calorie diet, which results in ketosis. The diet is designed to change the way your child gets energy from food - instead of getting energy from glucose (carbohydrate), the diet forces the body to burn fat. The diet consists of 3-4 times as much fat as carbohydrates and protein combined. Some of the fat is given in the form of cream or butter. Calories are strictly limited and parents need to be very careful not to allow your child to eat anything - even cookie crumbs - that is not on the diet or has not been pre-measured and pre-weighed within the formula. The diet is usually begun in the hospital where your child can be watched closely. You need to be sure to be
followed closely by a nutritionist and your Doctor. After asking many parents who have tried the ketogenic diet for seizure control, many say it did seem to work for 1-2 months and controlled seizures along with the use of medications, but then the seizures would begin to reappear again.

Common answers to questions asked regarding the ketogenic diet:

- The diet seems to be most effective for myoclonic and minor motor seizures, but may also be helpful in tonic-clonic and complex partial seizures.
- Make sure you talk to your Doctor and other families who have been on the diet before starting it on your own. It is usually used as a secondary method of treatment when medications do not seem to adequately control seizures. Also, if the adverse effects of the medications are too great, the diet may be introduced so that the medications can hopefully be reduced.
- Not all hospitals have an active keto team. Your Doctor or neurologist will be able to help you make a decision as to the appropriateness of your child to try the diet. If hospitalized to start the diet, usually 4-5 days is all. Your child can be on the diet 2 years and weaned off into the 3rd year.
- If your child has allergies to foods or intolerant to dairy products, it can be adjusted to fit a ketogenic diet.
- How do we manage birthdays, holidays? These can be managed and do not need to be food centered. For example – trade Halloween candy for nickels to buy a new toy.
- How will my child feel on this diet? During the fasting phase, he may feel lethargic, sleepy, and cranky. As the diet begins, lethargy may continue as well as nausea and vomiting, which may be due to excessive ketosis or the side effects of the change in metabolism from using glucose to using fats. It may be related to drug levels. Children should return to normal – some kids even get more energetic with time. One common side effect of a high fat diet for everyone is a slower gastric emptying time, thus even though the portions look smaller, the food will stay in the stomach longer and give a longer feeling of fullness.
- What if your child “cheats” on the diet? Be prepared for this to happen at least once - try to minimize this, but if it does happen, recognize the mistake and pick up with the regular meal plan for the next meal.
- Will medications (including anticonvulsants) be discontinued after your child starts on the diet? This totally depends on your child and your Doctor. They may very well be reduced, but to completely stop medications may not be wise.
- If the diet seems to be working, how long will your child be on the diet? If your child were seizure free for 2 years, most neurologists would recommend switching back to a normal diet. The success rates of the ability of children to remain seizure free are not well studied.
• Is a 2 year old too young to start the diet? No, it is not too young. This is a great age to start the diet - no problems have been experienced. Out of 15 patients on the diet in one particular study, the youngest was 11 months and the oldest was 12 years. The best thing to do in the fasting period is to check blood sugar levels frequently, and to treat them accordingly.

• Can the diet be used for your child with a gastrostomy (Gtube) who is allergic to dairy products? The answer is yes, despite the allergies. You can use a formula that has no dairy products in it. You should also use a very good Vitamin/Mineral supplement.

• What about nutritional supplements? The ketogenic diet is very nutritionally inadequate for Vitamins and Minerals. One report suggests using a child’s complete supplement alternating with an adult complete Multi Vitamin to get all the trace elements. This same report suggests adding Calcium 750-1200 mg to meet daily Calcium needs. Another big source of the diet is in the constipation medications, so be careful with those also; this article suggests using Milk of Magnesia. What about fluoride supplements? There are several on the market with carbohydrates - Fluoritab (Fluoritab Corp) and Karidium (Lorvic Corp).

• What are some good finger foods for toddlers? Chicken strips, veggie pieces dipped in seasoned mayonnaise dip, chunks of bananas or melon dipped in whipped cream, Ritz Bitz with butter or peanut butter on top.

• Some strategies to increase low morning ketone levels - try a later dinner or try 4 meals/day instead of 3. Make sure you check ketones frequently enough.

• Can children develop kidney stones with the diet? Yes - if one develops, slight liberalization of fluids seems to correct the problem.

**Halitosis (Foul Breath)**

Halitosis is defined as an offensive breath resulting from poor oral hygiene, dental or oral infections, the ingestion of certain foods - onions or garlic, or some systemic diseases as the odor of acetone, a sign of diabetes. Halitosis describes any breath odor that is unpleasant, disagreeable, or offensive. Usually, it is easy to detect, but an embarrassed person may take measures to hide it. Occasionally, the person is unaware of halitosis, although he may complain of a bad taste in his mouth or he may believe he has bad breath, but no one else can detect it. Halitosis can result from disorders of the oral cavity, nasal passages, sinuses, or respiratory tract, as well as gastrointestinal disorders associated with belching, regurgitation, or vomiting. It may also be a side effect of oral or inhalant drugs.
Medical causes for halitosis:

- **Bowel obstruction** - a late sign of both small and large bowel obstruction. In small bowel obstruction, vomiting of gastric, bile, or fecal (stool) material produces a related breath odor, may also find diarrhea or constipation, abdominal distention, and intermittent periumbilical cramping pain. Auscultation (listening) initially reveals hyperactive bowel sounds, later hypoactive or absent bowel sounds signaling complete bowel obstruction. In large bowel obstruction, fecal vomiting produces fecal breath odor. Unlike small bowel obstruction, abdominal pain is milder, more constant, and usually located lower in the abdomen. Abdominal distention may be dramatic and loops of large bowel may be visible.

- **Bronchiectasis** - (a condition where dilatation and destruction of the bronchial walls, resulting usually from infection) usually, this disorder produces foul or putrid halitosis, however, some may have a sickening sweet breath odor. Typically, your child would also have a chronic productive cough with copious, foul smelling, mucopurulent sputum. The cough is aggravated by lying down and is most productive in the morning. Other signs and symptoms include exertional dyspnea, fatigue, malaise, weakness, and weight loss. Lungs will have rales (crackles) noted over the affected areas during inspiration. Clubbing of the fingers is a late sign.

- **Common cold** - a musty breath odor may accompany the common cold. Usually, this disorder also causes a dry, hacking cough with sore throat, sneezing, nasal congestion with rhinorrhea (thin, watery discharge from the nose), headache, malaise, fatigue, and aching joints and muscles.

- **Gingivitis** - characterized by red, edematous gums can cause halitosis. The gingivae between the teeth become bulbous (swollen) and bleed easily with slight trauma - a big and common problem with children with Batten Disease - a lot of times your child will be unable to use a toothbrush due to the pain of the gums, so toothettes (little sponges on a stick) are an alternative. This is also a big problem especially if taking Dilantin (a side effect of this drug).

- **Ketoacidosis** - can produce a fruity breath odor, when diabetes is a possibility.

- **Lung abscess** - causes putrid halitosis. The major sign is a productive cough with copious (large amounts), purulent, often bloody sputum, chills, dyspnea, headache, anorexia, malaise, pleuritic chest pain (like pleurisy where the lining of the lungs is inflamed), weight loss, and temporary clubbing of the fingers. Will also hear rales (crackles - usually fluid) as breath sounds and chest percussion will be dull on the affected side.

- **Periodontal disease** - halitosis is accompanied by an unpleasant taste. The gums bleed spontaneously or with slight trauma and are marked by pus filled
- Pharyngitis – (inflammation of the pharynx – which is the passageway for the respiratory and digestive tracts and changes shape to allow the formation of various vowel sounds) halitosis is a chief sign, also complains of a foul taste in the mouth, an extremely sore throat, and a choking sensation. You will see a swollen, red, ulcerated pharynx, possibly with a grayish membrane, fever and cervical lymphadenopathy (disease of the lymph nodes)
- Kidney disorder (chronic) – breath may smell like urine or ammonia, your child may be lethargic, irritable, decreased mental status, muscular twitches, muscle wasting, anorexia, or signs of gastrointestinal (GI) bleeding
- Sinusitis – acute sinusitis causes a purulent nasal discharge that leads to bad breath, will cause postnasal drip, nasal congestion, sore throat, cough, malaise, headache, facial pain, tenderness, and fever, chronic sinusitis causes mucopurulent discharge that leads to a musty breath odor, also post nasal drip, chronic productive cough
- Thrush which is a yeast infection of the mouth is a problem with our children with Batten Disease – normally need to have an oral liquid “swish and swallow” antibiotic to be helpful – you will see white patches in the mouth and it is usually painful to eat anything orally if not treated, poor nutrition will result for at least a few days until treated, food and fluids need to be encouraged
- Zenker’s diverticulum – is a condition of the esophagus causing bad breath and a bad taste in the mouth associated with regurgitation
- If your child no longer eats oral food – this too may be a cause of bad breath. As we eat and drink we help keep our mouth clear of food particles between our teeth or secretions to be dried in our mouth

If you feel there is a medical problem that is causing the halitosis of your child – be sure to talk to your Doctor about it. He may order mouth, sinus, chest, upper gastrointestinal (GI) series or endoscopy (EGD) to try and get a diagnosis.

To help control halitosis, encourage good oral hygiene, using mouthwash and peridex (a combination of hydrogen peroxide, normal saline and water) frequently (may need to do every 1-2 hours while awake). A water pic or battery operated toothbrush may also be helpful, but not necessarily better than a regular toothbrush.

**Dental Issues**
Some of the issues in the Halitosis section can also be applied here as well. It is important to have your child/children brush their teeth daily or twice a day to prevent dental caries. If your child is unable to brush his own teeth, then you will have to do it for them. Also, with the use of mouthwash and/or peridex can be helpful. You may need suction available to clean out your child’s mouth if he/she
has swallowing difficulties or excessive saliva. The amount of sugars a child eats also can increase the amount of cavities. Hereditary factors can play an important role, for example, gum disease or soft teeth (enamel) are commonly passed on from one generation to another.

If your child needs to have dental work done there are some issues you need to remember. There are various indications for the use of sedatives in children with disabilities and the need for dental care. These can include children who are unable to cooperate because of extreme anxiety or phobia concerning dental treatment, individuals who exhibit involuntary movement caused by neuromotor disorders, and children who are unable to understand the need for dental care and are unable to cooperate in a way that allows the dental professional to provide optimal care. Additionally, some children capable of cooperating for brief, minor procedures may require sedation for more extensive treatment needs. Dental professionals are trained in a number of sedative techniques that can alleviate a child’s anxiety and/or control disruptive behaviors in the course of dental treatment. It is very important that you familiarize the Doctor with your child’s medical history and provide information on any medications your child may be taking. Sedative techniques run along a continuum from light, conscious sedation, through unconscious sedation all the way to general anesthesia.

I have asked Doctors and also on the recent survey that we conducted about any side effects from anesthesia for children with Batten Disease and from the Doctor’s viewpoint, the use of nitrous oxide and the main other drugs used in dentistry should not present a problem for your child with Batten Disease. The major problem that parents have reported is the increase of seizures the day of and possibly the following day after dental treatment.

A complete section on dental issues will be addressed on its own coming soon.

**Oral Stimulation and Treatment Program**

It is very important that an ORAL STIMULATION program using various tastes in drops of liquids that refresh and moisten the mouth be started as soon as possible. You can use a toothbrush, a NUK, a toothette, a cloth moistened with a liquid, or a spray. You need to keep your child’s mouth clean of crusty build up, the roof and the tongue, as well as the teeth. By running your finger along the outside of the gums to the back where the jaw is hinged, and by applying pressure at that joint, you can get the mouth to open. Using a bite stick or a jaw prop (ask your dentist) a thorough cleaning can be done. Your child still needs to see a dentist on a regular basis and there are more and more dental technicians trained to work with children with special needs (some areas even have dentists that will come to your home, so call your state dental association if you need help). It may be helpful as times goes
on to have a suction machine handy with a hard plastic tube (Yankauer or tonsil tip) attached to suction the back of the throat. It is important that you stimulate your child’s mouth so that the swallowing process will be maintained. This allows your child to manage his own saliva and secretions for as long as possible. As changes occur, you may find that the gag reflex may become easier to stimulate and you will have to be very careful when you are working in the mouth, so not to antagonize aspiration; and as time goes on, the gag reflex may disappear entirely, so you will recognize that you will have to think about doing more suctioning.

**Oral-Motor Treatment**

Oral-motor treatment helps children develop the appropriate use of their oral, breathing, and voicing systems. Opportunities are created for exploration, sound play, and as the exploration of sensorimotor skills required for oral feeding. An oral-motor treatment program emphasizes the development of sensory awareness, perception, and discrimination within the mouth, and the use of oral movement to explore and understand the world of toys, clothing, body parts, and sounds. Small amounts of food and liquid may be introduced to provide tastes. Smells, and temperatures, elicit specific oral movements when your child is medically able to handle them. It can also emphasize your child’s acceptance of cleaning the mouth with a washcloth, swab, or toothbrush. Regular cleaning reduces the amount of bacteria carried in the saliva, and lowers the risk of pneumonia if your child aspirates saliva. A positive oral-motor treatment program emphasizes the underlying sensory and motor prerequisites for developing feeding skills. This builds the foundation of comfort and skill that enables your child to learn to eat without a struggle. We have to feed children to help them develop the skills they will need.

**Swallowing Safety and Aspiration**

What is Good Eating and Swallowing?

If miss-swallowing occurs, some of the food and drink may get into their airway and cause them to cough or choke. These respiratory events may result in an airway blockage or may cause respiratory infections and may damage their lungs.

We think about swallowing as having four phases:

- **First** - we regulate the amount of food that goes into our mouths and get the food ready for swallowing. This may involve chewing it or just mixing it with saliva, collecting it on our tongue and moving it into place where it is ready to be swallowed.
- **Second** - we move it out of our mouth and into our throat. This movement begins the swallowing reflex.
- **Third** - we move it past the opening to our lungs and toward the esophagus. The esophagus is the structure that leads to the stomach.
Fourth - the food is moved through the esophagus and into the stomach

Swallowing is a motor skill. The general skills and competencies we use to regulate swallowing are not unlike those used for other motor skills. Alertness and attention to the task is important. We must regulate the rate of intake by pacing the activity properly and by limiting the amount of food that is swallowed at one time. Essential components of good eating and swallowing are:

- Having the motor skills and the muscle competencies to prepare the food and liquid for swallowing
- Knowing when it is ready to be swallowed
- Coordinating breathing and swallowing so as to avoid getting food in the airway

If we begin to have trouble with something we are swallowing, it is important to know when, and how to fix the situation. We may use a drink to clear the trouble - some material or expel it, or continue to swallow until we feel safe once again.

What are the signs of feeding and swallowing disorders? Feeding and swallowing disorders may appear in a variety of ways:

- Early on, your child may not advance his or her eating skills. Chewing, biting off pieces of food, drinking from a cup and regulating the pace of eating are some of the more common skills that may not develop well
- Your child may refuse to eat enough or may eat only a restricted variety of foods. (Picky eating can be a sign of a child’s temperament. And as long as your child is doing well, it is not necessarily a problem)
- Eating behaviors may be disruptive
- Your child may not want to sit down to eat
- He or she may cry or get angry during eating
- Your child may not maintain good attention to eating
- He or she may have difficulty keeping food or saliva in their mouths and preparing the food properly for swallowing

Associated Nutritional And Health Problems
Feeding and swallowing problems may predispose your child to choking and may interfere with the quality of life by making meal times difficult times. These are the immediate problems. However, in the long term, feeding and swallowing problems can cause health problems. Children may become malnourished or dehydrated. Dental and gingival disease, as well as respiratory disorders, can result from feeding and swallowing problems.
Improving Feeding and Swallowing Problems

The first consideration in promoting safe swallowing is to make mealtime, taking medications, and teeth brushing, as easy as possible for your child. This can be achieved by adjusting seating for eating, adjusting diet textures and consistencies, and using utensils that can be easily managed. Feeding techniques may need to be adjusted. Extra supervision and assistance may be needed. Good communications between caregiver and your child or adult is essential for regulating behavior and for reducing the stresses that exist when a task is difficult or when a routine task is changed. Environmental stresses play a role in the difficulties that your child may have when they eat. An unfamiliar place with unfamiliar people should be considered as extra stresses. Noise, confusion, and lighting can all make a difference. When the environmental stresses are greater, the caregivers can help by simplifying the eating task. Easier foods, slower pace, calmer setting, and close, gentle supervision can help. Improving skills, behaviors and competencies can be achieved through therapy, education, and home programs. Once improvements in the basics have been made, new routines can be incorporated into daily activities. This is so for children as well as adults. The ultimate goal is safe swallowing and enjoyable experiences. Safety and enjoyment are two sides of the same coin – they cannot be separated.

Implications for your child with swallowing dysfunction:

- The absence of a swallowing reflex leaves the airway unprotected
- Delay in elicitation of the swallowing reflex places the airway in a risk position
- Small cavities formed by sinuses in the mouth can serve as catching pools for small boluses of food
- The shared use of the pharynx by respiratory and feeding systems increases the risk of aspiration in children whose respiratory systems are compromised
- The infant anatomical differences create additional protective and learning systems which may not be present in the older infant or child with severe swallowing dysfunction

Difficulties with swallowing may interfere with taking oral medications or handling the fluid that collects in the mouth during brushing teeth. The problems with eating and swallowing may be caused by neuromuscular disorders, such as cerebral palsy, problems with motor organization and planning, or by insufficient early experiences to acquire the necessary motor skills. Individuals may have behavioral and psychiatric problems that interfere with their eating. They may have medical disorders that have made it difficult for them to acquire the skills and controls needed for safe eating. Gastrointestinal, pulmonary, cardiac, or neurological disorders are among the large number of medical disorders that can directly or
indirectly affect swallowing. A feeding evaluation by a skilled speech-language pathologist knowledgeable about feeding and swallowing in children can be very valuable in sorting out typical eating patterns, behavioral - problem eating patterns, and underlying swallowing problems.

Difficulty in swallowing (Dysphagia) is common among all age groups. The term dysphagia refers to the feeling of difficulty passing food or liquid from the mouth to the stomach. This may be caused by many factors, most of which are temporary and non-threatening. Difficulties in swallowing rarely represent a more serious disease. When the difficulty does not clear up in a short period of time, you should make an appointment and see your Doctor or a specialist in that field. People normally swallow hundreds of times a day to eat solids, drink liquids and swallow the normal saliva and mucus that the body produces.

What causes swallowing disorders?
Any interruption in the swallowing process can cause difficulties. It may be due to simple causes such as poor teeth or a common cold. One of the most common causes of dysphagia is gastroesophageal reflux disease. This occurs when stomach acid moves up the esophagus to the pharynx, causing discomfort. Other causes may include: progressive neurological disorder, the presence of a tracheostomy tube, a paralyzed or unmoving vocal cord, a tumor in the mouth, throat or esophagus, or surgery in the neck or esophageal areas.

Symptoms of swallowing disorders may include:
- Drooling
- A feeling that food or liquid is sticking in the throat
- Discomfort in the throat or chest (when gastroesophageal reflux disease is present)
- A sensation of a foreign body or “lump” in the throat
- Weight loss and inadequate nutrition due to prolonged or more significant problems with swallowing
- Coughing and choking caused by bits of food, liquid, or saliva not passing easily during swallowing, and being sucked into the lungs

Who Evaluates and Treats Swallowing Disorders?
When dysphagia is persistent and the cause is not apparent, the Doctor will discuss the history of the problem and examine the mouth and throat. He may also use a laryngoscope (a flexible tube with a light and mirror) to see the back of the tongue, throat and larynx - voice box). They may also want to do x-rays of the swallowing mechanism, a barium swallow or an upper gastrointestinal (GI) series.
If special problems exist, a speech pathologist may consult with the radiologist regarding a modified barium swallow or videofluoroscopy. These help to identify all four stages of the swallowing process. Using different consistencies of food and liquid, and having your child swallow in various positions; a speech pathologist will test the ability to swallow. An exam by a neurologist may be necessary if the swallowing disorder stems from the nervous system.

Possible Treatments

Many of these disorders can be treated with medication. Drugs that slow stomach acid production, muscle relaxants, and antacids are a few of the many medicines available. Treatment is tailored to the particular cause of the swallowing disorder. Gastroesophageal reflux disease can often be treated by changing eating and living habits, For example:

- Eat a bland diet with smaller, more frequent meals
- Eliminate caffeine
- Reduce weight and stress
- Avoid food within three hours of bedtime
- Elevate the head of the bed at night

If these do not help, antacids between meals and at bedtime may provide relief. Many swallowing disorders may be helped by direct swallowing therapy. A speech pathologist can provide special exercises for coordinating the swallowing muscles or restimulating the nerves that trigger the swallow reflex. Children may also be taught simple ways to place food in the mouth or position the body and head to help the swallowing process occur successfully. Some children with swallowing disorders have difficulty feeding themselves. An occupational therapist can aid your child and family in feeding techniques. These techniques can make your child as independent as possible. A dietician or nutritional expert can determine the amount of food or liquid necessary to sustain an individual and whether supplements are necessary. Once the cause is determined, swallowing disorders may be treated with medication, swallowing therapy and surgery. Surgery is used to treat certain problems. If a narrowing or stricture exists, the area may need to be stretched or dilated. If a muscle is too tight, it may need to be dilated or released surgically. This procedure is called a myotomy and is performed by a specialist. Many causes can contribute to swallowing disorders. If you have a persistent problem swallowing, please see your Doctor.

When A Child Aspirates

The ability to swallow safely is the primary prerequisite for becoming an oral feeder. When your child aspirates, oral feedings are often discontinued, and your child is given a feeding tube for eating. Many professionals recommend stopping the use of food at home and in therapy programs until your child swallows without
aspirating as seen on a modified barium swallow study. This leaves parents and therapists with many questions, and implies a wait-and-see approach.

If your child is prepared physically and supported emotionally, a swallowing study can provide invaluable information.

- A swallowing study can identify aspiration that occurs during the study. When your child aspirates during a swallowing study, it can be observed through fluoroscopy. This indicates that your child has a vulnerable swallow, and has aspirated during this specific swallowing study. The vulnerability of the swallow is an important consideration, because it suggests that your child may aspirate at other times when there is physical or emotional stress.

- A swallowing study can identify children who have "silent aspiration". When food or liquid enters the airway, a protective reflex triggers a cough to propel the food upward and prevent it from entering the lungs. Children who cough and choke during feeding are at high risk for aspiration, because we know clinically that a part of the meal has entered the top of the airway. Coughing is a good sign, but it does not tell us that your child always protects the airway and does not aspirate. A swallowing study can tell us whether your child coughs out everything that goes astray, or whether some enters the lungs in spite of the cough. Many children do not cough when they aspirate. Low sensory awareness or difficulty controlling movement of the vocal folds can allow food or liquid to pass through the airway and make a silent journey to the lungs. The feeder does not have immediate feedback of the times when the liquid goes into the airway. A modified barium swallow study is the only way to verify aspiration. Many parents are surprised to find that their child is experiencing aspiration, because your child shows no indication through coughing.

- A swallowing study can identify the consistency of food or liquid, which your child can handle safely. Liquids and foods of different consistencies can be used and compared during the study. Some children do well with one or more consistencies, yet aspirate with other consistencies. Although we often do a swallowing study to identify or rule out aspiration, its primary clinical value is to identify situations in which swallowing is more or less safe for your child. There are many young children, for example, who aspirate on thin liquids who swallow well when the liquids are thickened. These children are able to remain oral feeders if thin liquids are eliminated from their diet.

- A swallowing study can identify risk factors for aspiration. Children, who do not aspirate during the brief period of the swallowing study, may still be at high risk for aspiration in other circumstances. A child who does not clear the final swallow of liquid out of the small pocket between the base of the tongue and the epiglottis may experience an overflow of the liquid into an open airway when he moves. Food residue may cling to the walls of the pharynx when pharyngeal
The swallowing study is extremely limited in telling us all we want to know about your child's swallowing ability. It is important to recognize what the study cannot do.

- A swallowing study cannot tell us that the child does not aspirate. In order to limit your child's exposure to radiation, a modified barium swallow study observes a very small set of your child's swallow. If your child's swallowing ability varies under different conditions, aspiration may not occur during the swallows that are filmed. Some children swallow well at the beginning of a meal, but tire after 10-15 minutes. When they are fatigued, their swallow may deteriorate and cause aspiration. Other children have a great deal of difficulty getting themselves organized to eat. They may do poorly at the beginning of a meal, but do well once they have established a comfortable suck-swallow rhythm. It is critically important to integrate clinical observations of your child's eating a full meal with information from the swallowing study.

- A swallowing study cannot tell us how often or in what circumstances a child will aspirate. The study tells us only that your child aspirated during the swallowing study. This is a very small sample of your child's abilities. Under more ideal circumstances, your child may be able to swallow more safely.

- A swallowing study cannot tell us whether oral feeding should be discontinued. The information from a swallowing study is integrated with other knowledge about your child and family. It is only one part of the objective and subjective data that is taken into consideration in making a decision about oral feeding. It is very important to talk to parents about what they want and what their child wants. There are always ways of improving the safety of a child's oral feeding skills. If parents want to continue feeding their child orally, it is important for therapists to support their decision, and work together to find easier, more effective ways of eating.

- A swallowing study cannot predict whether your child will be able to eat safely in the future. A swallowing study tells us about the present moment. With maturation and therapy many children who once aspirated are able to eat and drink safely. Other children, who did not show aspiration when younger, may begin to aspirate during periods of illness or if their overall coordination deteriorates.
The Impact of Aspiration On The Lungs

All instances of aspiration are not equal. The effect of aspiration on the lungs and on health depends upon at least 5 different features.

- **Acid**: When a child aspirates refluxed food that has been mixed with stomach acid (aspirated coming up), it is more likely to cause an aspiration pneumonia or damage the lungs than food or formula that is more alkaline (aspirate going down).

- **Fat**: Food or liquid containing fat molecules (milk, yogurt, meat broth) is more dangerous to the lungs, and may trigger pneumonia faster, than food or liquid that is composed primarily of water (fruits, vegetables, grains). This is because the lungs are used to handling water in the air we breathe and can release it more easily than a fat, which is foreign to the lungs.

- **Amount**: There are estimates that our lungs can handle aspiration of 10-20% of what we swallow. Children often aspirate small amounts when they are learning to eat by mouth. If this is a very small amount of a safe food, the aspiration is less likely to trigger aspiration pneumonia. If larger amounts are aspirated, or if smaller amounts are aspirated every time your child swallows, it is more dangerous.

- **Bacteria**: The mouth itself plays host to colonies of bacteria. The number and type of bacteria depend a great deal on dental health and oral hygiene. When the mouth is kept clean through regular brushing of the teeth or wiping of the gums, bacterial growth is kept to a minimum. When your child resists oral care, bacterial growth multiples. Children can develop cavities and gum inflammation, which further increase bacterial growth. If your child is on medication to reduce mucous and other secretions, the bacteria in the existing saliva, alone or mixed with small amounts of food or liquid, the bacteria will be carried into the lungs. An aspiration pneumonia can result from a bacterial infection.

- **Health**: The overall state of your child’s health and wellness, and specifically the health of the lungs plays a major role. This is the guiding principle we use in understanding that when a group of people are exposed to a virus and get sick. Our bodies are full of bacteria and viruses that float around the environment we live in. We tend to get sick when our overall health is poor, when we are fatigued, under stress, or lack control over our lives. Many young children have very healthy lungs. Aspiration may not initially cause pneumonia. However, with constant aspiration, the lungs may become weaker or more vulnerable. At some point, aspiration begins to cause a severe pneumonia because the lungs are no longer strong enough to stay well. Chronic aspiration pneumonia may result. Infants and children who have already experienced lung damage because of prematurity, respiratory distress syndrome, or broncho-pulmonary dysplasia are more vulnerable to aspiration than children who start out with strong, healthy lungs. Some
Struggling to Eat
The struggle to eat contributes to aspiration and to feeding aversion. The ability to suck and swallow safely is built on a foundation of sensory skills, motor skills, and comfortable coordination of swallowing and breathing. When one or more of these skills is missing or compromised, eating can be frightening, uncomfortable, or take an excessive amount of effort. Stress and struggle often convinces an infant that eating is dangerous and uncomfortable. Feeding aversion often has its roots in your child’s early memories of panic and inability to breathe that are associated with early feeding attempts.

Asking the Right Questions
A swallowing study can tell us so much more than simply whether your child is aspirating or not. Each study should be centered on a set of questions that have been prioritized. What are the most important questions for your child at this time?

- Is there a delay in the swallow with any consistency? A delayed swallow indicates that your child may be at risk for aspiration even when aspiration does not occur during the swallowing study.
- Is the swallowing ability influenced by the consistency of the food or liquid? Are there differences between thin vs. thicker liquids or thick liquids and pureed consistency? This information can help identify the consistency that promotes the coordinated and safe swallow.
- Is swallowing ability influenced by the amount of the food or liquid? Is there a difference in swallowing skill when a single swallow of food or liquid is compared with 2 or 3 consecutive swallows? Some children are very safe when they take a few swallows and then have a short pause. A child can do very well with small sips, but may aspirate when drinking multiple consecutive suck-swallows.
- Does the timing of the meal influence swallowing ability? Is there a difference between the beginning of a feeding and the end? Some children do very well at the beginning of a meal, but the swallow deteriorates, as they get tired. If your child typically does better at the beginning of a meal, and begins to have more trouble after 20 minutes, you can ask the therapist and radiologist to set up the swallowing study in two parts. They would evaluate...
Guidelines for Introducing Food

Use the following guidelines for selecting the food you offer to your child in the early stages of therapy. These suggestions reduce the risk of damaging the lungs if food or liquid is aspirated.

- **A child who develops aspiration pneumonia should always be checked for gastroesophageal reflux.** Remember that reflux does not automatically result in vomiting or spitting up. Many children reflux enough acid stomach contents to enter the lungs without any external sign that this is happening.

- **Until your child is swallowing well and safely, use primarily water, fruits, vegetables, and grains.** If aspirated, these foods will do less damage to the lungs. Begin with a low-acid fruit or vegetable such as bananas or carrots. Introduce small amounts of a more-acid fruit such as peaches or applesauce later. Avoid any food that has a high fat content. This includes most meat and dairy products.

- **Brush your child's teeth or clean the mouth before offering food or liquid.** Remember that the mouth contains bacteria. These bacteria can increase the risk of aspiration if they are mixed with the food or liquid that your child swallows. A clean mouth reduces the risk of illness if there is some aspiration during this learning period.

- **Give very small amounts of food at times when your child's coordination is the best.** Children who have poor coordination for eating often do well at the beginning of a meal. As they fatigue, their coordination gets worse, and they may begin to aspirate. Do not push children to eat more when they want to stop. Some children are very aware of their vulnerability for aspiration. They know that if they eat more, they are uncomfortable, or do not feel well. Trust your child, and appreciate the small amounts that are taken easily and happily.

- **Look carefully at your child's state of health and wellness.** Seek alternatives that increase your child's overall wellness. Wellness is quite different from not being sick. Talk to Doctors, dieticians and health care providers who use complementary medicine approaches. Use food to work on feeding skills only when your child is healthy.

- **If your child has had a swallowing study that showed aspiration, look carefully at alternatives with the Doctor, therapist, and parents.**
Fistula, Atresia, or Stricture
Just a few words for these three problems. A fistula is defined as an abnormal passage between two internal organs due to a congenital defect, injury, or infection. Atresia is defined as a congenital anomaly in which a normal body opening, duct or canal fails to form as in the mouth or nares. And a stricture is defined as an abnormal narrowing of the lumen of a hollow organ as the esophagus, owing to inflammation, external pressure or scarring. Treatment varies depending on the cause.

These are mentioned only because these are several congenital anomalies that may occur which will greatly affect the swallowing abilities of your child that may not be related to Batten Disease. These will most likely show up early in life, but need to be reported to your Doctor. For example, many people have their esophagus dilated to allow food to enter the stomach more easily – it needs to be done periodically to keep the stricture open. These anomalies can be diagnosed with further examination or on x-ray.

Hiccups
Hiccups are paroxysmal, involuntary contractions of the diaphragm that occur along with contractions of the larynx and closure of the glottis, arresting the inflow of air. Hiccups are commonly induced by common digestive disturbances or minor stomach upsets, irritation of the diaphragm, often by overfilling of the stomach with food or drink. Sometimes hiccups occur for no apparent reason. Cause of consistent or chronic hiccups could be anything that affects the head, chest or abdomen in where you have a contraction of the diaphragm, by stimulation of the vagus nerve, either by the brain or by irritation anywhere along the length of the vagus nerve. The vagus nerve sends the signal to the phrenic nerve, which leads to the diaphragm, to spasms, to hiccups. Rare causes may include some intestinal, lung, liver or kidney disorders. Occasionally, hiccups may be due to psychogenic causes originating in the mind. Mild cases of hiccups usually disappear without treatment or may last hours, when medical treatment may be necessary.
Hiccups are the result of an action the body takes to protect itself. Hiccups can start because hot food has irritated some passage inside, or when gas in the stomach presses upward against the diaphragm. The diaphragm separates the chest from the stomach. The diaphragm tightens and pulls air into the lungs. But air cannot get through and we feel a "bump" at the moment the air is stopped. So, hiccups are a reflex action of the body trying to get food or gas out of the stomach, thereby irritating the diaphragm. This in turn, affects the passage of air in and out of the lungs. We feel this as a "bump" and say we have the hiccups.

Anything that causes irritation of and compression around the diaphragm can cause the condition. Hiccups usually disappear within minutes. Most often, stimulation of the phrenic nerve, which begins at the brain and leads to the diaphragm via the esophagus, brings on attacks of hiccups. Culprits are likely to be breathing in too much air at once, rapid swallowing, or stress. Hiccups occur when the diaphragm and the muscles between the ribs suddenly contract. This causes a sharp, uncontrollable inhalation of air, which does not reach the lungs because the muscle spasm has closed the windpipe. Hiccups usually occur repeatedly in short spasms lasting a few minutes. Sometimes, a small child or older child can "suck in" too much air by sucking through a straw when there is no more liquid in the glass or cup.

What medications are prescribed for hiccups?

- Prochlorperazine (Compazine)
- Chloropromazine Hydrochloride (Thorazine)

These drugs are not a cure but would be worth trying.

Intractable hiccups may require surgery to cut the link between the phrenic nerve and the diaphragm as a means of stopping the spasms.

Safe Natural Cures For Hiccups

- Carbon dioxide helps to stop hiccups; this can be achieved by holding your breath, or breathing in and out of a paper bag (not plastic) about 10 times
- Slowly drinking water or sucking ice may help
- Avoid eating or drinking quickly
- Yell or sing as loud as you can
- Give an older baby a bottle of water with some sugar or honey in it - or simply a small spoonful of sugar or honey, babies should not have honey because many are allergic to it
- Lay on your back (they say that almost no one gets hiccups in the dentist's chair)
- Eat a spoonful of peanut butter
- "Sidekick" (a magazine) says to plug your ears with your fingers and drink through a straw. If you do not have a straw than have someone help you drink while you plug your ears

Hiccups are a fairly common problem seen in children with Batten Disease.
Pain
Pain is defined as a sensation in which a person experiences discomfort, distress, or suffering. Pain may vary in intensity from that which produces mild discomfort to that of intolerable agony. In most cases, pain stimuli are harmful to the body and tend to bring about reactions by which the body protects itself. Adaptation to pain stimuli does not readily occur. Pain is one of the cardinal symptoms of inflammation.

As our children grow, we as parents get to know them as well as anyone. They could be having pain by crying, pointing to an area, moaning, drawing up their legs or many other forms of letting you know they hurt. Parents have to be in tuned to their children and to pay attention to non-verbal or verbal ways of communication with our children of Batten Disease. Keeping our children as comfortable as possible has to be number the #1 priority. Due to the fact that our children with Batten Disease have difficulty communicating, it is important to watch for little signs of your child being uncomfortable and treat accordingly. In the latter stages of Batten Disease, stronger medications may need to be used to help keep a child comfortable and the thought of drug addiction should not become an issue. As parents, you must be thinking of your child and sometimes may even need to “demand” stronger drugs be prescribed to ease your child’s discomfort. Most of the time, Physicians are extremely sensitive to your situation and will be more than happy to help keep your child comfortable. Have a list of questions to ask your Doctor and discuss what would be best for your child – does more testing need to be done or is this something that we need to treat with pain medications? The key to getting the right answer is knowing what questions to ask, and asking the right questions is an important step that you can take to find the right treatment for the specific issue of pain for your child.

There are many forms of pain relief, which are not related to medications. Many have responded well to therapies such as music, hypnotics, herbal remedies, magnets, water therapy, or muscle stimulants. There is also The American Pain Foundation, which is an online resource for people with pain, their families, friends, caregivers and the general public. This site is devoted to patient information and advocacy, and provides many links to additional resources. The American Pain Foundation (APS) web site will direct you to various resources for finding a pain specialist to treat your pain. If you do not have personal access to the Internet you can get online at your public library. The website is www.painfoundation.org. Most painful conditions can be treated and we hope you will find successful treatment options and compassionate care for your own situation. Another avenue to pursue is Hospice nursing. There philosophy is comfort. They work with the Physician to promote and provide comfort in the last stages of a terminal disease.
Most communities have a Hospice office where you can get specific information that will be helpful for your child and your family when the time is appropriate.

**Nausea and Vomiting**

Nausea is defined as a sensation of profound repulsion to food or of impending vomiting. Vomiting is defined to expel the contents of the stomach through the esophagus and out of the mouth.

Common causes of nausea are sea and motion sickness, intense pain, emotional stress, gallbladder disease, food poisoning, and various enteroviruses. Often accompanied by autonomic signs (involuntary vital functions), such as hypersalivation (increased saliva), diaphoresis (sweating), tachycardia (fast heart rate), pallor (paleness), and tachypnea (retaining more carbon dioxide in the blood), it is closely associated with anorexia and vomiting.

Vomiting is usually preceded by nausea. Vomiting results from a coordinated sequence of abdominal muscle contractions and reverses esophageal peristalsis. Ask your child to characterize the onset, duration, and intensity of the vomiting. What precipitated the vomiting? What makes it subside? Explore any associated complaints, particularly nausea, abdominal pain, anorexia, and weight loss, changes in bowel habits or stool character, excessive bloating or fullness. Projectile vomiting unaccompanied by nausea may indicate a brain disorder called increased intracranial pressure, which would require immediate attention and treatment.

Nausea and vomiting is a common symptom of gastrointestinal (GI) disorders and always affect ingestion and digestion; decreased gastric motor activity, gastric mucosal pallor, and duodenal contractions usually accompany nausea; also occurs with fluid and electrolyte imbalances; infections; and metabolic, endocrine and cardiac disorders as a result of drug therapy, surgery, and radiation. Nausea and vomiting may also rise from severe pain, anxiety, overeating, or ingestion of distasteful food or liquids. When checking your child for verbal complaints, focus on gastrointestinal (GI), endocrine, and metabolic disorders, recent infections, look at the medications - was a new one introduced recently - ask about any associated complaints, particularly vomiting, abdominal pain, anorexia, and weight loss, changes in bowel habits or stool character, excessive belching or flatus (gas), and a sensation of bloating. Check out the color of his skin for jaundice, bruising and skin turgor, the abdomen for distention, listen for bowel sounds, and palpate for rigidity and tenderness. Make sure you look at other factors such as: has your child been playing with a dirty toy, is he in the potty training stage, have you ever noticed your child eating grass, dirt, paint chips, or other non-food materials? Has your child complained of things outside the abdomen, possible a sore throat, a cough, or burning when he urinates?
Both parasympathetic (vagal) and sympathetic nerves in the pharynx, stomach, bile ducts, bowel, mesentery, and peritoneum (as well as in the heart) carry impulses to the brain's vomiting center. Therefore, pharyngeal, gastric or peritoneal irritation, as well as distention of a hollow viscous and myocardial ischemia, may result in nausea and vomiting. Vestibular, neurologic, and metabolic disturbances that stimulate the brain's vomiting center do so by way of a chemoreceptor trigger zone, located in the fourth ventricle in the brain. Drugs and toxins may have the same effects.

Vomitus: Characteristics and Causes - When you collect a sample or observe your child's vomitus, observe it carefully for clues to the underlying disorder. Here's what this vomitus may indicate:

- Bile stained (greenish) vomitus - obstruction below the pylorus, as from a duodenal lesion (ulcer)
- Bloody vomitus - upper gastrointestinal (GI) bleeding, as from gastritis or peptic ulcer if bright red; if dark red, as from esophageal or gastric varices
- Brown vomitus with a fecal odor - intestinal obstruction or infarction
- Burning, bitter-tasting vomitus - excessive hydrochloric acid or gastric contents
- Coffee-ground vomitus - digested blood from slowly bleeding gastric or duodenal lesion
- Undigested food - gastric outlet obstruction, as from gastric tumor or ulcer
- Black, tarry, or red stools - indicate gastrointestinal (GI) bleeding could be upper or lower gastrointestinal (GI) system

Medical causes for nausea and vomiting:

- Adrenal insufficiency for endocrine disorders in the adrenal glands can cause nausea, may also see anorexia, diarrhea, weakness, fatigue, weight loss, bronze skin, hypotension, and a weak irregular pulse
- Appendicitis - a brief period of nausea may accompany onset of abdominal pain. The pain may begin as vague epigastric or periumbilical discomfort to rapidly progressing to severe stabbing pain in the right lower quadrant of the abdomen, along with rigidity, tenderness, fever, constipation, diarrhea, tachycardia, anorexia, and moderate malaise
- Cholecystitis (acute) - gallbladder inflammation - nausea often follows severe right upper quadrant pain that may radiated to the back or shoulders along with tenderness, rigidity, distention, fever with chills, and diaphoresis
- Cholelithiasis - (actual gallstones) attacks of severe right upper quadrant or epigastric pain after ingestion of fatty foods can cause nausea and vomiting. Other symptoms include tenderness, guarding, flatulence, belching,
• Congestive heart failure – can see nausea and vomiting, especially with right heart failure, tachycardia, ventricular gallop, fatigue, dyspnea, rales (crackles) in the lungs, peripheral edema (seen a lot in our children with swelling of the lower legs in the last one-two years of Batten Disease, usually due to inactivity and the body slowing down), and jugular vein distention (noticed in the neck)

• Diverticulitis – can see nausea with intermittent abdominal pain, constipation, low-grade fever, and frequently a palpable mass

• Electrolyte imbalance - with low minerals in the body can see nausea and vomiting along with dysrhythmias, tremors, seizures, anorexia, malaise, and weakness

• Food poisoning – with certain toxins can cause nausea, vomiting, and diarrhea

• Gastritis – nausea and vomiting is very common in this disease, especially after eating spicy foods, aspirin, or caffeine. Vomiting of mucus or blood, epigastric pain, belching fever, and malaise

• Gastroenteritis (flu) – can produce nausea and vomiting (often of undigested food) and also cause diarrhea, abdominal cramping, fever, malaise, hyperactive bowel sounds, pain and tenderness, and also may see dehydration

• Increased intracranial pressure – (neurological condition where there is increased pressure in the brain) projectile vomiting that is not preceded by nausea is a sign, also a decreased level of consciousness, bradycardia, hypertension, and respiratory changes in the pattern. Your child may also have a headache, widened pulse pressure, impaired motor movement, visual disturbances, and pupil changes

• Infection – acute localized or systemic infection often causes nausea, also fever, headache, fatigue, and malaise

• Intestinal infection – nausea and vomiting (bile or stool) occurs frequently, especially with high small bowel intestinal obstruction. Vomiting may be bile or stool, abdominal pain is usually episodic and colicky, but can become more severe and steady with strangulation of a loop of bowel. Constipation occurs early in large intestinal and later in small intestinal obstruction; obstipation (extreme and persistent constipation) may signal complete obstruction. Bowel sounds are usually hyperactive and high-pitched in partial bowel obstruction and hypoactive or absent in complete obstruction. Abdominal distention and tenderness occur with visible peristaltic waves and a palpable abdominal mass (stool)

• Irritable bowel syndrome – you will see dyspepsia (heartburn or uncomfortable feeling in the stomach area), abdominal distention and nausea in this disease, lower abdominal pain, tenderness, diarrhea alternating with constipation or normal bowel function, plus small stools with visible mucus
• Metabolic acidosis - if the acid-base balance is distorted, there may be nausea and vomiting, anorexia, diarrhea, Kussmaul’s respirations, and decreased level of consciousness, usually seen in diabetes
• Migraine headache - nausea and vomiting may occur with photophobia (sensitivity to light), light flashes, increased sensitivity to noise, partial vision loss and paresthesias (numbness and tingling) of the lips, face, hands, until the headache subsides
• Peptic ulcer - nausea and vomiting may follow attacks of sharp or burning epigastric pain. Attacks usually happen when the stomach is empty or after ingestion of aspirin or caffeine, they are relieved by eating or Antacids, may also see bloody emesis or stools
• Peritonitis – (inflammation within the abdominal cavity) nausea and vomiting usually accompany acute abdominal pain localized to the area of inflammation, high fever with chills, tachycardia, hypoactive or absent bowel sounds, abdominal distention and tenderness, weakness, pale, cold skin, diaphoresis, hypotention, shallow respirations and hiccups
• Renal disorders – (kidney) if there is an infection or kidney stone there could be nausea
• Ulcerative colitis – (inflammation in the intestines) nausea, vomiting and anorexia may occur but the most common symptom is recurrent diarrhea with bloody, pus, and mucus

If your child is experiencing severe nausea and vomiting, prepare him for blood tests to check levels of electrolytes or possibly drug levels that may alter other blood tests, have him breathe deeply to ease the nausea, keep the room smelling fresh, keep his head elevated or position him on his side. Because pain can precipitate or intensify nausea, administer pain medication if available. Nausea is one of the most common childhood complaints and is caused most often by overeating. In a newborn, pyloric obstruction may cause projectile vomiting, whereas Hirschsprung’s disease may cause fecal vomiting. Intussusception (prolapse of one segment of bowel into the lumen or opening of another segment of bowel) may lead to vomiting of bile and fecal matter in an infant or toddler. Because an infant may aspirate vomitus, as a result of his immature cough and gag reflexes, position him on his side or abdomen and clear any vomitus immediately.

If your child has nausea and vomiting, tell them or give them small, frequent sips of fluid, such as water or flat ginger ale. Advise him to not eat solid food until vomiting subsides. After vomiting subsides for 4 hours, have him eat plain toast or crackers; he can resume a regular diet after 24 hours. Also keep in mind that certain medications may cause symptoms of nausea and vomiting as well:
• Analgesics – Aspirin, Motrin
• Anti-infectives – Sulfonamides, Penicillin’s
• Antacids – Maalox, Milk of Magnesium
• Narcotics – Codeine, Demerol, Morphine

Anti-emetics (examples – Reglan, Compazine, and Phenergan) which are given to help control nausea and vomiting do so because the stimuli that causes vomiting can originate in any part of the gastrointestinal (GI) tract; distention or irritation of the stomach or duodenum provides the strongest stimulus. Impulses are transmitted by both vagal and sympathetic afferents to the medulla oblongata’s vomiting center in the brain, which lies in the chemoreceptor trigger zone. Motor impulses that produce vomiting are then transmitted from the vomiting center in the brain, through various cranial nerve branches to the upper gastrointestinal (GI) tract. From there, these impulses are sent through the spinal nerves to the diaphragm and abdominal muscles to trigger vomiting. Certain drugs like the Phenothiazines (a group of drugs which exert significant influence on many organ systems of the body at once), prevent vomiting by interrupting the afferent pathways and preventing impulses from reaching the vomiting center.

Gastroenteritis – Diarrhea and Vomiting

Almost everyone has or will have what most of us refer to as stomach flu. The medical technical term is called gastroenteritis, which means irritation of the stomach and the intestines. It often goes away by itself in a couple of days (thus the 24 hour flu), it sometimes lasts longer and having it is a miserable experience for everyone concerned.

Symptoms include the following:
• Diarrhea – almost a sure thing. Many people feel that any stools “looser” or softer than normal constitutes diarrhea. This is not the case. Our stools vary in consistency depending on our diet. Diarrhea usually is defined as watery or nearly so. “Watery” in this context means that the stool has no “chunks” in it, and if your child is wearing diapers, the stool is usually running out of the diaper. Also, in true diarrhea, your child is usually having many (sometimes up to 1-2 per hour) bowel movements. The biggest danger with frequent watery stools is losing so much fluid that dehydration occurs especially in small children or toddlers/infants
• Vomiting – a forceful ejection of material from the stomach. It can be caused by stimulation from something (infection or other irritants) in the stomach, on its way to the stomach, or beyond the stomach in the intestines. Besides being really miserable, vomiting makes gastroenteritis harder to treat because a vomiting child cannot keep fluids down and thus becomes dehydrated much faster
• Fever - often but not always, accompanies gastroenteritis, especially the viral and bacterial types since the body turns up its thermostat to help fight infections. Your child may not be able to keep Tylenol down to help with the fever.

• Dehydration - you can go without food for awhile, but going without water or liquids is much more serious. We lose water from our bodies by sweating, water contained in the air we breathe, urine, and water in stool. In order to make up for these loses, we need to drink fluids. We also produce urine constantly not only to rid of excess water, but also the kidneys are the chemical filters for the blood. How can you tell if your child is getting dehydrated - dry mucous membranes in the mouth, sunken eyes, a drop in urine output, weight loss over days or hours? Slow weight changes are usually dietary, quick weight loss is usually because of dehydration.

Dry diapers, no tears when crying, coarse dry tongue and parched lips, sunken eyes, weight loss, pinching the skin on the abdomen leaving the skin standing up (poor skin turgor) are all signs of dehydration. If any of these symptoms are noted, please call your Physician.

Causes of gastroenteritis -
• Viral - most common reason
• Bacterial - not as common in the US but are seen where sanitation is not as good. They can also come from contaminated food (Salmonella - potato salad or egg-based dishes, or E-Coli in undercooked meats) This one will need treated with antibiotics, stool cultures will usually be done to help with diagnosis
• Chemical cause of diarrhea is lactose intolerance. Many can just not digest lactose (milk sugar) no matter what, unless they take supplementary enzymes to help with digestion

Treatment
• Fluids - wait from 1-2 hours after vomiting before starting liquids, (even though your child says he is thirsty, his stomach is saying don’t put anything in me). Please don’t appease your child because odds are that they will continue to vomit and become further dehydrated, give what fluids your child can tolerate, Pedialyte, Gatorade, unsweetened kool-aid, or very small amount of plain water ( avoid large amounts of plain water - it is not absorbed as well as water with sugar and minerals). Keep an eye on the urine output to judge how hydrated your child is. (Please do not give milk or milk products)
• Diet - stool consistency depends largely on what kinds of food we eat - clear liquids are most easily absorbed, also provide extra water, (clear soups - like bouillon, tea - even with a little sugar because of the caffeine, heavily
• Medicine - there is no real medicine to help with viral infection, if it is bacterial - antibiotics may help, antidiarrheal medicines may be helpful as well

When to call the Doctor -
• If your child has not urinated for 6 hours or more and you can not get him to take or keep clear liquids down
• If your child is becoming lethargic or listless which means that your child is breathing but basically not responding to your attempts to wake him up or is not playing or active as usual
• If your child's mouth looks dry, eyes sunken (these are late signs of dehydration)
• Your child may need intravenous (IV) fluids until the worst part of the virus is gone

Gastroesophageal Reflux Disease (GERD)
Gastroesophageal reflux disease (GERD) is a digestive disorder that affects the lower esophageal sphincter (LES) - the muscle connecting the esophagus with the stomach. Many people suffer from heartburn or acid indigestion caused by gastroesophageal reflux disease (GERD). Doctors believe that some people suffer from gastroesophageal reflux disease hiatal hernia. In many cases, heartburn can be relieved through diet and lifestyle changes; however, some people may require medication and surgery.

Gastroesophageal refers to the stomach and esophagus. Reflux means to flow back or return. Therefore, esophageal reflux is the return of the stomach’s contents back up into the esophagus. In normal digestion, the lower esophageal sphincter (LES) opens to allow food to pass into the stomach and closes to prevent food and acidic stomach juices from flowing back into the esophagus. Reflux occurs when the lower esophageal sphincter (LES) is weak or relaxes inappropriately allowing the stomach's contents to flow up into the esophagus. The severity of reflux depends on the sphincter dysfunction as well as the type and amount of fluid brought up from the stomach and the neutralizing effect of saliva. Factors that increase the LES (lower esophageal sphincter) pressure include: protein, carbohydrate, nonfat milk, low dose alcohol. Factors that decrease LES (lower esophageal sphincter) pressure include: fat, whole milk, orange juice, tomatoes, antiflatulent (simethicone), chocolate, high-dose alcohol, cigarette smoking, lying on right or left side, sitting
Heartburn is a pain behind the breast bone, often described as "burning" in quality. Pain can also be felt at the same level in the mid-line of the back. Most people suffer from heartburn at one time or another. In fact, heartburn has nothing to do with the heart - it is a digestive problem. Heartburn is generally related to meals and posture and can be relieved by remedies for indigestion.

Pain from the heart is also felt in the chest and sometimes in the upper abdomen. There are two kinds of heart pain. The first, angina, is a pain in the chest due to a temporary shortage of oxygen being carried in the blood to the heart muscle. Angina should be suspected if the chest pain is brought on by exercise and relieved by rest. The second is the more severe and prolonged pain of a heart attack. A heart attack should be suspected if the pain is felt intensely in the center of the chest (possibly through to the back), spreading perhaps to one or both arms (especially the left) and into the lower jaw; or feels like a heavy pressure or is "vice-like". Potentially dangerous confusion can arise when someone neglects his or her heart pain believing it to be heartburn.

What causes heartburn? Acid is present in the stomach to digest food. Heartburn occurs when small amounts of this acid rise above the esophagus - the tube which carries food from the mouth to the stomach. This is called reflux. The esophagus, unlike the stomach, does not have a protective lining. So, when it is exposed to the acid, it can become inflamed and painful. At the bottom of the esophagus there is a muscle, the LES lower esophageal sphincter, which by its contraction, acts as a barrier to keep the acid in the stomach. If this does not work properly, reflux occurs. The reason why this muscle fails to work properly is not fully understood. Some known factors that can lead to heartburn include: eating large meals, being overweight, bending a lot, wearing tight clothing around the waist, or smoking. In most of these cases, it is the increased pressure, which overcomes the normal muscle contraction and causes heartburn. Smoking, on the other hand, relaxes the muscle around the esophagus, with the same result. Other factors that may present with reflux are: hoarseness, chronic cough, asthma, laryngitis, recurrent pneumonia, and ear, nose, and throat infections, nocturnal choking, sleep apnea, loss of dental enamel, bad breath, and globus sensation. In small children or toddlers you will see reflux to some degree. Most of them outgrow it by 6 months to 1 year but some may take longer. Signs you would see in your child: frequent spitting up, vomiting or milk stains around the baby's mouth or in his bed after sleeping, frequent swallowing between feedings, frequent hiccups, sneezing, coughing, feeding problems such as crying, arching, refusing to eat, gasping, gagging, choking, wheezing (high-pitched sound with breathing), trouble breathing, or poor weight gain.
How is reflux diagnosed? Some tests may include: upper gastrointestinal system (GI) and/or esophagram (barium swallow), the stomach is filled with barium and x-rays taken to measure the frequency and severity of reflux; milk scan - similar to the upper gastrointestinal series (GI), although this is done to measure how long it takes the stomach to empty and evaluate reflux; pH probe monitoring - a small flexible tube is passed through the nose into the esophagus. This tube measures how often acid from the stomach comes up into the esophagus - it stays in place for 24 hours - if no reflux is seen, your Doctor will probably not do a fundoplication; endoscopy - your child is given conscious sedation, then your Doctor uses a flexible scope with a light to examine the esophagus, stomach, and the first part of the small intestine; or a bronchoscopy - again with conscious sedation, the Doctor uses a scope with a light and examines and check for aspiration (stomach contents in the lungs). This is usually done when the endoscopy is done.

If reflux is left untreated, other complications may occur:
- Increased or severe chest pain that can mimic a heart attack
- Esophageal structure (a narrowing or obstruction of the esophagus)
- Dysphagia - (difficulty in swallowing) a feeling that food is trapped behind the breast bone
- Bleeding - vomiting blood or tarry, black bowel movement
- Choking - sensation of acid refluxed into the windpipe causing shortness of breath, coughing, hoarseness of the voice

Treatment can include many things:
- Feeding - hold your baby or child in an upright position during eating, burping your baby frequently, never leave your baby or child alone while eating, do not over feed your child or going to bed within 2-3 hours of eating, since gastric distention promotes reflux, it is better to feed smaller amounts more often, avoid foods that may worsen symptoms (citrus, tomato, caffeine which directly can irritate the mucosa while onions, garlic, chocolate, peppermint and high fat lower the pressure). Avoid traveling for at least ½ hour after feeding. You may also notice or your child may tell you that certain foods seem to aggravate reflux, then please omit them from his diet. Encourage your child to eat slowly and chew his food well before swallowing
- Positioning - keep your baby upright for at least 2 hours after eating - avoid the sitting position after eating because this puts pressure on the stomach, so therefore do not feed your child and then lay them down for a nap. Reflux symptoms may be reduced simply by elevating the head end of the bed or using a wedge under the upper body or under the legs of the bed. The esophageal acid gravity time is reduced by gravity
Clothing – avoid tight diapers or clothing around the waist – pressure on the stomach can make symptoms of reflux worse

Medication – medicine may be prescribed to help decrease the production of stomach acid or help the stomach empty more quickly. These drugs include: H2 Antagonists (Tagamet, Zantac, Pepcid, Axid), and proton pump inhibitors (PPI) (Prilosec, Prevacid, Aciphex, Protonix or Nexium) for treatment of acute disease. There are also prokinetic agents, which promote gastrointestinal motility (Reglan, or Cisapride). Antacids may also be used – Maalox, Mylanta, etc.

What if medications do not help, is surgery possible to help the symptoms? Yes, some people with reflux may need surgery because of severe reflux and poor response to medical treatment. Fundoplication is a surgical procedure that increases pressure in the lower esophagus. This topic will be discussed a little later in this presentation. A young child with severe gastroesophageal reflux disease (GERD) may require years and years perhaps life long medical treatment. This entails a lot of cost and while these drugs appear to be safe, long-term effects are not known. So in younger children with severe esophagitis and normal peristaltic function, surgical option should be considered even when medical treatment may be effective.

When Do I Call The Doctor?

- Poor, little, or no weight gain
- Choking
- Increased spitting up or vomiting
- Wheezing
- Gagging or trouble swallowing
- Blood in the vomit
- Continued eating problems

Over time, we have found it helpful to use medications to prevent reflux. There are medications, which increase the contractions of the muscles of the stomach and help it empty faster, and there are medications that lower the acidity by altering the amount of acid that is secreted into the stomach. This last group is really very helpful. With the decrease in acidity, a little bit of reflux does not cause the irritation to the lower end of the esophagus that a lot of acid can, and so it seems to eliminate some of the real discomfort that goes with reflux. Symptoms of reflux that you can see may include: retching, gagging, hyperextension of the head and body, increased congestion during the feedings, intermittent low grade fever which occurs as a pattern, increased arching, and aspiration and pneumonia. Reflux can vary from day to day and may increase as the degenerative process continues.
Surgery may have to be considered, but only after positioning and medication choices have been exhausted.

Many children with Batten Disease have moderate to severe problems with reflux and require treatment of some form. Many times medication can control reflux, but also some children with Batten Disease have required surgery and fundoplication has been done.

**Gas Formation**

There may be gas formation in the stomach. You may hear increased belching after a meal, when you open the gastrostomy (GT) tube you may hear the air escape, or you may find that you need to "burp" after a feeding. Sometimes, it may be helpful to just leave the tube open with a syringe attached for a short period after the feeding (keep it elevated so that the contents of the stomach do not flow out). If you are using a “button” (type of gastrostomy tube), there is a special vent tube that you will need which holds the little valve open so that air can escape and you can aspirate (pull back gently with a syringe). Aspiration and venting may be done routinely in the beginning after a gastrostomy tube has been inserted, but usually become less and less necessary as you develop a "feel". Should your child experience bloating prior to or following any feeding, your child's stomach and intestinal tract should be decompressed. Decompression is easily accomplished by removing the feeding adapter cap (from the tube) and allowing the tube to be open to air, encouraging your child to cough will expedite the removal of excessive air. Gas is a common problem with children who have Batten Disease.

**Hiatal Hernia**

The hiatal hernia is one of the most misunderstood and maligned conditions in medicine. People blame this hernia for much more than it ever does. People need to know what it is and what might occur with it. Most importantly, they need to know it is unusual for serious problems to develop from this type of hernia.

Anatomy – the diaphragm is a sheet of muscle that separates the lungs from the abdomen. When your child takes a deep breath, the dome-shaped diaphragm contracts and flattens. In doing this, the diaphragm pulls air into the lungs. The left diaphragm contains a small hole through which passes the tube-shaped esophagus that carries food and liquid to the stomach. Normally this hole, called a hiatus, is small and fits snugly around the esophagus. The j-shaped stomach sits below the diaphragm.

What causes a hiatal hernia? - the hiatus or hole in the diaphragm weakens and enlarges; it is not known why this occurs. It may be due to heredity, obesity, exercises such as weightlifting, or straining at stool. Whatever the cause, a
portion of the stomach herniates, or moves up, into the chest cavity through this enlarged hole. A hiatal hernia is now present.

The different types of hiatal hernias. In most children, hiatal hernias cause no symptoms:

- **Sliding Hiatal hernia** - the most common - the herniated portion of the stomach slides back and forth, into and out of the chest. These hernias are normally small and usually cause no problems or even symptoms. If symptoms occur, you may only see regurgitation and heartburn.

- **Rolling or paraesophageal hiatal hernia** - the upper part of the stomach is caught up into the chest. Even with this hernia, there may be few symptoms. However, the potential for problems in the esophagus is increased. You may also see chronic reflux of acid into the esophagus, which may cause injury and bleeding. Anemia or low red blood cell count can result. Further, chronic inflammation of the lower esophagus may produce scarring and narrowing in this area. This in turn makes swallowing difficult, and food does not pass easily into the stomach.

- **Complicated or serious hiatal hernia** - this type of hernia is uncommon - it includes a variety of patterns of herniation of the stomach, including cases in which the entire stomach moves up in the chest. There is a high likelihood that medical problems will occur with this hernia and that treatment, frequently involving surgery, will be required - very uncommon.

Do hiatal hernias cause pain and indigestion? It is wrong to always blame a hiatal hernia for pain and indigestion. They usually do not cause acute pain. Pain may result from other disorders, such as peptic ulcers or even heart disease. Some people with coronary heart disease fool themselves into believing their discomfort is due to a hiatal hernia. If this occurs, you should seek medical advice.

Diagnosis - is made through an upper gastrointestinal (GI) barium x-ray. Also, an endoscopy may be done to visualize the stomach and esophagus while your child is lightly sedated.
This picture is of a normal stomach and then the presence of a sliding hiatal hernia and a rolling hiatal hernia (paraesophageal) where the hernia is a sac (part of the stomach) above the diaphragm.

Complications of a hiatal hernia are:

- Chronic heartburn and inflammation of the lower esophagus, called reflux esophagitis
- Anemia due to chronic bleeding from the lower esophagus
- Scarring and narrowing of the lower esophagus causing difficulty in swallowing
While sleeping, stomach secretions can seep up the esophagus and into the lungs, causing chronic cough, wheezing, and even pneumonia.

Treatment and medications/surgery are the same as with gastroesophageal reflux disease (GERD).

**Fundoplication**
A fundoplication (Nissen) is one of the most common surgical procedures used to treat severe gastroesophageal reflux disease (GERD). Gastroesophageal reflux disease (GERD) is the backup of stomach contents into the esophagus (the tube between the mouth and the stomach). A fundoplication is performed by wrapping part of the upper stomach around the lower part of the esophagus to create a nipple valve that stops the reflux. This is a decision that you as parents will have to make for your child. A small number of children do not get complete relief of the symptoms. Secondly, the continued used of medications; usually the proton pump inhibitors (PPI) will still need to be used along with possible side effects. After the surgery new symptoms such as gas, bloating and dysphagia, which probably result from a hyper-competent lower esophageal sphincter (LES) produced by the fundoplication, are common. The surgery usually lasts from 1-2 hours.

What can I expect after surgery?
Your child may have a nasogastric (NG) tube passed through the nose into the stomach while asleep under anesthesia. The tube will be connected to gentle suction to keep the stomach empty, decrease nausea and vomiting, and to promote healing. Your Doctor will decide when the tube can be removed, usually when your child is passing gas or has a bowel movement. Instead of the nasogastric (NG) tube, your child may have a gastrostomy tube, a tube through the abdomen directly into the stomach, which comes out to the surface of the abdomen or a jejunostomy tube which goes directly into the small intestine and comes out to the surface of the abdomen. After the nasogastric (NG) tube is removed and/or the gastrostomy tube (GT) or jejunostomy tube (JT) is clamped, your child can begin to drink clear liquids, progressing to eating regular foods as tolerated. The incision will be covered with a small dressing, either of gauze or clear plastic saran like, or steri-strips (little pieces of tape). The stitches inside will dissolve on their own. Your child will have an intravenous (IV) line, a plastic tube that goes into the vein, to give fluids and medications. An intravenous line (IV) is needed until your child is drinking well to prevent dehydration.

Other things to expect include:
- May not be able to burp
- May gag but not be able to vomit
Picture Of A Nissen Fundoplication

- Needs to eat more slowly
- May feel full earlier (your child may eat smaller amounts at one time)
- Bloating (stomach fills with gas and becomes big and round)

What will be done for pain? Every effort will be made to keep your child as comfortable as possible. Your Doctor will prescribe medicine to relieve pain, usually by the IV route until he is eating. If you feel your child continues to have pain, do not hesitate to request more medications. If your child can still communicate with you, ask him if he is having pain. If he can not answer you, you know him better than anyone and then go by his usual methods to tell you he is uncomfortable.

How should I care for my child at home? Your child may have a tub bath. Do not soak the incision. The plastic dressing should be removed in a week. Steristrips will fall off on their own. Encourage quiet play. No active play or swimming until seen by the Doctor.

When should I call the surgeon?
- Increasing swelling, redness, or pain at the incision or the area around it.
- Drainage from the incision
- Signs of reflux return
- Temperature higher than 100.5 degrees by mouth or 101.5 degrees rectally

**Stomatitis, Gastritis, and Dyspepsia**
Stomatitis is any inflammatory condition of the mouth. It may result from infection by bacteria, viruses, or fungi; from exposure to certain chemicals or drugs; from vitamin deficiency; or from a systemic inflammatory disease.
- Thrush - a yeast infection; will see white patches on the tongue; this inflammation should be treated with good oral hygiene, a nonirritating diet, topical anesthetic rinses to relieve pain, and antibiotic or antifungal drugs
- **Gingivitis** - inflammation of the gingiva; will see inflammation with painless swelling, redness, change of normal contours, bleeding, and periodontal pocket - gum detachment from the teeth; treatment includes removal of irritating factors, good oral hygiene, regular dental check-ups, vigorous chewing

- **Peridontitis** - progression of gingivitis and inflammation of the oral mucosa, a major cause is poor oral hygiene, will see acute onset of bright red gum inflammation, painless swelling, easy bleeding, loosening of teeth typically without inflammatory symptoms progressing to loss of teeth and possibly bone, and possibly acute systemic infection including fever and chills, treatment includes infection control, possibly periodontal surgery to prevent recurrence, and good oral hygiene, regular dental checkups and vigorous chewing

- **Vincent’s angina** - (trench mouth) necrotizing ulcerative gingivitis - infection, other predisposing factors include: stress, poor oral hygiene, insufficient rest, nutritional deficiency, smoking; will see sudden onset, painful superficial bleeding gingival ulcers covered with a gray-white membrane, ulcers become punched out lesions after slight pressure or irritation, malaise, mild fever, excessive salivation, bad breath, pain on swallowing or talking, enlarged lymph nodes; treat by removal bad tissue, antibiotic therapy, analgesics as needed for pain, hourly mouth rinses with equal parts of hydrogen peroxide and warm water, soft nonirritating diet, rest, no smoking, with treatment, improvement common within 24 hours

- **Glossitis** - inflammation of the tongue, a streptococcal infection, irritation or injury, jagged teeth, ill-fitting dentures, biting during seizures, spicy foods, smoking, sensitivity to toothpaste or mouthwash, Vitamin B deficiency, or certain skin conditions; will see reddened ulcerated or swollen tongue - may obstruct airway, painful chewing and swallowing, speech difficulty, painful tongue without inflammation; treatment of underlying cause, topical anesthetic mouthwash or systemic analgesics (Aspirin and Tylenol) for painful ulcers, good oral hygiene, regular check-ups, vigorous chewing, avoidance of hot, cold or spicy foods and alcohol

*Gastritis is an inflammation of the stomach lining. Gastritis is usually one of two main types: fundal gland gastritis which is in the main body of the stomach including a reddened and swollen lining of the stomach with small hemorrhages and erosions to inflammation of all of the stomach layers, and the second types is the pyloric gland gastritis which is in the lower portion of the stomach that connects to the duodenum. Acute gastritis may be caused by the ingestion of aspirin or other medications or by the presence of viral, bacterial or chemical toxins, in which*
antacids may be helpful. The symptoms including anorexia, nausea, vomiting, feeling of fullness, belching, and vague discomfort after eating in the epigastric area of the stomach, usually abates after the causative agent is removed. Chronic gastritis is usually a sign of underlying disease, as a peptic ulcer, which often progresses to acute gastritis. During acute attacks, conservative treatment calls for dietary modifications, rest, drug therapy (Antacids, Tagamet, etc.) and parenteral nutrition. Complications, such as hemorrhage and peritonitis, may require surgery.

Dyspepsia is defined as a vague feeling of gastric discomfort felt after eating. There is an uncomfortable feeling of fullness, heartburn, bloating and nausea. Dyspepsia is not a distinct condition, but it may be a sign of underlying intestinal disorder as a peptic ulcer, gallbladder disease or chronic appendicitis. Treatment may include antacids or as prescribed by your Doctor.

Many children with Batten Disease have one or all of these three problems at some time during the course of Batten Disease – just treat the symptoms as they occur from one day to the next.

Ulcers - Peptic (Gastric) and Duodenal
A peptic ulcer is an ulcerative lesion of the upper gastrointestinal mucosal membrane. Studies indicate that the two major forms of peptic ulcer, gastric and duodenal, occur when the gastrointestinal tract’s protective mucosa is unable to resist corrosion by acid-pepsin during digestion. Damaged duodenal or gastric mucosa permits further erosion of each layer of the abdominal wall, possibly causing bleeding and/or perforation. Although different factors may cause them, gastric and duodenal ulcers have essentially the same pathophysiology. An ulcer is a focal area of the stomach (gastric) or duodenum that has been destroyed by digestive juices and stomach acid. It is an erosion of the lining of the intestinal tract usually in the stomach caused by contact with strong gastric secretions (pepsin or hydrochloric acid).

- **Gastric** - it results from the destruction of the protective mechanisms that shield the lining of the gastrointestinal system (GI) tract, consequently this lining shows decreased resistance to gastric secretions, particularly pepsin. Gastric ulcers have decreased mucosal resistance to normal or subnormal acid production, in the presence of conditions such as gastritis, or irritants such as aspirin, steroids, alcohol or caffeine, allows back-diffusion of gastric acids from the lumen to the mucosa. This leads to erosion where histamines are released, to further stimulation and increased swelling of the stomach wall, the erosion continues to finally breaking through the abdominal wall where perforation and/or peritonitis can occur.
- Duodenal ulcer, the lesions usually occur near the pylorus of the stomach. The stomach secretes excess hydrochloric acid and also empties food more rapidly than normal; only part of the acid load is used on food. Acid hypersecretion may result from an overactive vagus nerve where the same results will eventually happen as in gastric ulcers. This reduces the food’s buffering effect and dumps the excess acid in the duodenum, where it erodes the gastrointestinal (GI) tract lining. Most ulcers are no larger than a pencil eraser, but they can cause tremendous discomfort and pain. Children with Batten Disease are very prone to ulcers due to the medications they have to take, especially the anticonvulsant group. Usually a medication like Zantac or Tagamet will ease the symptoms, so ask your Physician if your child shows symptoms of ulcer disease.

The most common symptom of an ulcer is a gnawing or burning pain in the abdomen located between the naval and the bottom of the breastbone. The pain often occurs between meals and sometimes awakens you from sleep. Pain may last minutes to hours and is often relieved by eating and taking antacids. Less common symptoms of an ulcer include nausea, vomiting, loss of appetite and weight loss. Acute peptic ulcers are almost always multiple and superficial. They may be totally asymptomatic and usually heal without scarring. Chronic ulcers are single, deep craters and can be treated with Prevacid, Aciphex, Protonix or Nexium. Scientists now believe that many persons have a genetic predisposition and also then development the infection of H.pylori (bacteria). If the ulcer perforates you may see: a history of previous cyclic pain that occurred when the stomach was empty, melena (black, tarry stools), bloody emesis (vomit), signs of shock (profuse sweating, pallor, palpitations, confusion, increased pulse and respirations, decreased blood pressure, a rigid and board-like abdomen with rebound tenderness and absent bowel sounds.

Others who develop ulcers are sometimes regular users of pain medications called non-steroidal anti-inflammatory drugs (NSAIDS), which include common products like Aspirin and Ibuprofen (Motrin). An ulcer is caused by the constant irritation of the stomach by using NSAIDS. NSAID-induced gastrointestinal side effects can best be avoided by using alternative therapy whenever possible. Low dose Corticosteroids or supportive drugs such as Acetaminophen (Tylenol) are alternatives to consider. Four grams (two 500 mg tablets four times a day) has been shown to be comparable to analgesic and antiinflammatory doses of Ibuprofen (Motrin) for osteoarthritis pain and is not associated with an increased risk of gastrointestinal side effects, or you could use Antacids or a prescription product for decreasing acid, etc.
Complications of ulcers include:

- **Bleeding** – bleeding can occur from an ulcer in the stomach (gastric) or the duodenum and is sometimes the only sign of an ulcer. Bleeding from an ulcer can be slow, causing anemia and fatigue. More rapid bleeding can cause bowel movements to become sticky and tarry black or even bloody. Bleeding ulcers may cause nausea and vomiting of acidified blood that looks like "old coffee grounds", rapid shallow breathing, chills, sweating, dizziness upon standing, and restlessness. (Remember iron products given on a regular basis can also produce dark black stools)

- **Perforation** – when ulcers are left untreated, digestive juices and stomach acid can literally eat a hole in the intestinal lining. Bacteria, food, and digestive juices can spill into the abdominal cavity causing sudden, intense pain that requires hospitalization, and often surgery. You may see rapid shallow breathing, facial flushing, fever, dizziness, sweating, abdominal
• **Obstruction** – chronic inflammation from an ulcer can cause swelling and scarring to occur. Over time, scarring may close the outlet of the stomach, preventing food to pass and causing vomiting and weight loss. You may have a foul taste in your mouth and a coated tongue, abdominal fullness or distention worsening after meals and at night, nausea and vomiting of foul smelling gastric contents, anorexia, or weight loss.

These are the complications, but if effective compliance to medications and avoidance of foods that aggravate the symptoms, along with the decrease or stoppage of tobacco or alcohol use, are adhered to, the severity of the ulcer can be controlled and maintained.

Ulcers are diagnosed by one of two different methods – either an Upper gastrointestinal (GI) Series or a procedure called an Endoscopy or EGD (most widely used today). The Doctor will have you try 2 weeks of treatment with an acid-blocking medicine (Tagamet, Zantac, Pepcid, or Axid). If the discomfort or pain continues, then one of the other tests will be ordered. An upper gastrointestinal (GI) series is an x-ray test where you are given a chalky material (barium) to drink while x-rays are taken to outline the anatomy of the digestive tract. The endoscopy is a test, which involves the insertion of a small-lighted flexible tube through the mouth into the stomach to examine for abnormalities. The test is usually performed using medications to sedate you (conscious sedation). During the test biopsies of tissue can be taken for examination. A biopsy will not cause any pain or discomfort and is usually only the size of a match head.

Ulcers are treated first of all to avoid the foods, which are usually the culprits that worsen the symptoms not as in the past where they had you avoid foods like spicy, fatty or acidic foods. Ulcer patients who smoke should stop. It has been shown that those who continue to smoke are linked to ulcer recurrence. And in general, ulcer patients should not take NSAIDS.

If surgery is required, several things may be done. If there is an ulcer that needs to be extracted, it is called a gastrectomy, usually partial, with or without a vagotomy, excising the part of the stomach that is necessary thereby removing the hormonal stimulus of the parietal cells, followed by anastomosis or reattachment of the rest of the stomach to the duodenum or jejunum. Sometimes a vagotomy and pyloroplasty is necessary where the Doctor severs one or more branches of the vagus nerve to reduce hydrochloric acid secretion, and refashioning the pylorus to create a larger lumen and facilitate gastric emptying.
Gastrointestinal Bleeding – GI Bleeding

Hyperactive bowel sounds provide the most immediate indication of persistent bleeding. Associated signs and symptoms may include abdominal distention, bloody diarrhea, rectal passage of bright red blood clots and jellylike material (bloody stools are also called melena stools), and pain during bleeding, decreased urinary output, tachycardia, and hypotension, accompanies blood loss. Hemorrhage from a peptic ulcer may be accompanied by a very severe headache, which disappears with supportive therapy or cessation of bleeding. Vomiting of grossly bloody, bloodstained or coffee-ground material are symptoms.

- **Airway** - if very active bleeding is occurring you will want to make so there is open airway – vomitus and blood commonly cause airway blockage with gastrointestinal emergencies (also there is a possibility of aspiration of vomitus, suctioning or inserting an nasogastric tube (NG) may be necessary)
- **Breathing** - make so you check their breathing, oxygen may be needed. Severe abdominal pain may cause breathing problems more so in males due to the fact that males use their abdominal muscles when they breathe. If they are vomiting, their respirations may be slower and deeper to compensate for loss in electrolytes. Or if abdominal distention - respirations may be affected to do the diaphragm being involved
- **Circulation** - may need to watch for signs of shock due to blood loss from an ulcer. Signs to watch for include: rapid thready pulse, cool clammy skin, restlessness, confusion, or further decrease in blood pressure

Treatment requires immediate attention especially if the vomiting of blood or the passage of blood rectally is almost a continuous issue. Measures need to be taken to halt the bleeding and to replace the lost blood and fluids. Small, frequent, bland feedings are provided to prevent hunger contractions. Medication is given if indication of extreme restlessness or pain is present.

The other time to call your Doctor is if you see “coffee ground” material or a large amount of blood in anything you would gently pull back from a gastrostomy (GT) / Jejunostomy (JT) tube). This might be only irritation from the tube, but you need to let your Doctor know.

Inactive Bowel, Hypoactive or Hyperactive Bowel Sounds

Inactive bowel syndrome is the hypotonicity (of a lesser tone) of the bowel resulting in decreased contractions and propulsive movements and a delay in normal 12-hour transit time from the bowel contents of the cecum to the rectum. Colonic inactivity (bowel inactivity) may be caused by acquired or congenital colon, drugs, depression, faulty habits of elimination, inadequate fluid intake, lack of exercise, a low-residue or starvation diet, prolonged bedrest, or a neurologic disease.

Treatment includes a stimulus response training program to establish regular bowel
habits, the use of stool softeners, diet or medication to increase bulk and roughage in the diet.

Hypoactive bowel sounds, detected by using a stethoscope, are diminished in regularity, tone, or loudness from normal. They result from decreased peristalsis, which can result in a developing bowel obstruction (especially if other signs of bowel problems are presenting themselves – refer to the section on bowel obstruction), or from certain drugs and abdominal surgery. Hypoactive bowel sounds are normal during sleep. In children, it may simply be due to bowel distention from excessive swallowing of air while eating or crying. However, be sure to observe your child for further signs of illness.

Hyperactive bowel sounds can a lot of times be heard without the use of a stethoscope. It is sometimes referred to as the stomach “growling” or “gurgling”. It reflects increased intestinal motility (peristalsis). Hyperactive bowel sounds can stem also from bowel obstruction, gastrointestinal (GI) irritable bowel syndrome (IBS), food allergies, or stress. Hyperactive bowel sounds in children usually results from gastroenteritis, erratic eating habits, excessive ingestion of certain foods (such as unripened fruit), or food allergy.

**Gallbladder Disease**
The gallbladder is a pouch that sits beside the liver and stores bile, a green-yellow fluid, produced by the liver. After eating, the gallbladder releases bile into the small intestine where it helps to digest fats. Gallstones are solid clumps of cholesterol crystals or pigment material that form in the gallbladder. Some fatty components (such as cholesterol) are not easily dissolved in bile. When there is too much of these bile components, they precipitate and form solid crystals. These clump together forming gallstones - also known as cholelithiasis. Gallstones are not all the same. There are many different types of gallstones, depending on what component of the bile has solidified. Also, the stones may vary in size ranging from tiny, sand-like particles less than one millimeter in diameter to pea-like particles more than four centimeters in diameter. Almost 90 percent of gallstones are composed of cholesterol. The remainder consists of pigment material (bilirubin). The reason for the formation of pigment stones is not fully understood. The risk of gallstones increase with age and obesity.

Symptoms that are associated with gallstones are:
- Severe abdominal pain to the right side of the abdomen
- Jaundice (yellowing of the skin or eyes)
- Inflammation of the gallbladder, bile ducts, liver, or pancreas
- No symptoms called silent gallstones with no associated pain
• Gas and indigestion are not specific symptoms of gallstones or gallbladder disease

Gallstones are diagnosed by ultrasound, x-rays, or detected incidentally during the investigation of another problem.

Treatment of gallstones – silent gallstones require no treatment. Several gallstone therapies are available with symptomatic gallstones.
• "Open" cholecystectomy is the classic surgical procedure, requiring an abdominal incision. The patient remains in the hospital 3-5 days
• "Laparoscopic" cholecystectomy is a newer surgical procedure whereby the gallbladder is removed through small abdominal incisions (usually four of five) using a lighted tube (called a laparoscope). The entire procedure is viewed on a television monitor. Because there is no cutting of the muscle, recovery time is much shorter. Hospital stay is 1-2 days
• Oral dissolution of gallstones by means of medication (ursodeoxycholic acid generic name is Ursodiol) involves no surgery and is therefore suitable in patients for whom surgery may be risky. The rate of success is 40-80% and treatment usually requires 6-12 months. Recurrence is common. The best candidates are those with very small cholesterol stones and those who have mild symptoms
• Extracorporeal biliary lithotripsy is a procedure in which Doctors find the gallstones using ultrasound machines and position the patient so that high-energy shock waves focus on the stones. The waves break the gallstones into fragments, which either pass into the intestine or are dissolved with the help of medication. This procedure is done in an outpatient setting; however, very few centers have this technique available

This issue of gallbladder problems is discussed only because your children if in their late teens to early twenties have been known to have gallbladder pain more so if evident in family history.

Inguinal Hernia
A hernia occurs when part or all of a viscous (sticky substance of the tissue) protrudes from a normal location in the body.
• Inguinal hernias are most common, which is a protrusion of the abdominal wall in the groin area. Inguinal hernias can be reduced, but if they can not be and become incarcerated (if the hernia can not be reduced) or strangulated (where part of the herniated intestine becomes twisted or edematous, seriously interfering with normal blood flow and peristalsis and possibly leading to intestinal obstruction and necrosis) then surgery may become necessary. The cause of an inguinal hernia in males is usually that
These are the Common Sites for Abdominal Hernias

- Umbilical hernia - results from abnormal muscular structures around the umbilical cord. It is quite common in newborns - but usually close
- Incisional hernia - (ventral hernia) - develops at the site of a previous surgery usually due to a weakness in the abdominal wall as a result of an infection or impaired wound healing, inadequate nutrition or abdominal distention.
- Femoral hernia - occurs when the femoral artery passes into the femoral canal where it enlarges and eventually creates a hole big enough to accommodate part of the peritoneum and bladder. It will appear as a bulge at the pulse point of the femoral artery. It also often becomes incarcerated or strangulated to where surgery is necessary.

Treatment - the Doctor will reduce the hernia if possible. If the hernia is presenting any serious complication of incarcerated or strangulation, surgery to repair the hernia will be required. This problem of inguinal hernias is seen more in boys - usually in their early to late teenage years.

Peritonitis
Peritonitis is an acute or chronic inflammation of the peritoneum, the membrane that lines the abdominal cavity and covers the visceral organs. Inflammation may extend throughout the peritoneum or may be localized as an abscess. The peritoneum commonly decreases intestinal motility and causes intestinal distention with gas. The causes of peritonitis - although the gastrointestinal (GI) contains bacteria, the peritoneum is sterile and with an inflammation, bacteria invade the peritoneum - usually a result of appendicitis, diverticulitis, peptic ulcer, ulcerative colitis, obstruction, or pancreatitis.

Signs and symptoms include: the key symptom is sudden, severe, and diffuse abdominal pain that tends to intensify and localize in the area of the underlying disorder, anorexia, nausea, vomiting, altered bowel habits (particularly constipation). For example, if appendicitis causes a rupture, pain eventually localizes in the lower right quadrant - displaying weakness, pallor, excessive sweating, and cold skin as a result of excessive loss of fluid, electrolytes and protein into the abdominal cavity. Intestinal obstruction causes nausea, vomiting and abdominal rigidity. Typical other features are hypotension (low blood pressure), tachycardia (fast heart rate), signs of dehydration (oliguria - decreased urine output), thirst, dry, swollen tongue, acutely tender abdomen associated with rebound tenderness, temperature of 103 degrees or higher and hypokalemia (low potassium blood level). Inflammation of the peritoneum may cause shoulder pain, hiccups, abdominal distention, which can reduce respiratory capacity due to the
diaphragm pushing upward with the distention. Typically, your child may tend to breathe shallower and move as little as possible to minimize pain due to diaphragmatic irritation. Diagnosis is by abdominal x-rays, which show the edema and gas distention of the small and large bowel and free air will be seen in the abdominal cavity, blood studies will also support the diagnosis with an elevated white cell count.

Treatment – early treatment of gastrointestinal (GI) inflammatory conditions and pre and post-operative antibiotic therapy help prevent peritonitis. After peritonitis develops, emergency treatment must combat infection, restore intestinal motility and replace fluids and electrolytes. When peritonitis results from perforation (a rupture), surgery is necessary. The aim of surgery is to eliminate the source of infection by evacuating the spilled contents and repairing any organ perforation. Your Doctor will be doing blood work to evaluate closely the white blood cell count which would be indicative of an infection.

Pancreatitis
Pancreatitis is an inflammation of the pancreas in where the enzymes normally excreted by the pancreas digest pancreatic tissue (auto digestion). It can be mild to severe. The most common causes are biliary tract disease and peptic ulcer disease.

Signs and symptoms is steady epigastric pain centered close to the umbilicus. The pain usually begins as a gradually increasing mid-epigastric pain reaching its maximum intensity several hours after the beginning of the illness. Nausea and vomiting generally accompany the abdominal pain - if more severe, it will cause extreme pain, persistent vomiting, abdominal rigidity, diminished bowel activity (suggesting peritonitis).

Diagnosis is with clinical presentation along with lab tests (some tests will be or can be extremely elevated - amylase and glucose levels because insulin is produced in the pancreas) and x-rays (including abdominal, chest and a computerized tomography scan (CT)).

The treatment goal is to maintain circulation and fluid volume, relief of pain and decrease pancreatic secretions, and keeping an eye on the blood tests.

Urinary Tract Infection
A urinary tract infection is usually an infection of the bladder, but could also be caused from an infection in the kidney itself. Lower urinary tract infection is a prevalent bacterial disease in children. Most infections are caused by single gram-negative enteric bacteria, such as E.coli, Klebsiella, Proteus, Enterobacter,
Pseudomonas or Serratia. However, in a neurogenic bladder, an indwelling urinary catheter (foley), or a fistula (a track) between the bladder and the intestine, lower urinary tract infection may result from simultaneous infections with multiple pathogens (bacteria).

Signs and Symptoms of urinary tract infection include:
- Urgency
- Frequency
- Dysuria
- Cramps or spasms of the bladder
- A feeling of warmth during urination
- Itching
- Nocturia
- Urethral discharge
- Hematuria
- Fever
- Yeast infection - seen primarily in girls with Batten Disease because of treatment of infections (whatever kind) with antibiotics

Other common features include:
- Low back pain
- Malaise
- Nausea
- Vomiting
- Abdominal pain or tenderness over the bladder area
- Chills
- Flank pain

Diagnosis – a urinalysis, culture and sensitivity will show the exact organism so it can be treated appropriately with the antimicrobial agent, or a voiding x-ray may detect congenital anomalies that predispose the patient to recurrent urinary tract infections. Also to watch for the WBC's (white blood cells) for signs of infection along with the clinical picture of fever, etc.

Evaluating urine color
- Colorless or straw-colored (diluted urine) - excessive fluid intake, kidney diseases, or possibly nervous conditions
- Dark yellow or amber (concentrated urine) - low fluid intake, acute fever issues, vomiting or diarrhea
- Cloudy urine - infection, purulence, blood, fat, vegetarian diet or parasitic disease
- Yellow to amber urine with pink sediment - gout (excess of uric acid in urine)
- Orange-red to orange-brown urine – some drugs to treat kidney problems such as Pyridium, or obstructive jaundice (tea-colored urine)
- Red or red-brown urine – red blood cells or some drugs
- Green-brown urine – bile duct obstruction
- Dark brown or black urine – acute kidney disease or typhoid fever
- Smoky – prostate problems, fat droplets or blood

Treatment – appropriate antimicrobials are the treatment of choice for most urinary tract infection. A 7-10 day course of antibiotic therapy is standard, but recent study suggests that a single dose of an antibiotic or a 3-5 day antibiotic regimen may be sufficient to render the urine sterile. After 3 days of antibiotic therapy, urine culture should show no organisms – if it shows bacteria, then a different antibiotic needs to be ordered, because the resistance to the current treatment is not appropriate.

Special considerations – watch for gastrointestinal (GI) disturbances from antimicrobial therapy, and collect all urine samples for culture and sensitivity testing carefully and promptly. Urinary tract infections are frequently seen in children with Batten Disease and need to be on antibiotics a lot during the last few years of the illness.

Also to check for a full bladder (to see if your child needs to go to the bathroom or possibly is not emptying his bladder) have him lie on his back. Take your fingers (2-4 fingers wide) and just below the umbilicus, you can feel the bladder being hard if it is full (bladder distention). If the hardness you fill is the pubic bone then you will feel that hardness down much further where the pelvis comes together at the pubic bones.

**Constipation**
Constipation is usually defined as having infrequent bowel movements that are hard and painful. Infants that strain or groan when they have a bowel movement are not constipated if their stool is soft, even if they only have a bowel movement every two or three days. It is also important to remember that many breastfed infants only have a bowel movement once every week or two. Constipation means that a child has three bowel movements or fewer in a week. Some people think they should have a bowel movement every day. That is not really true. There is no “right” number of bowel movements per day. Each person’s body finds its own normal number of stools. Constipation is a symptom not a disease, and may be caused by many different disorders. Children with Batten Disease have a huge problem with constipation – the two biggest reasons are side effects of medications and the inactivity of motor skills as the disease progresses.
Constipation is a common problem for infants and children. Warning signs that may indicate a more serious condition causing your child to be constipated include vomiting, weight loss, poor weight gain, fever, abdominal distention or having a poor appetite. Constipation may be difficult to treat but having painful bowel movements is not something that your child has to “learn to live with” - proper diet and medical intervention should help your child have regular bowel movements. You may need to be referred to a specialist if your child has any warning signs of a more serious condition or if he is not improving with your current therapies.

Normal Physiology – the colon receives approximately 1.5 liters of fluid each day but the normal fluid volume of stool is about 100 ml (which is approximately 3 ½ ounces). The ascending and transverse colon serves as a site for storage and fluid and electrolyte absorption. The descending and sigmoid colon functions as a conduit (holding area). Feces (stool) empty rapidly from the cecum and ascending colon and are retained for several hours in the transverse colon. The descending colon propels material into the rectum, which is stored prior to defecation. Following the ingestion of a meal, and after awakening, high amplitude contractions propagate from the proximal to distal sigmoid colon, pushing the stool mass into the rectum. Normal transit time from the cecum to the rectum occurs over 24-100 hours in adults. Normal defecation is controlled by the pelvic complex, a funnel consisting of two overlapping sphincters surrounding the rectum; an internal sphincter composed of involuntary smooth muscle and an external sphincter composed of voluntary skeletal muscle that maintains continence. When the rectum is empty, the internal sphincter muscle is contracted tonically and the external sphincter is relaxed. When stool is propelled into the rectum, stretch receptors in the walls are stimulated. These receptors are active nerve cells in the intramural plexus. In turn, inhibitory interneurons decrease the activity of the muscles of the internal rectal sphincter, causing it to relax. Following internal sphincter relaxation, stool contacts (the very sensitive lining of the external rectal canal) leads to the urge to defecate. If convenient, toileting proceeds by assuming a squatting position (if constipation is a real problem, you may elevate your feet on a footstool in front of the toilet or bend forward so that your abdomen rests against your thighs), which straightens the rectal canal, and then a Valsalva maneuver is performed which increases intra-abdominal pressure, and defecation proceeds, evacuating the rectum. Alternatively, the external rectal sphincter and gluteal muscles can be contracted voluntarily; the urge to defecate subsides until the rectum again becomes distended.

Causes of Constipation in Children
Non-organic
• Developmental - cognitive handicaps, attention deficit disorder
- Situational – coercive toilet training, toilet phobia, school bathroom avoidance, excessive parental interventions
- Depression

Organic
- Neuropathic conditions – spina bifida, spinal cord trauma, encephalopathy
- Intestinal nerve or muscle disease – Hirschsprung disease, myopathies, neuropathies
- Constitutional – colonic inertia, genetic predisposition
- Reduced stool volume and dryness – low fiber
- Dehydration – underfeeding/malnutrition
- Anatomic malformations – imperforate rectum, anal stenosis, anterior displaced rectum, pelvic mass
- Metabolic – hypothyroidism, hypercalcemia, hypokalemia, cystic fibrosis, diabetes, hypermagnesemia, adrenal insufficiency
- Abnormal abdominal musculature – down syndrome, prune belly, gastroschisis
- Connective tissue disorders – scleroderma
- Drugs – opiates, sucralfate, antacids, antihypertensives, anticholinergics, tricyclic antidepressants, sympathomimetics
- Other – heavy metal ingestion, Vitamin D intoxication, Botulism

Why do children become constipated?
- Each child has his own specific dietary needs
- Having infrequent bowel movements – usually happens after a child has had a large and painful stool – he may associate a bowel movement with pain, therefore he will try and hold his stools, which creates a viscous cycle.
  Many parents mistake the behaviors that children develop to hold in stool as straining to have a bowel movement, but they are usually stiffening their muscles or fidgeting as an attempt to hold their stool in and avoid a painful stool
- Having a bad experience with potty training
- Also found in children with special needs and also as a side effect of many medications
- Causes include dietary factors, physical inactivity, mechanical obstruction, numerous drugs, metabolic factors, endocrine abnormalities, and psychogenic disorders (depression and the drugs used to treat it)

Treating Infants with Constipation
Younger infants and children with constipation should be carefully evaluated by your Doctor. Poor feeding can lead to dehydration and constipation, so it is very important to make sure that your child is gaining weight normally.
- The ultimate goal in treating constipation is for your child to have a soft bowel movement each day
One of the main ways to prevent constipation is modifying your child’s diet by decreasing foods that are constipating including cow’s milk, bananas, yogurt, cheese, cooked carrots, and other foods that are low in fiber, soy milk is a good alternative since it is less constipating

Increase the amount of fiber in your child’s diet - a daily recommendation is that your child receives 5-6 grams of fiber plus their age

Read nutritional labels to choose foods that are high in fiber. Fruits (apples, peaches, raspberries, and tangerines) and vegetables (raw squash, broccoli, Brussel sprouts, cabbage, carrots, cauliflower, zucchini, cooked spinach, black-eyed peas baked beans, kidney, navy, pinto and lima beans, sweet potatoes, peas, turnip greens and raw tomatoes), especially if they are raw and unpeeled, are good choices

Other foods that are good for children with constipation include vegetable soups (lots of fiber and extra fluid) and popcorn. Extra bran can also be helpful, including bran cereals (All-bran, Total, Bran Flakes), bran muffins, shredded wheat, graham crackers, and whole wheat or 7-grain bread, and whole grain cereal (oatmeal. Wheatena)

Increase the amount of fluids that your child is drinking - minimum of 2-3 glasses of water and juice each day, apple pear, or prune juice or other juices high in sorbitol, are good choices. Caffeine tends to dry out your system

Get enough exercise - regular exercise helps your system stay active and healthy. You do not need to become a great athlete

Allow your child enough time to have a bowel movement - sometimes we feel so hurried we do not pay attention to our body’s needs. Make sure you do not ignore the urge to have a bowel movement

Use laxatives only if a Doctor says you should

Check with your Doctor about any medicines you take

Understand that normal bowel habits are different for everyone

Medications to Treat Constipation - dietary changes take time to become effective, and until they do, your child may need to be on a stool softener. These are often used long term as maintenance therapy and are considered to be safe, effective and non-habit forming or addictive. You do want to avoid chronic use of stimulate laxatives, such as Bisacodyl, Exlax or Castor oil. An osmotic type laxative, which works by drawing extra fluid into the colon to soften the stool, is usually safer for long-term use.

Commonly used constipation medications include:

- Milk of Magnesia - an osmotic laxative with a chalky taste that some children may not tolerate - mixing it with 1-2 teaspoons of tang, nestle quick or a milk shake (1 - 12 teaspoons 1-2 times per day)
- **Mineral Oil** - a lubricant that you can mix with orange juice, may cause leakage and staining of underwear (1-2 teaspoons 1-2 times per day)
- **Docusate** - Colace or Surfak - a lubricant laxative - also available as a stimulant laxative in the combination medicine Peri-Colace (1/3 - 6 teaspoons 1-4 times per day)
- **Malt Soup Extract** - Maltsupex - (1-6 teaspoons 1-2 times per day)
- **Senokot** - a stimulant laxative
- **Bisacodyl** - a stimulant laxative - Correctol and Dulcolax
- **Lactulose** - an osmotic laxative by prescription (1-2 ml/kg 1-2 times per day)
- **Miralax** - a tasteless osmotic laxative

In addition to a stool softener, it may also help to give added fiber by mixing Metamucil or Citrucel (1 – 3 teaspoons 1-3 times per day) with 8 ounces of water or juice, or another bulk forming laxative or fiber supplements. The above dosages will depend on your child's age and weight, but consult your Doctor before starting them or changing dosages.

**Disimpaction or Treating Acute Constipation**
Because there is often a large, hard mass of stool that has "backed up" in your child's rectum, your child often has to have a "clean out" or disimpaction. Fortunately, this is rarely done manually; instead it is usually done (with your doctor's approval) using an enema or suppository, or sometimes can be done with Mineral oil up to 1 ounce per your child's age in years up to 8 ounces per dose for 2-3 days, or Miralax. Children under 18 months can be given a glycerin suppository, between 18 months and 9 years - a pediatric fleets or 1/3 of a dulcolax suppository, older children can be given a regular fleet's enema or a whole dulcolax suppository. You should avoid regular usage of enemas or suppositories.

**Behavior Modification**
Once your child's stools have become soft and regular, it is important to modify his behavior and encourage him to have regular bowel movements - have him sit on the toilet for 10-15 minutes after meals once or twice a day - keep a diary or sticker when he tries/takes medicine/or has a stool.

**Complications of Constipation**
Constipation can lead to anal fissures or tears in the skin around the rectum, bleeding hemorrhoids, rectal prolapse, and impaction. Encopresis (incontinence of stool, or the inability to know when a child has to have a bowel movement) can lead to involuntary leakage of stool secondary to the impaction of large masses of stool.
The main mistake parents make in treating their children with constipation is stopping the medication once their child begins to have soft stools. If stopped too early, your child is likely to relapse and become constipated again. Instead of stopping the medication, decrease the dosage by 25%. Do not make too many changes based on a single stool. Once your child is having regular soft stools, you can then talk with your Doctor about decreasing the dosages of the laxative that you are using.

We mentioned constipation briefly as causing a problem with feedings. Work with your Physician on a plan for keeping this under control. You can start with things like prune juice. Fiber additives, suppositories, enemas, and manual removal are steps, which may have to be added. (Do not forget that extra water may help). Preventing constipation is better than treating it, once it occurs, so do not hesitate to be aggressive. You may also find the use of an antacid, such as Maalox which combines a little Milk of Magnesia with a little Aluminum Hydroxide) will help soften the stool as well as cut down on some of the acidity, try one that only has Aluminum or Calcium Hydroxide, caretakers get real expert at juggling the two of them. If there is an episode of diarrhea, you may want to switch to clear liquids for 12-24 hours if there is a fever, and then work your way back up from dilute to full strength formula again. Many antibiotics have the side effect of wiping out the “good” bacteria in the intestines and you can ask your Physician about ways of replacing these (there are pills “Acidophilus” that could be crushed and given or you can use yogurt diluted in water or formula).

The one thing that you need to be aware of as an acute situation where you need help is a bowel or intestinal “blockage”. There is usually distention and the entire feeding will remain in the stomach. This is different from the occasional ounce or two that might remain in the stomach from one feeding to the next, as if it was an “off” meal. You may be fooled into thinking that things are ok, because there is some dark colored seepage (liquidy stool) around the impacted stool on to the diaper. If you pull gently back on the gastrostomy (GT) tube with the syringe and almost all of the feeding is there, do not replace it. Give several ounces of water, wait 30-45 minutes and gently pull back again. If the water is gone, try some diluted formula. If you find that the amount is close to what you put in, contact your Physician. You should not have to withdraw on the syringe if your child has a jejunostomy tube, the formula should already be going into the intestines and the absorption phase in process.

**Appendicitis**

Appendicitis - is the most common surgical procedure in children. It is caused by an acute inflammation of an obstruction of the intestinal lumen caused by a fecal mass, stricture, barium ingestion, or viral infection. This obstruction sets off an
inflammation process that can lead to infection, thrombosis, necrosis, and
perforation. If the appendix perforates or ruptures, the infected contents spill
into the abdominal cavity, causing peritonitis, the most common complication of
appendicitis.

Signs and symptoms usually start with generalized or localized colicky abdominal or
epigastric pain, followed by nausea, anorexia, and a few episodes of vomiting. Pain
eventually localizes in the right upper quadrant, increasing tenderness and spasms.
Later signs may be diarrhea or constipation, slight fever, and tachycardia. Sudden
cessation (stoppage) of abdominal pain indicates a perforation or infarction of the
appendix.

Diagnosis is by physical findings and clinical symptoms - fever and an elevated white
cell count. The diagnosis must rule out other gastrointestinal (GI) disorders.

Treatment - the only effective treatment is an appendectomy. Laparoscopic
appendectomies, which decrease the recovery time and hospital stay, are now
performed. If peritonitis develops, hospital stay will be longer and further
treatment of intravenous fluids (IV), antibiotics, etc. will be necessary.

**Intestinal (Bowel) Obstruction**

An intestinal obstruction is a partial or complete obstruction of the lumen of the
small or large bowel. A small bowel obstruction is far more common (90% of
patients) and usually more serious. A complete obstruction in any part of the bowel,
if untreated, can cause death from shock and vascular collapse. Intestinal
obstructions are most likely to occur from adhesions caused by previous abdominal
surgery, hernias, or Crohn’s disease.

The three forms of intestinal obstruction are:

- **Simple** - blockage prevents intestinal contents from passing with no other
  complications
- **Strangulated** - blood supply to part or all of the obstructed section is cut
  off in addition to blockage of the lumen
- **Close-looped** - both ends of a bowel section are occluded, isolating it from
  the rest of the intestine

When intestinal obstruction occurs, fluid, air, and gas collects near the site.
Peristalsis increases temporarily as the bowel tries to force its contents through
the obstruction, injuring intestinal mucosa and causing distention at and above the
site of the obstruction. The distention blocks the flow of venous blood and halts
Different Causes for Bowel Obstructions

**WHAT HAPPENS IN BOWEL OBSTRUCTION**

A partial or complete blockage of the small or large intestine results in bowel obstruction—a potentially life-threatening condition. Small-bowel obstruction is more common (because the ileum is the narrowest segment and most prone to obstruction) and is usually more serious (because of the accompanying fluid loss).

**COMMON CAUSES**

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<th>Adhesions</th>
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<td>Neoplasia</td>
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<td>Occlusion of mesenteric vessels</td>
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normal absorptive processes. As a result, the bowel begins to secrete water, sodium, and potassium into the fluid pooled in the lumen. This results in distention and enormous amounts of fluid in the gut (intestine/abdomen). An obstruction in the upper intestine results in metabolic alkalosis from dehydration and loss of gastric hydrochloric acid; a lower obstruction causes slower dehydration and loss of intestinal alkaline fluids, resulting in metabolic acidosis.

Signs and symptoms of small bowel obstruction include: colicky pain, nausea, profuse vomiting, abdominal distention, dehydration and constipation (which signify a complete obstruction). As the obstruction becomes more complete depending on the site of the obstruction, spasms, more severe vomiting of stomach contents, bile and then fecal material will be evident. Small amounts of mucus and blood may be passed. There is minimal or no fever. Large bowel obstruction develops more slowly because the colon can absorb fluid from its contents and distend well beyond its normal size. Constipation may be the only sign for many days. Colicky abdominal pain may appear suddenly, producing spasms, continuous hypogastric pain and nausea, but vomiting is initially absent. As it progresses to a complete obstruction, vomiting of fecal material, continuous pain, or localized peritonitis may be apparent.

Diagnosis is made by the progressive, colicky abdominal pain and distention, with or without nausea and vomiting, suggesting bowel obstruction, x-rays show the presence and location of intestinal gas and fluid, lab tests are also valuable in the decrease of electrolytes, increased white cell count, and amylase level increased (possibly due to irritation of the pancreas by a loop of bowel).

Treatment starts with correcting fluid and electrolyte imbalance, decompressing the bowel to relieve vomiting with insertion of a nasogastric tube (NG) and treating the peritonitis with antibiotics. Close monitoring of your child's condition determines the duration of treatment; if your child fails to improve or if the condition deteriorates, surgery will be necessary – surgery is performed on all patients with large-bowel obstruction.

**Diverticulitis**

Diverticulitis is an out-pouching of the colon, usually in the sigmoid area of the colon. It develops from the musculature in the colon working against increased intraluminal pressures (contributing factor may be diet and lack of roughage) to move hard stools through. Two clinical forms appear: diverticulosis where diverticula are present, but usually the patient is asymptomatic (may have abdominal pain, fluctuating bowel habits, or constipation) or the symptoms are questionable because they may be related to underlying irritable bowel syndrome (IBS). In diverticulitis, diverticula are inflamed and may cause obstruction, infection or hemorrhage (where retained undigested food mixed with bacteria
accumulates in a diverticular sac, forming a hard mass, which then cuts off the blood supply to the thin walls of the sac, making them more susceptible to attack by bacteria).

Diagnosis is usually found incidentally when an upper gastrointestinal series (GI) is done, then a plain abdominal x-ray is done to confirm diagnosis to see the barium filled diverticular sacs or sometimes the sacs are filled with impacted stool and only outlines are seen. A sigmoidoscopy and colonoscopy can be done for further confirmation, but again should not be done with an acute attack of diverticulitis.

Treatment includes:

- **Diverticulosis** - means that the disease exists and will probably have episodes of diverticulitis at times, but does not usually require treatment. If pain, nausea, or constipation occur, a liquid or low residue diet, stool softeners, and occasional doses of mineral oil may be helpful. These measures relieve symptoms, minimize irritation, and lessen the risk of progression to diverticulitis. After the pain subsides, continuing with a low residue diet, Psyllium (to add more bulk to the stool) may be added twice per day and increased water consumption to 8 glasses a day will help.

- **Diverticulitis** - without signs of perforation, aims to prevent constipation and combat infection. This includes bed rest, a liquid diet, stool softeners or bulking agents, antibiotic (Flagyl or Cipro), medication for the pain and top relax smooth muscle and antispasmodic (Propantheline - generic name is Probanthine) to control muscle spasms.

Complications of diverticulitis includes:

- Perforation (rupture), peritonitis (infection), obstruction (blockage) or a fistula (a tract running to another place in the abdomen or another body organ such as the kidney) may require a temporary colostomy to drain abscesses and rest the colon, 6-8 weeks after inflammation or infection subsides, the colon can be reconnected.

- Formation of fistulas involving the bladder, ureters, bowel, and abdominal wall, or colon stricture - which may result in partial or complete obstruction of the bowel may need to be repaired.

- Hemorrhage - (bleeding) usually stops spontaneously, but may need blood replacement and careful monitoring of fluids and electrolytes.

**Intussusception**

Intussusception is where a portion of the bowel telescopes into an adjacent portion of the bowel. It is most common in infants between 3 months and 3 years. This telescoping produces edema (swelling), bleeding from venous engorgement, incarceration and obstruction.
Signs and symptoms include: intermittent attacks of severe colicky abdominal pain, which causes the child to scream, draw his legs up, turn pale and diaphoretic (sweating profusely), and between bouts may be sleepy and lethargic; initially vomiting of stomach contents then will see bile stained or fecal emesis (vomiting stool contents); "current jelly" (red colored) stools - a mixture of blood and mucus; tender, distended abdomen with a sausage shaped right upper abdomen.

Diagnosis is with barium enema (will see a coil-spring sign), upright abdominal x-rays (may show a mass and the obstruction) and a blood test (that will show an elevated white cell count).

Treatment - surgery is most frequently required in children especially if it is a recurrent event. Sometimes they can reverse the telescoping.

Irritable Bowel Syndrome

Irritable bowel syndrome (IBS) is a chronic gastrointestinal disorder characterized by altered bowel habits, usually associated with abdominal pain, in the absence of detectable structural abnormalities. Recent information indicates that irritable bowel syndrome (IBS) is a syndrome complex of motor disorders, not limited to the colon, but which may affect other parts of the gastrointestinal tract and affects the smooth muscle or afferent processing tissue of the body.

The clinical picture may be variable, but your child may complain of abdominal pain, alternating constipation and diarrhea with one being dominant and abdominal distention with belching or flatulence (gas). Some children may also have dyspepsia (gastric discomfort), nausea or vomiting. Alterations in gastric emptying have also been demonstrated in irritable bowel syndrome (IBS) patients. Irritable bowel syndrome (IBS), especially in children and adolescents, is often initiated by excessive attention to bowel movements, which can result in laxative abuse, the use of enemas, and over involvement of the parent in the child's bowel regimen.

Diagnosis of irritable bowel syndrome (IBS) rests on two elements: a history of compatible symptomatology and the exclusion of other possible pathology. Although the clinical picture can vary considerably, diarrhea or constipation, abdominal distention, and pain are the most prevalent symptoms, and most children fall into one or two categories. In one type of clinical presentation, abdominal pain is the predominant symptom, and is often associated with meals. Altered bowel habits may be present, but this is not the major complaint. In the second category of children, the main symptom is changes in bowel habits, although pain may also be present. The clinical picture consists of alternating diarrhea and constipation,
which may be due to the child’s use of laxatives for constipation and antispasmodics for the resultant diarrhea. There is also a group of children who present with painless, watery diarrhea. Some clinicians feel this is a variant of irritable bowel syndrome (IBS), but others believe this represents other clinical entities and deserves further attention to the different diagnosis. It is interesting to note that irritable bowel syndrome (IBS) and dyspepsia syndromes may overlap and that symptom profiles can change over time. Several studies have also demonstrated that emotional stress alters colonic motility in patients with irritable bowel syndrome (IBS). Generally, motility is inhibited with depression and stimulated with hostility.

A thorough carefully recorded history is of primary importance for establishing the diagnosis of irritable bowel syndrome (IBS), and for differentiating it from other gastrointestinal disorders. The major clinical features of irritable bowel syndrome (IBS) - abdominal pain, bloating, and altered bowel habits - are common to many gastrointestinal disorders. There are, however, some important clues, which strongly suggest irritable bowel syndrome (IBS):

- A long history of symptoms without progressive deterioration
- The absence of nocturnal diarrhea
- The absence of systemic signs and symptoms such as fever, weight loss, anorexia, or anemia
- Bowel movements primarily in the morning
- Increased symptoms during periods of increased stress
- A feeling of incomplete evacuation
- Relief of discomfort with evacuation
- The absence of blood in the stool

A medication history should also be taken. A recent history of antibiotic or antiinflammatory use is of particular importance, because both can induce diarrhea. Antibiotic use is also related to the likelihood of Clostridium difficile enterocolitis (c. diff). The use of over the counter antiflatulents and antacids should also be noted, and the child or parents should be asked about laxative use in order to exclude possible chronic laxative abuse - which sometimes usage is concealed. Also, diuretics, iron, calcium channel blockers and anticholinergics, including some antidepressants can cause constipation.

The medical history should include information about previous diseases of the gastrointestinal (GI) tract, abdominal or rectal surgery, bleeding, or blood in the stool. Personal family history questions should also be asked as well as potential sources of chronic stress including problems arising from the family circumstances of your child. There may be a hereditary component here, in that other family members may have experienced similar symptoms. Questions about diet should
focus on foods that seem to provoke symptoms. Certain foods such as corn, legumes, and dairy products may be associated with increased symptoms. Food intolerances, particularly milk and alcohol should be identified to help differentiate such things as lactase deficiency and alcohol induced diarrhea.

The physical exam includes an abdominal and rectal exam. The abdominal exam will pinpoint the locality of the pain and any distention. The rectal exam is to identify any fissures (grooves), fistulas (tracts running to another part of the body), or ulcers, which would signal a diagnosis other than irritable bowel syndrome (IBS), such as Crohn’s disease. A stool for occult blood should be done to establish a differential diagnosis other than irritable bowel syndrome (IBS) as well. A sigmoidoscope (a tube with a light to examine the lower colon) or a colon exam is done if there is rectal bleeding, weight loss, anemia, or polyps (usually fibrous) are found with the scope.

Management of irritable bowel syndrome (IBS) often includes reassurance, stress reducing activities, life style changes, dietary changes, drug therapy, and referrals if necessary. For children who present with both diarrhea and constipation, the Doctor should determine which is the most pressing symptom and manage accordingly. Foods to avoid in diets include: disaccharides, salad dressings, gravy, alcohol, sauces, coffee, tea, and cola drinks (if they worsen symptoms); milk or milk products should be excluded if lactose intolerance is confirmed, limiting Sorbitol and Mannitol may help decrease diarrhea; beans, lentils, Brussel sprouts, and cabbage, if flatus increases with these foods. Tobacco use is another issue to discontinue due to symptoms. Diets with high-fiber and stool-bilking agents such as bran may help constipation. Antispasmodics may help relieve the pain of intestinal cramps - example Dicyclomine (Bentyl) and Hyoscyamine (Levsin) (side effect is dryness of the mouth), antidiarrheal drugs can be treated with Diphenoxylate (Lomotil) or Loperamide (imodium) for symptomatic relief, some anti depressants such as Amitriptyline (Elavil), Doxepin (Sinequan), Imipramine (Tofranil), Fluoxetine (Prozac), and Trazodone (Deseryl) have been reported by some to be helpful with chronic pain of irritable bowel syndrome (IBS) due to there therapeutic effects in irritable bowel syndrome (IBS) unrelated to underlying depression or mood improvement. And education is always an important aspect of medical care, especially in dietary management, avoidance of precipitating factors, and control of stress response. Follow-up care is also important. If at the end of 6 months there has not been significant improvement, your Doctor should consider referring you or your child to a specialist.

**Crohn’s Disease**
Crohn’s disease in an inflammation of the intestinal tract. It can affect any portion of the tract from the mouth to the rectum, mostly affecting the small and large
Causes are unknown, but possibilities include allergies, genetic component or other immune disorders and infection. Whatever the cause of Crohn's disease, lacteal blockage in the intestinal wall leads to edema and eventually to mucosal inflammation, ulceration, structuring, and fistula and abscess formation. Symptoms of acute disease may mimic appendicitis and include:

- Steady, colicky pain in the right lower quadrant
- Cramping
- Tenderness
- Flatulence
- Nausea
- Fever
- Diarrhea
- Bleeding - usually mild

Symptoms of chronic disease are more typical and include:

- Abdominal distention
- Crampy abdomen
- Low-grade fever
- Weight loss
- Fatigue
- Weakness
- Diarrhea – non bloody and intermittent with right lower quadrant pain or pain around the umbilicus
- Fistulas may occur from the large to small colon and can see diarrhea, weight loss, and malnutrition

Complications may lead to intestinal obstruction, fistula formation between the small bowel and the bladder, perianal and perirectal abscesses and fistulas, intra-abdominal abscesses and perforation.

Diagnosis - Upper gastrointestinal (GI) series with small bowel follow through may demonstrate ulcerations, stricture, and fistulas. Lab tests can often help diagnose with increased white cell count, low hemoglobin, etc. A barium enema showing the string sign (segments of stricture separated by normal bowel) supports the diagnosis. Flexible sigmoidoscopy and colonoscopy may show patchy areas of inflammation, ulcers, or strictures, thus helping to rule out ulcerative colitis. However, a definitive diagnosis is possible only after a biopsy.

Treatment - no cure for Crohn's exits and treatment is symptomatic but can be very effective. If your child is debilitated, they are not allowed to eat so as to let the bowel rest and are fed through an IV. Drug therapy including antiinflammatory corticosteroids, immunosuppressive drugs, antispasmodics, anti-bacterial, anti-diarrheals may be used. Effective treatment requires important lifestyle changes
including: physical rest, low-residue diet, and elimination of dairy products for lactose intolerance. Surgery may be necessary if more severe symptoms of bleeding and perforation occur.

**Ulcerative Colitis**

Ulcerative colitis is an inflammation that affects the surface of the colon, most commonly, the rectum and sigmoid colon. It can move upward and affect the larger colon and rarely affects the small colon. Severity ranges from a mild, localized disorder to a full-blown disease that may lead to a perforated colon, progressing to peritonitis and toxemia.

**Symptoms for ulcerative colitis include:**
- Bloody diarrhea – hallmark symptom – the intensity of these attacks varies with the extent of inflammation
- Five or fewer bowel movements per day with intermittent bleeding and mucus production
- Left lower quadrant pain relieved by defecation, along with fecal urgency and tenesmus
- More progressed symptoms include more than five bowel movements per day, resulting in anemia, hypovolemia, and impaired nutrition

**Complications of ulcerative colitis include:**
- Blood – anemia from iron deficiency, coagulation defects due to Vitamin K deficiency
- Skin – rash on the face and arms, legs and ankles
- Eye – uveitis (inflammation of the eye)
- Liver – cirrhosis
- Musculoskeletal – arthritis, loss of muscle mass
- Gastrointestinal (GI) – strictures, perforated colon

**Diagnosis**
- History and physical examination – all of the pertinent information about stool pattern, color, etc.
- Sigmoidoscopy – will show increased mucus, edema, and erosions (wearing away), biopsy can also help with diagnosis
- Colonoscopy – may be done to determine the extent of the disease
- Stool specimen – should be done for specific organisms
- None of these should be done during an acute attack of ulcerative colitis

**Treatment for ulcerative colitis:**
- Relieve symptoms of the acute attack
- Prevent recurrent attacks
To replace nutritional losses and blood volume
Prevent complications
Intravenous (IV's), blood transfusions, clear liquid diet, iron supplements may be necessary
Drug therapy - to control inflammation (Prednisone), antidiarrheal to control diarrhea (Lomotil), topical agents for rectal area (Mesalamine - generic name is Asacol), sulfa drugs
Surgery if necessary may require a colostomy or ileostomy

Hemorrhoids
Hemorrhoids are defined as a varicosity (twisted, knotted) in the lower rectum or anus owing to congestion in the veins in the hemorrhoidal plexus. Straining to have a bowel movement, constipation, prolonged sitting or standing, coughing, sneezing or vomiting contribute to the development of hemorrhoids
- Internal hemorrhoids - originate above the internal sphincter of the anus. If they become large enough to protrude from the anus, they become constricted and painful, small ones may bleed with having a stool
- External hemorrhoids - originate outside the external sphincter. They are usually not painful and bleeding does not occur unless a hemorrhoidal vein ruptures or thromboses.

Signs and symptoms will cause the following:
- First-degree hemorrhoids - bright red blood appears on the stool or on toilet paper due to injury of the fragile mucosa covering the hemorrhoid, may itch due to poor anal hygiene
- Second-degree hemorrhoids - may prolapse but are usually painless and spontaneously return to the anal canal following a bowel movement
- Third-degree hemorrhoids - cause constant discomfort and prolapse in response to any increase in intra-abdominal pressure. They must be manually reduced. Thrombosis of external hemorrhoids produces sudden rectal pain and a large, firm lump that you can feel. If hemorrhoids cause severe or recurrent bleeding, they may lead to secondary anemia with significant pallor, fatigue, and weakness

Treatment includes: measures to ease pain, combat swelling congestion and regulate bowel habits, local application of a topical medication to lubricate, anesthetize, and shrink the hemorrhoid (Preparation H - lotions, creams or suppositories), sitz baths and cold and hot compresses are also soothing. You may want to increase the amount of raw vegetables, fruit, and whole grain cereals in your diet, or by using stool softeners.
Rectal Polyps
Rectal Polyps are defined as masses of tissue that rise above the muscular membrane and protrude into the gastrointestinal tract. Most polyps are benign. You may see in children under age 10 and are characterized by rectal bleeding as the major symptom. Predisposing factors include heredity, age, infection and diet. They appear large, inflammatory lesions, often without a tissue covering. Mucus-filled cysts cover their usually smooth surface. Watch for and report any form of rectal bleeding.

Pressure sores - will also have its' own section and will be completed soon

Difficult Tests That May Be Done To Help With Diagnosis

Barium Swallow
A barium swallow is sometimes done first because it is less invasive. A barium swallow can be a part of an upper gastrointestinal series (GI) or an endoscopy (EGD). It is done to rule out esophageal issues and to rule out aspiration problems, to watch barium slide down the esophagus and into the stomach. It can show diverticulum, varices, aspiration, ulcers, motility disorders, and gastrointestinal reflux disease (GERD) - where they do a scan to watch for transit time from the esophagus to the stomach).

Tell your child he will have nothing to eat or drink from the midnight before the exam. It will take approximately 30 minutes to do the exam. Barium looks like a milkshake and is thick like a milkshake also. They are usually flavored. At first the radiologist will want you to drink some thick barium, and he will watch it slide down your throat and then the liquid will be a thinner consistency and they will again watch it slide down through your esophagus. Your child will be placed on a tilt table to view the esophagus and stomach in different positions. Avoid taking antacids prior to the test.

Endoscopy
An endoscopy - (esophagogastroduodenoscopy) - EGD - is the visual examination of the lining of the esophagus, the stomach and the upper duodenum, using a flexible fiber-optic endoscope. It is indicated in children with bloody vomiting, bloody stools, or substernal or epigastric pain, and in post operative children with recurrent or new symptoms. This procedure is generally safe, but it can cause perforation (rupture) of the esophagus, stomach, or duodenum, especially if your child is restless or uncooperative. Endoscopy (EGD), which can detect small or surface lesions/cysts missed by x-ray, eliminates the need for extensive exploratory surgery. It also permits lab evaluation of abnormalities first detected
by x-ray because the scope provides a channel for biopsy forceps or a cytology brush. Similarly, it allows removal of foreign bodies by suction (for small, soft objects) or by electrocautery snare or forceps (for large, hard objects).

**Purpose of the endoscopy (EGD)**

- To diagnose inflammatory disease including esophagitis, gastritis and duodenitis, benign tumors and acute or chronic ulcers, Mallory-Weiss syndrome (refer to glossary), and structural abnormalities, may also demonstrate diverticula, varices, esophageal and pyloric stenosis (constriction) and esophageal hiatal hernia
- To evaluate the stomach and duodenum postoperatively
- To obtain emergency diagnosis of duodenal ulcer or esophageal injury

**Patient teaching**

Your child will not have anything to eat from midnight before the exam. A consent form will need to be signed prior to the test. He will have a conscious sedation medication to allow him to not remember the procedure. His vital signs will be checked frequently immediately after the test. A safe environment will be provided until he recovers from the sedation with the side rails up on the bed. He will not be allowed any food or fluids until the gag reflex returns, which is usually within one hour. If your child is fed with a gastrostomy (GT) tube, it will be turned off at least 4 hours prior to the exam and then resumed as the Doctor orders. Your child may complain of a sore throat for 3-4 days and may belch more air than normal. Remember to watch for signs of any complications like increased difficulty in swallowing, pain, fever, black stools, or bloody vomiting.

**Colonoscopy**

A colonoscopy is the visual examination of the lining of the large intestine with a flexible fiber-optic endoscope. This test is indicated for children with a history of constipation and diarrhea, persistent rectal bleeding or lower abdominal pain. Colonoscopy is usually a safe procedure, but it could cause perforation.

**Purpose of a colonoscopy**

- To detect or evaluate inflammatory and ulcerative bowel disease
- To locate the origin of lower gastrointestinal (GI) bleeding
- To aid diagnosis of colonic structures and benign or malignant lesions
- To evaluate the colon postoperatively for recurrence of polyps

**Patient Teaching**

Tell your child that he will just have clear liquids (consists of jello, broth, tea, sprite, 7up, apple juice, grape juice or cranberry juice) 24-48 hours prior to the test, and the night before the test to take nothing by mouth. The test will take 30-60 minutes. Also, the intestine needs to be thoroughly cleansed for the test to
be effective and he will have to drink a laxative (example - Go Lytely). He will probably have an intravenous (IV) inserted in his arm to have an access for a relaxant to be given prior to the test. A consent form will need to be signed prior to the test. Vital signs will be taken frequently during the test and for one hour after the test. He will be in a safe environment until he is fully awake from the sedation. He may also pass a large amount of gas from the air that was introduced during the procedure. Biopsies and polyps may also be removed during the procedure if warranted.

**Abdominal Girth**

Abdominal girth measurement can detect significant changes in size of the abdomen. Measuring the abdomen is a test you as a parent can do at home if you feel that your child may be uncomfortable, having pain, or possibly a bowel obstruction. What you will be checking for if abdominal distention - the stomach size can increase 3-4 inches or more during certain abdominal problems. Examples of abdominal distention may occur if residuals from the stomach are high (tube feedings are not being digested properly and you may have a residual of 100-400cc of tube feeding in the stomach), a lot of gas build up in the stomach and intestines, constipation - where your child has not had a bowel movement for quite a few days and a lot of stool can be in the intestines. The abdomen may not only appear swollen or distended, but also may be tight and shiny.

Procedure:

Have your child lie completely flat on his back. Explain to him exactly what you are going to do and why if he can understand you. Take a tape measure and place it around his back and directly over his umbilicus, measure his abdominal girth to obtain a baseline reading. Along the tape on his body, take a felt tip pen and mark in three places - one on each side and then one in the center at the umbilicus, so as to always measure at the same place. If the pen markings wear off with bathing, just take the pen and remark the areas. Then keep a record of the date, time, and inches of the measurement for future comparisons.

**Insertion of an NG (Nasogastric) Tube**

The nasogastric tube, inserted into the stomach through the nose, has diagnostic and therapeutic uses. It can be used to assess and treat upper gastrointestinal tract bleeding, to collect gastric contents for analysis, to perform gastric-lavage, to aspirate gastric secretions, and to administer medications and feedings. It is also used commonly after major surgery to decompress the stomach and prevent vomiting by keeping the stomach empty.

The diameter of a nasogastric tube is larger than some of the feeding tubes and therefore normally medications are inserted through the tube with little difficulty.
Parents can be taught to insert a nasogastric tube (NG) very easily - if your Doctor feels it necessary to intermittently insert a nasogastric tube (NG) or whatever the circumstance may be, will be your Physician's decision. Explain to your child what you will be doing and why. You will want to have your child sitting up in a straight position. Lubricate the end of the tube with KY jelly before insertion. To know how far down to put the tube, take the tube, measure from the tip of the ear to the nose and then from the nose to just below the sternum to the stomach area. Tilt your child's head down a little, insert the tube in either nostril. You will feel the tube sliding past the opening to the lungs and it will go down into the esophagus and then the stomach. Make sure you tape the tube securely on the nose. Take a piece of tape approximately 3 - 4 inches long, tear it in half, all but about 1-1 ½ inches or the size of your child's nose, make so your child's nose is free from oily skin, you can clean the nose with an alcohol pad or if you have some tincture of benzoin (it will make the area sticky so the tape adheres better), wipe some on his nose, let it dry for 30 seconds or so, put the piece of the tape that was not torn on the nose, then wrap each half of the tape around the tube, one half and then the other. Make so you check to make sure you have the tube in the stomach by connecting a syringe on the end of the tube and pulling back on the plunger until you get stomach contents (usually yellow or green liquid). Another way to tell if you have the tube in the stomach is to put the end in a glass of water, if you do not see any bubbles, the tube will be placed correctly. Also, if you are getting the tube in your child's lungs, he will usually have difficulty breathing and may gag or cough and you will see bubbles if the end of the tube is placed in a glass of water.

Insertion of a nasogastric (NG) tube and listening of bowel sounds
Checking the Stomach contents for Residual
If your child has a nasogastric (NG), gastrostomy (GT) or jejunostomy (JT) tube, you can check to make sure that the feedings are being digested and useful for his body. Take a syringe and connect it to the end of the nasogastric tube (NG) or the feeding tube. Pull back on the plunger and measure the total amount of fluid that you can withdraw - this is called the residual amount. If you are going to check for residual, do so before giving meds or a feeding unless it is a continuous feeding or you will pull the stomach contents out that you just put in. If your child is vomiting and he has a tube (nasogastric (NG) or feeding tube gastrostomy / (GT) Jejunostomy (JT) tube), checking for residual is important - you may have 100-300 or so cc's that are still in the stomach. Do not replace that liquid unless your Doctor wants you to. There will be a lot of minerals etc. in that fluid, and your Doctor will instruct you on what he wants you to do. Usually, an amount greater than 100-150 cc's would indicate stopping the feeding for awhile, but each Doctor will tell you his preference as to his limits for residuals.

Checking for an Impaction
If your child is having problems with constipation, it may require you to manually break up the stool in order for the stool to be expelled. Your Doctor may ask you if you feel comfortable doing this procedure at home or if you have a health care where a nurse could assist you in your home.

Lubricate a gloved finger with KY jelly and insert your finger into the rectum of your child. If impacted, you will feel hard chunks of stool in the rectum. Sometimes all you may feel is soft stool which probably means that there may be harder pieces of stool higher than what you can reach with your finger (your Doctor may order a fleet enema which helps in getting the process started of having a stool). If hard stool is felt (a mineral oil fleets may be ordered by your Doctor to soften the stool enough so your child can then expel it), then try to break up the pieces and expel it for your child. Encourage him to “push” which usually working together can get the job accomplished. If your child seems to be experiencing a lot of discomfort and you see bleeding around the rectal area, do not “dig” too much, sooner wait a little while and try again. Also, refer to the section on preventing constipation.

Enemas For Diagnostic Testing
Your Doctor will be the one to tell you or give you a prescription for laxatives or enemas. Refer to the section on constipation for more information. For diagnostic testing, especially of the lower intestine, it will have to be “cleaned out” or laxatives, enemas given in preparation for the test. Depending on the diagnostic test will determine the laxatives or enemas required for the test to be done. Golytely is usually given but it will be your Doctor’s decision. You should adhere
strictly to the instructions prior to diagnostic test of the gastrointestinal (GI) tract when laxatives or enemas are ordered, to achieve maximum results from the test.

**Insertion Of A Rectal Tube**
A rectal tube may be ordered if the abdomen is extremely distended or if watery diarrhea is a real problem where the rectal area is raw from the acid in the watery stool.
If there is a large amount of gas seen on an abdominal x-ray, it may be necessary to insert a rectal tube. This is also where measuring the abdominal girth will be helpful as described in an earlier in this section under diagnostic testing.
Abdominal distention can be very uncomfortable and painful. If watery diarrhea is a complication and is causing a lot of rectal excoriation of the skin, your Doctor may order a rectal tube until the diarrhea can be controlled.
The tube is inserted 4-6 inches and then taped to the skin of the buttocks. The tube has holes on the end to allow the stool to be passed through the tube.

**Stool specimen for mucus or for blood testing**
Stool specimens can be ordered to help in diagnosing intestinal infections, gastrointestinal (GI) bleeding and other gastrointestinal (GI) disorders. If a stool specimen is ordered by your Doctor, you will need a container to collect the stool.
You will want to make sure you know if you will need to get the specimen to the lab as soon as possible or if it can wait until the next day (some specimens need to be warm when they get to the lab). If your child has a rectal tube - you can disconnect the tube from the drainage bag and collect a specimen into your specimen collection container and then take it to the lab.

Evaluating stool characteristics - as you probably know, the appearance of stool may help to identify the location of gastrointestinal (GI) bleeding and other gastrointestinal (GI) problems as well. The following lists specific abnormal stool characteristics and the possible causes.

- Black, tarry stool (melena) - upper gastrointestinal bleeding (gastrointestinal tract) or slowly bleeding problems from the colon
- Black stool - rapid elimination of bile or the ingestion of iron
- Stool streaked with blood or blood clots on the stool surface - bleeding in the lower colon at the site of stool formation or hemorrhoids
- Red or maroon stool - lower (sometimes upper) gastrointestinal (gastrointestinal tract) bleeding
- Mucoid stool - colitis or mucus-producing lesion
- Large, bulky, foul-smelling stool that floats on water - malabsorption of fat (steatorrhea) or large quantity of air or other gas in the stool
• Clay-colored stool – liver problems (for example, hepatitis) or bile obstruction or residue from barium studies

Changes in stool color are not always the result of a disease or disorder. Some causes of variant stool color follow below.

• Red – carrots, beets, tomatoes, red peppers or a drug called Pyrvinium
• Black – licorice, grape juice or drugs with iron in it or Phenylbutazone
• Brown – cocoa, high intake of meat protein (dark brown) or a drug called Anthraquinone
• Green-blue or black – spinach or Bismuth preparations (used in nausea, vomiting and indigestion
• Yellow – rhubarb, high intake of milk (yellow-brown) or Senna (laxative)
• White discoloration or speckling – Antacids containing aluminum hydroxide (Maalox)

Abdominal X-rays and CT Scans (Computerized Tomography)
Regular abdominal x-rays and computerized tomography (CT) scans as well as other radiographic tests can also be very helpful in diagnosing gastrointestinal (GI) tract disorders – having the ability of seeing abdominal distention, a lot of gas in the bowel, free air which may signify intestinal perforation, stool impactions, hiatal hernias, ulcers, gallbladder disease, and other disorders to detect, differentiate, distinguish, diagnose and evaluate gastrointestinal (GI) disorders.

Laboratory Tests
There are also many, many lab tests available today to aide in diagnosing each specific disorder of the gastrointestinal (GI) tract for our children.

Positive Things That May Be Helpful In GI Disorders

Diets and Dental Issues - Refer to the sections on diets and dental issues. Also with gastrointestinal (GI) problems, bland foods (cooked cereals, soft-boiled eggs, toast, mashed potatoes, puddings, cottage cheese, pasta’s – foods without a lot of spices) may be required, more frequent feedings during the day, possibly eating something small with medications or more fiber in the diet can all be useful approaches to your child’s diet.

In ulcer disease, the treatment aims to help the stomach rest through dietary changes, medications, and physical and emotional relaxation. Small hourly feedings may relieve your child’s symptoms by reducing the extent of distention, by reducing digestive juice secretion and gastric motility. During the acute phase, make so you follow the prescribed diet which may include a “sippy” diet which is small amounts
of milk alternating with antacids every 30 minutes - this is an older diet, but if all else fails this may prove to be effective. Gradually, frequent small meals of bland foods will be added.

Foods to be avoided include: high-fiber foods (cabbage, irritating foods such as soups and gravies), large meals, and fruit juices, carbonated, caffeinated, and alcoholic beverages as they increase gastric secretions. Constipation may occur and the Doctor will order laxatives. A normal diet will be resumed usually after a repeat x-ray is done to see if ulcer healing has occurred. In irritable or diverticular disease, the diet therapy is to allow the bowel to heal by decreasing its activity while providing the calories and nutrition necessary for healing. It is very important to follow the diet to achieve remission and prevent complications - to understand the prescribed diet - high in protein, calories and vitamins. Avoid foods that irritate the intestines or that require excessive intestinal activity such as milk products, spicy or fried high residue foods, raw vegetables and fruits, and whole-grain cereals, carbonated, caffeinated, or alcoholic beverages as they increase bowel activity. Also discourage extremely hot or cold food or fluids because they can cause gas. Extra vitamins are given to compensate for the bowel's inability to absorb them.

Schedules - Scheduling of medications and feedings can also be helpful in dealing with gastrointestinal (GI) problems. Scheduling of meals prevents the stomach from becoming totally empty, thereby avoiding the acidic condition - which may mean to modify the timing, size, and content of the meals to decrease the amount of acid secreted for digestion - 4-6 small meals or more may be needed for awhile. A small meal prevents a large outpouring of digestive secretions and reduces stomach bulk, thus relieving symptoms resulting from displacement of other organs. To decrease nighttime distress, eating a small evening meal at least 3 hours before bedtime may be helpful and also to eat slowly to avoid more gastric secretions at one time. Scheduling of medications is very important. To schedule medications around mealttime can be a real plus to have food in the stomach. Taking antacids neutralize the gastric secretions - they taste better cold and keeping chewable antacids handy could be helpful too. You may also want to eat something small if you have to take medications at bedtime like a couple of crackers or a bite or two of pudding or something. But remember, some medications are not to be given with food, so ask your pharmacist specific questions about each medication so you will know if it needs or can be given with or without food.

Medications

- Antacids - represent an important adjunctive treatment for ulcers and gastroesophageal reflux disease (GERD). Antacids can be divided into two
• **Anticholinergics** - they inhibit gastrointestinal (GI) motility and prolong gastric emptying, thereby enhancing the effects of these drugs. They are used primarily to relieve peptic ulcer pain, but can be used to treat irritable and spastic bowel, other functional gastrointestinal (GI) disorders and neurogenic bowel disease. Common side effects include tachycardia (fast heart rate), nausea, vomiting, and visual disturbances (blurred or double vision). Their purpose is to inhibit the effects of the neurotransmitter acetylcholine at the junction between postganglionic nerve endings and effector organs – they block the action of acetylcholine on the vagus nerve which reduces gastric acid secretion and intestinal motility, the antispasmodics directly relax GI smooth muscle. They can be given before or with meals. Report any side effects to your Doctor, avoid central nervous system (CNS) depressants which may potentiate side effects, avoid overexertion in hot or humid weather because the drug decreases sweating, thereby causing body temperature to rise and possibly lead to heatstroke, wear sunglasses if experiencing photophobia, try to chew sugarless gum to relieve dry mouth, examples – Belladonna, Phenobarbital, Atropine, or Probanthine

• **Antidiarrheals** - by inhibiting peristalsis and prolonging gastric emptying, these drugs help to control acute or chronic diarrhea resulting from laxative abuse, malabsorption disorders, food or drug reactions, and infectious or inflammatory conditions. The three most commonly prescribed medications are Loperamide (Imodium), Diphenoxylate with Atropine (Lomotil), and Opium
- Antiemetics – given to prevent or control nausea and vomiting. The purpose of these drugs is to prevent and control vomiting by acting on the chemoreceptor trigger zone in the medulla oblongata (the brain control center), also to inhibit transmission along the neural pathways from the inner ear. These drugs prove most effective when given prophylactically. Side effects of this class of drugs include sedation and use cautiously if other central nervous system (CNS) depressants are also being given, may also cause extrapyramidal symptoms especially if taken for a long time, and also hypertension, tachycardia, or orthostatic hypotension, fever, sore throat, weakness, constipation and urinary retention. Antacids interfere with the effectiveness of these drugs and should be given separately (at least 2 hours) from other medications. Do not give with cough and cold remedies or sleeping pills, report chest pain, palpitations, or persistent headache, can cause dizziness or drowsiness, rise slowly due to the fact that the blood pressure may drop, chew sugarless gum to relieve dry mouth,
• Antiinflammatory – this group of drugs will help decrease inflammation especially in intestinal disorders like Crohn’s disease, irritable bowel syndrome or diverticulitis (Prednisone, Azulfidine). The purpose of these drugs are to reduce inflammation. Side effects are weight gain, aching joints and muscles, dizziness, fever, headache, hematuria, itching, jaundice, low back pain, photosensitivity, rash, unusual bleeding or bruising, anorexia, GI upset, and urine discoloration. Food, beverages and over the counter drugs do not influence the safety or effectiveness of this drug, take with food to prevent stomach upset, do not chew, break or crush the drug – may cause gastric irritation, may turn urine orange yellow color, also protect your skin from the sun’s direct rays - increases sensitivity to ultraviolet rays.

• Histamine Receptor Antagonists – these drugs are the treatment of choice for ulcer disorders this group include Tagamet, Zantac and Pepcid. They are used for prophylactic and short-term treatment of duodenal and gastric ulcers and to prevent gastrointestinal (GI) bleeding by helping to heal ulcers within 6-8 weeks. The purpose of this group of drugs is to inhibit the action of histamine at the parietal cell receptor sites. H2 receptor antagonists reduce gastric secretion of hydrochloric acid and reduce the volume of gastric juices and secretion of pepsin in the stomach. Side effects include central nervous system (CNS) effects, dizziness, confusion, nausea vomiting, muscle pain, skin rash, fever, diarrhea, or constipation. You will need to take the full course of treatment, report any signs of high fevers, confusion, fatigue and weakness, if taking Antacids – do not take within 1 hour of the drug prescribed, avoid spicy foods, hot drinks, caffeine, aspirin (to prevent gastrointestinal (GI) irritation), take with or immediately after a meal – food delays the absorption of the drug, thereby prolonging its effects.

• Laxatives – these drugs are designed to ease the passage of feces through the colon and rectum causing relief or preventing constipation. Monitor for abdominal cramps, nausea, vomiting, diarrhea, bowel movements (amount, consistency, and color, also degree of effort required to have a bowel movement), fluid intake to ensure adequate hydration to prevent dehydration (fever, tachycardia, hypotension, decreased urine output, poor skin turgor, and extreme thirst), and electrolyte and acid-base balance (weakness, diminished reflexes, twitching, vomiting, hypotension, and a rapid thready pulse). Look to the individual group of laxatives for side effects. Do not take laxatives if experiencing abdominal pain, nausea or vomiting, drink plenty of water 6-8 glasses a day, if after taking the laxative, does not have a bowel movement (but it is not necessary to have a bowel movement every day), and to maintain regular exercise, adequate fluid and fiber intake,
o Bulk-forming - this group of laxatives causes the bowel to absorb water and expand, increasing the bulk and fluid content of stool, also enhances peristalsis and evacuation. Examples are Barley malt extract, Metamucil, and Psyllium. Side effects include nausea, vomiting, or gastrointestinal (GI) stricture when taken dry and abdominal cramps. Laxative effect occurs within 12-24 hours but may be delayed up to 3 days, drink at least 8 hours with laxative, and it may decrease the appetite if taken before meals. This group of drugs is contraindicated in patients who are on sodium restricted diets, and in people with abdominal pain, nausea, vomiting, intestinal obstruction, ulceration, adhesions, or swallowing difficulties.

o Stool softeners - these laxatives reduce the surface tension of interfacing liquid bowel contents by increasing the fluid content of stool and softening the fecal mass. Example is Colace, or Pericolace. Side effects include - throat irritation, bitter taste in the mouth, abdominal cramps, and diarrhea. It is good for those who should not strain with defecation, onset is usually 24-48 hours, discontinue if severe cramps occur, also contraindicated if abdominal pain, nausea, vomiting, intestinal ulceration or obstruction.

o Hyperosmolar - this group of laxatives act in different ways. Glycerin draws water into the feces, increasing bulk and promoting peristalsis, lactulose produces an osmotic effect, which draws water into the colon resulting in bowel distention which stimulates peristalsis, the saline laxatives exert an osmotic effect in the small intestine, producing distention and enhancing peristalsis, also promoting secretion of cholecystokinin by the intestinal mucosa, which stimulates the intestinal motility and inhibits fluid and electrolyte absorption in the jejunum and ileum (small intestines). Examples are Glycerin, Lactulose, Magnesium or Sodium salts. Side effects are abdominal cramps, nausea, vomiting, dehydration, electrolyte, and acid-base imbalance. Drink plenty of water, hold oral or other drugs for least 2 hours after giving, will produce watery stool within 3-6 hours give so it does not interfere with other activities or sleep. Contraindicated also with abdominal cramping nausea, vomiting, intestinal obstruction or irritation, fecal impaction or rectal fissures.

o Lubricant - this group of laxatives create a barrier between the colonic wall and the fecal mass (stool), preventing absorption of fecal water by the colon and promoting its retention in the stool. Example is Mineral oil. Side effects: abdominal pain, nausea, vomiting or
Stimulating - these laxatives are thought to increase peristalsis by exerting a direct effect on intestinal smooth muscle, either by irritating the muscle or by stimulating the colonic intramural plexus, they also promote fluid and electrolyte accumulation in the colon and small intestine. Examples are Dulcolax, Cascara, Castor oil, and Senna. Side effects include - nausea, vomiting, abdominal cramps, diarrhea in high doses, breathing difficulty. Do not give oral drugs within 2 hours of laxatives, usually effective within 2-8 hours - again schedule so not to interfere with other activities or sleep. Contraindicated also with abdominal cramping, nausea, vomiting, intestinal obstruction or irritation, fecal impaction or rectal fissures

Medications that affect the gastrointestinal (GI) system

- Analgesics - examples Aspirin, Indocin, Pyridium, Butazolidin - side effects include nausea, vomiting, gastrointestinal (GI) distress, rectal bleeding, diarrhea, peptic ulcers
- Anti-infectives - examples: Sulfonamides, Achromycin - side effects include oral ulcerations, nausea, vomiting, diarrhea, abdominal pain, tooth discoloration, stomatitis
- Hypnotics - example Seconal (sleeping pill) - side effects include nausea, and vomiting
- Narcotics - examples - Codeine, Demerol, Morphine - side effects include nausea, vomiting, constipation, dry mouth

Diets for Children with Special Needs

*Foods your children like* - if children are having any type of problems with their diet whether it be, anorexia, weight loss, weight gain, difficulty swallowing, illness such as the flu, reflux, or intestinal problems, every attempt should be made to prepare foods that they like in order to get enough calories and nutrients in their daily diet, and as your child slowly begins to lose his oral skills, it becomes that much more important.

*Well-balanced meals* have to be a #1 priority in making so their diets include foods of the 4 basic food groups. Whether you as parents have to give your child 5-6 small meals in order for your child to get enough calories and nutrients for a day,
feed them or assist them with their meals (due to visual problems), or whatever the situation may be, it is so highly important to achieve the correct number of calories and nutrients for your child/children. Lab tests need to be evaluated periodically because, as Batten children continue to deteriorate, lab tests will also decrease as amounts of nutrition and proteins are eaten - for example - albumin measures the amount of protein in our bodies - when the lab values decrease for our Batten children, it is usually due to malnutrition and the need for gastrostomy/jejunostomy (GTube/JTube) will be necessary if that is your decision. When albumin levels are low then we need to be concerned about skin breakdown, swelling of the hands, feet and face, etc, because the body no longer can replace the necessary amounts of proteins.

**Characteristics seen in children who are tube fed**

- Hyperextension of the neck, accompanied by scapular adduction and shoulder girdle elevation affecting the feeding and respiratory abilities
- Respiratory difficulties - reflecting the incoordination of sucking and swallowing patterns with breathing
- Dysfunctional and disorganized sucking patterns - sucking rhythm is often lacking
- Swallowing disorders - as deterioration of the disease progresses, swallowing becomes increasingly difficult
- Hypersensitive responses to oral stimulation - seen in tube feeding children because they no longer have to use sensory input to the mouth
- Sensory defensive responses - to facial and oral stimulation becomes a primary difficulty and they become afraid to swallow
- Gastroesophageal reflux - when the lower end of the esophagus fails to contract enough to prevent reflux or backwash of stomach contents into the esophagus and pharynx
- Delayed gastric emptying - when food remains in the stomach and is not efficiently emptied into the small intestine, contributing to gastroesophageal reflux and to a reduction in appetite
- Gagging, retching and nausea - when the gastrointestinal system is under severe stress, the unproduction retching and gagging is extremely distressing to your child and strongly reduces the desire to eat
- Eating aversion - a result of sensorimotor, gastrointestinal and environmental responses possibly to reduce or prevent discomfort with the eating experience
- Failure to thrive - end result of physical, sensory, metabolic, or environmental eating difficulties
- Malignment of teeth - developmental abnormalities such as problems with muscle tone, persistence of certain oral reflexes and patterns of movements
• Plague can build up causing bacteria that can produce acid by fermenting sugars from the food we eat - this can demineralize or destroy the enamel of the tooth leading to tooth decay and that bacteria can cause toxins and enzymes that cause gingivitis and the breakdown of gum tissue, gums look swollen, and bleed easily - periodontitis is a condition where the membrane holding the tooth to the gum is broken down may develop and eventually the tooth may be lost
• Calcium is mineralized plaque - if the muscles around the mouth do not work well, if the tongue does not wipe the teeth, your child does not chew, then calculus can build up readily, the presence of calculus makes it harder to clean around the gum margin
• Cleaning the teeth twice a day is best but if you do it once, choose a time that is least chaotic - the best position for brushing someone's teeth is from behind and flossing is best done from the front. Use a soft bristled brush with a small head. Electric toothbrushes are not better cleaners but may be easier to use. Some children may need to have suction equipment handy to suction out the toothpaste and water is gagging is a problem
• Fluoride is not a problem any longer since most water is fluoridated

Children with mild sensorimotor impairment
• Low-tone in the trunk with poor postural stability for movement - low tone contributes to tension and poor coordination in the very parts of the body which are required for skilled feeding and speech movements
• Sensory processing difficulties - children who experience difficulties processing and integrating sensory information often show mild sensorimotor difficulties in feeding and speech
• Drooling during speech or fine motor activities - children who lack trunk stability and/or show incomplete head control frequently drool during activities requiring higher levels of physical control or concentration
• Low-tone in the cheeks and lips with poor or inefficient movement during chewing - may result in loss of saliva or food from the mouth during eating, drinking, and transfer of foods for chewing
• Low-tone in the tongue with poor or inefficient movement during eating and drinking - the tongue may lack the normal curved or grooved configuration which makes it easier to move food from the front to the back of the mouth
• Mild patterns of jaw thrusting or lip retraction - during excitement or challenging feeding activities your child may show a tendency toward a sudden downward movement of the jaw or a horizontal pull-back or retraction of the lips, making it more difficult to develop movements for feeding and speech
Sensory defensiveness of the body, face and mouth - your child may respond in a very defensive "fight-flight" fashion when sensory input to the face or mouth is given by another individual

Poor sensory discrimination or awareness of food in the mouth - children may be unaware of small pieces of food still in their mouths for hours after a meal which may cause coughing or choking

Poor attending skills during eating, which may result in coughing and choking episodes or increased drooling - children who experience difficulty in maintaining attention during eating may choose to get up from the table and run around with food still in their mouth. This may cause coughing or choking from accidentally falling

Delayed development of the ability to drink with the jaw quiet or stabilized - your child may experience some difficulty with long drinking sequences or may lose liquid while drinking

Delayed development of the ability to suck or swallow with an up-down tongue movement

Delayed development of the ability to use the tongue to move food easily from one side of the mouth to the other during chewing - children with difficulties usually do not like meats which require a high level of concentration and endurance for chewing

Delayed development of the ability to use the tongue to clean the outside of the mouth

Delayed or difficult development of the ability to use the mouth in creative ways to explore the sensory input of food - these activities are important for the later ability to voluntarily control the mouth for motor-planning activities

Delayed development of motor planning abilities of the mouth during feeding - your child normally learns to voluntarily use the tongue to remove food stuck on different places on the lips and to execute other more playful sensorimotor strategies such as blowing bubbles through a straw or spitting at another child

Other delayed speech difficulties may be delayed onset of babbling, articulation errors which are often related to delays or limitations in feeding patterns, articulation errors which are often related to poor sensorimotor awareness and discrimination during speech, poor separation of tongue and lip movement from jaw movement during speech, difficulty with the limitation of non-speech movements of the mouth, and motor planning disorders or developmental dyspraxia (a partial loss of the ability to perform skilled coordinated movements in motor sensory functions)

When is it time to change consistency of foods - when swallowing safety becomes an issue - if you hear your child doing more coughing, maybe difficulty with drooling
or kind of spitting with their food, there may be a complication with having the ability to swallow correctly. Many times parents do not realize their child is having a problem until they end up with aspiration pneumonia - due to a condition called silent aspiration. A speech pathologist can do modified swallowing studies to watch your child swallow and see if the potential is there to aspirate, if so, she may find that your child does ok with thickened liquids or foods with the consistency of puddings, applesauce, mashed potatoes, etc. Positioning becomes extremely important; the consistency of the food becomes important. If there is difficulty with chewing, we begin to mash and grind food, we may need to thicken fluids, we may need to watch how much is given at one time. There may be times of the day when skills seem more coordinated than other times. This is when a speech therapist or occupational therapist who has been trained in oral motor stimulation may become a very valuable ally. Some of the adjustment will be made almost unconsciously. However, as more coughing and choking occurs, as difficulty with fluid intake begins to affect the consistency of the bowels and urinary output, the decision for giving supplementary feedings has to be made.

The use of a special swallow study where the food can be given in a variety of consistencies and amounts and the swallow recorded on videotape (videoesophagram) may give some guidance in extending oral intake, showing the exact trouble areas and what happens when you change position or the food/liquid texture. Or the possibility is there that to give foods orally will no longer be possible due to the inability to swallow foods and alternative ways for nutrition will have to be pursued quickly, which would mean most likely a GTube/JTube (gastrostomy tube which would go directly into the stomach or a jejunostomy tube which goes directly into the small intestines). Sometimes an NG tube (nasogastric tube which also goes directly into the stomach but is less comfortable for long term use) is inserted for a few days until a gastrostomy or a jejunostomy tube (GT/JT) can be inserted.

*Weight loss or weight gain* - weight loss will probably be one of the first signs (if you weigh your child on a regular basis) that your child is not eating adequate calories and nutrients or you may see some signs of anorexia (refer to the section on anorexia) especially if your child is having difficulty swallowing. Your child most likely will be almost afraid to eat because of the choking aspect. Then you also have to think about dehydration, increased chances of illness due to decrease in immune systems, decreased urine output and probably decrease in the number of stools he is having on a daily or weekly basis due to the decrease in food consumption. Depending on the age of your child and his normal weight - losing 5-10 pounds may be quite significant in the health of your child. Most likely in this situation, weight gain will not be an issue because your child will not feel like eating so much to gain weight due to the swallowing difficulties.
When to make a decision - the decision may be made for you if a modified swallowing study is done and it is apparent that your child is aspirating constantly or develops aspiration pneumonia. Hopefully, you will be able to see little signs that your child is having increasing difficulty with swallowing and be able to make a decision before aspiration pneumonia develops. It is much better to have a GT/JT (gastrostomy or jejunostomy tubes) inserted when there are no other problems to deal with and do it prophylactically before it really becomes a major issue. The issues involved in tube feeding have been openly discussed in the press over the last years in relation to the maintenance of life. The ethical and moral issues will continue to be and quantity debated, as quality of life is perceived differently by individuals.

The maintenance of adequate hydration and nutrition in your child who is no longer capable of being able to take sustenance orally is a very personal issue and must be left to those who are an integral part of your child's life. When it involves a family member who has a "degenerative syndrome" and each inch yielded is gone for good, it is often very difficult to face squarely the fact that something needs to be done. There are two choices - either you interfere and begin some type of supplementary feeding via a tube or you do not interfere and continue as best you can with the assistance of a speech pathologist or nutritionist in helping you to modify your child's diet to maintain adequate food and fluids as long as possible. A supplemental feeding will definitely prolong life and this becomes a major question. There is no right or wrong, and it is important that families openly discuss with a wide variety of professionals the various options that are available. The decision to tube feed is a very difficult one - the realization that there is a loss of skills, perhaps the guilt that you can not manage some part of this, the prospect of a surgical procedure and pain, and all the other emotionally charged issues with family, friends, and acquaintances, including what it will do to getting people to help care for your child (tube feeding is a "nursing" skill) and what about taking care of my child in school. If you know that you are going to support with supplementary feedings, it is better to begin (and to have a feeding tube if that is part of your plan for your child) before there is real nutritional compromise and dehydration. Once you as parents have reached a decision, then it is important to make sure that the professionals involved in the care of your child are fully aware of what is to be done; and that it is available in a legally binding form with all those who may be in a position to respond. If the decision is made to tube feed, it becomes imperative to see this as only a part of the total care of your child, and for things to go well, and for the best state of well being to be achieved and maintained, all parts have to be working together. If you as parents decide not to place a feeding tube, which we have some parents who do - they feel that by this time in the degenerative process of Batten Disease, they no longer want to prolong the agony and the life of their
child. And also remember, that just because you have made the decision to not start a tube feeding by placing a tube and withholding nutrition, you are not withholding other forms of care, especially comfort. But, please also, always remember, that whatever your decision, you will be supported by BDSRA.

**How do we accomplish comfort, hydration, and a state of nutritional well-being?** First, we need to look at what is happening and meet whatever needs are there. As the degenerative process occurs, there are gradual losses of oral skills. The ability to handle food orally requires the coordination of hundreds of muscles being activated by the nervous system in a very complicated but coordinated way. In the normal development of a child, the ability to drink and chew well occurred in a very sequential way over a five-year period. Beginning with a suckling motion, your child advanced to sucking, munching, and then chewing. From a tongue that could only move back and forth your child graduated to moving the tongue from side to side, sweeping food around the mouth. From being able to master a cookie that would get soggy and soft, your child learned to chew a piece of steak. From having liquid dribble down his chin, your child learned to close his lips and propel the liquid down his throat, closing off the airway, so that he did not cough or choke.

Even with all our years of practice, there is not one among us that has not burped on a carbonated beverage and had it go up our nose. We were guilty of not closing the opening between our soft palate and the back of the pharynx. There is not one of us who has not started to swallow something and realized that it was going down the wrong way. We forgot to close the epiglottis over the windpipe. Mother nature thoughtfully provides us with a cough so that we immediately begin to get it up from our lungs. And there is not one of us that have not experienced the discomfort of acid indigestion, to the point that perhaps we were nauseated and even vomited. Acid coming out of the stomach and back up into the esophagus is called reflux. Something going down the windpipe (trachea) and into the lungs is called aspiration. And, as the ability to control lessens; these two things begin to occur.

**Purpose of tube feedings**
The primary purposes for the alternative means of tube feedings are: safety, prevention of pneumonia (usually aspiration pneumonia), administration of medication, maintenance of hydration, preserving energy levels, maintaining weight, adequate caloric consumption, and for those children who demonstrate a progressive loss of oral motor skills. The term, feeding tube, has a different meaning for every individual who is faced with the decision of whether or not to pursue this treatment. There are many reasons to have a gastrostomy/jejunostomy (GT/JT) tube placed. These may include difficulty swallowing medications, difficulty swallowing food and weight loss, which are the usual problems that bring
the issue up during a doctor’s visit. Again, this is a problem that many families are faced with. It is totally a personal and family decision to insert or not to insert a g-tube. **The most important issue here is that you will be supported in your decision.**

The mechanics of placing a tube feeding are very straightforward and can be found in dozens of publications. The secret of tube feeding successfully comes in seeing tube feeding in the same light as what would occur if your child were verbally able to tell you about his hunger or thirst at the time you are offering a feeding. There are days when all of us are hungry and days when our appetite is "off". When we are “sick” or if we have a little temperature, we tend not to want a “heavy” meal but go for lighter foods and plenty of liquids. If we are constipated, we certainly do not feel like having a four-course dinner, and if we are tense, or have physical pain, then eating may be the last thing we think about. Just because we are able to put something down a tube, does not allow us the privilege of ignoring all the things that go into making nourishment a pleasant experience. Developing an intuitive sense about the total state of well-being is as important as the calories consumed and even though our ultimate goal may be to add a few pounds, comfort is important.

Things to think about when developing a health care plan either at home or school for your child in determining what kind of tube would be best for your child with the assistance of your Physician and your nutritional team.

**List of items to consider include the following:**

- Size and type of the feeding device
- Type of portable pump
- Type of feeding your child is receiving (bolus/continuous drip, liquid formula-pureed/liquefied food from home)
- Activity level after feeding
- Positioning during and after feeding
- Determining the need to measure gastric residuals
- Determining the need to vent the feeding tube
- Patency of the feeding tube (nasogastric - NG, gastrostomy - GT, or jejunostomy - JT) and time frame for reinsertion should the tube fall out
- Monitoring concerns (example - vomiting, abdominal distention, or pain)
- Amount of food or drink your child can take by mouth
- Amount of oral stimulation during feeding, as ordered
- Medications and schedule for administering
- Specific guidelines for feeding administration during transport for your child
- Allergies - food, medications or things like latex alert
- Universal precautions (anticipating the tasks to be done, the risk involved, and the personal equipment needed will enhance protection of both the caregiver and your child)
- Manufacturer's specific directions

**What is a feeding tube and what kinds are there?**

A feeding tube is a rubber-like catheter that is inserted through the nose to the stomach or inserted directly into the stomach or small intestine. This bypasses the mouth and esophagus (food pipe) and puts fluids, medications and nutrition directly into the stomach or intestine for absorption by the body. It is called a nasogastric tube (NG) gastrostomy tube (GT) or a jejunostomy tube (JT). Approximately 6 inches of the tube extends from the opening in the abdomen and can be anchored to the abdomen with tape or a special anchoring system when not in use. Signs of possible need for nasogastric (NG), gastrostomy (GT), or jejunostomy (JT Tube include: frequent choking during meals, increasing time to complete meals with fatigue from difficulty chewing/swallowing, weight loss with decreased energy, inability to take necessary medication, one or more bouts of pneumonia caused by aspiration. Often the nasogastric tube (NG) can be used temporarily with the placement of the gastrostomy tube seen as the long-term solution. Again individual decisions and the unique circumstances of your particular child make this decision a very "special" one.

**Nasogastric tube (NG)** - a rubber or plastic tube inserted through the nostril, down into the throat and into the stomach, it is used to give liquids, medications, and feedings when a person is unable to take these by mouth, some children will have a tube inserted for each feeding, several weeks or just as a temporary means until a gastrostomy or jejunostomy tube can be scheduled and inserted, placement needs to be checked before each feeding or giving medications, usually used in short term use, and takes only 5 minutes to insert nasogastric tubes (NG) - to prevent sore throat and mouth sores due to prolonged placement of tube, give good oral care with brushing of teeth, and using mouthwash, lemon and glycerine swabs. (Dry mucous membranes may indicate dehydration)

Check for proper placement of the nasogastric feeding tube because small bore tubing’s may slide into the trachea without causing immediate symptoms of respiratory distress, such as coughing, gagging, choking, gasping or cyanosis. To ensure that the feeding tube has not entered the larynx, ask your child to speak.

Another thing to think about if and when your child receives a feeding tube of any kind, is to develop a form for home health care nurses, aides, companions, school aides, teachers, nurses, or anyone who may come in contact with your child and at some point be a part of your child's care. It can be modified to fit your needs.
General Information Sheet

Children with Nasogastric (NG), Gastrostomy (GT) or Jejunostomy (JT) Tubes

Dear (teacher, bus driver, lunch aide, school nurse, home health nurse, home health aide):

____________________________ (child's name) has a condition that requires a different method of eating which may be a nasogastric (NG), gastrostomy (GT) or jejunostomy (JT) tube. This is a simple and safe way of giving food, medications, and fluids directly into the stomach and/or intestines because my child is unable to eat or take medicines by mouth.

A nasogastric tube (NG) is placed through the nose to the stomach and is taped in place on the nose and/or cheek. A gastrostomy or a jejunostomy tube is a surgical opening into the stomach or intestines. A flexible rubber tube is put into the surgical opening. It is held in place from the inside of the stomach as well as from the outside of the abdomen at all times. The tube is clamped or capped between feedings to prevent leakage. This tube does not normally cause my child discomfort and is covered by his clothing.

My child may receive feedings or medication through this tube as needed during the day while at home, school day in a classroom, the lunchroom, or the health office child or where ever we may be. Unless my child has a condition that otherwise would interfere with participation in physical education or other activities, there is no reason why my child can not participate fully. Special consideration may be needed, however, for field trips or other activities during which my child may not be able to receive a regularly scheduled feeding.

The following staff members (at home or at school) have been trained to deal with any problems that may arise with my child:

__________________________________________

__________________________________________

For more information about my child and his/her special needs about Nasogastric (NG), Gastrostomy (GT), or Jejunostomy (JT) tubes or any other needs he/she may have, consult the home health nurse, the school nurse or parents.

Sincerely,

__________________________________________

Parent/Parents/Guardian
If he cannot talk, the tube is in the larynx and should be removed immediately because misplacement can cause instillation of fluid into the respiratory system. Also pull back gently when checking for tube placement because negative pressure can cause a small bore tube to collapse. If you meet any resistance during aspiration, stop the procedure, because resistance may result simply from the tube lying against the stomach wall. Reposition or withdraw the tube a few inches, re-advance the tube and try to aspirate again. Look for a coiled tube in mouth to also check for placement.

**Placement Of A Nasogastric Tube (NG), Listening For Bowel Sounds With A Stethoscope**

**Gastrostomy Tube** - For a gastrostomy/jejunostomy (GT/JT), your child will be slightly sedated (conscious sedation, most likely) for the procedure. It usually takes 15-30 minutes from start to finish. You will be given instructions for home care after the procedure. Sometimes a percutaneous endoscopic gastrostomy tube (PEG) or foley (also a catheter that can be used to insert into the bladder for incontinence) is inserted first until the stomach gets used to the feedings and after healing, a button will be placed (usually 8-12 weeks). If your child is young when he receives his first gastrostomy tube, it may need changed to meet the growing needs of your child.

A gastrostomy tube is a surgical opening with a tube inserted directly into the stomach through the surface of the abdomen, usually needs to be changed every 6-9 months, absence of discomfort as with the nasogastric tube, easily hidden under clothing, tubes can be changed at home, the disadvantage is that initially it will have to be inserted in a hospital or same day surgery procedure and more costly, used for the long term, and takes 15-30 minutes to insert, there will be approximately 6 inches outside of the abdomen unless a skin-level tube is placed, which is a “T” shaped plastic device is held in place by a mushroom-shaped dome or fluid-filled balloon inside the stomach. The device remains in place at all times and is capped by an attached safety plug between feedings. In addition, the dome has an
antireflux valve to further prevent leakage of stomach contents. A feeding is administered by inserting a small tube into the device. When the feeding is complete, the tube is removed and the safety plug closed. The gastrostomy device may be used to administer food, fluids, and/or medications directly into the stomach. This method is used to bypass the usual route of feeding by mouth when there is an obstruction of the esophagus, swallowing is impaired and your child is at risk for choking/aspiration, or when your child has difficulty taking enough food by mouth to maintain adequate nutrition. Your child may receive a gastrostomy feeding by either bolus or continuous or slow-drip method. A bolus is a specific amount of feeding given at one time (over 20-30 minutes). A slow-drip or continuous, feeding is given slowly over a number of hours. The gastrostomy device also may be used to drain abdominal contents or to release air or gas when venting is required. This is done by inserting a special adapter or tube to open the antireflux valve.

This shows the placement of a gastrostomy tube (GT) and a jejunostomy tube (JT) in the picture on the right in regards to the stomach and small intestine. The picture on the right shows where both tubes would be placed if a child had them both simultaneously.

**Jejunostomy tube** - a jejunostomy is a surgical opening into the jejunum (the small intestine between the duodenum and the ileum) through the surface of the abdomen. The jejunostomy tube (JT) is a flexible, rubber or latex catheter that is
held in place on the abdominal wall with tape or is fed through the gastrostomy site (GT) through the intestine down to the jejunum and taped to the gastrointestinal tube (GT). The tube remains in the small intestine at all times and must not move in or out. The jejunostomy tube (JT) causes no discomfort when in place. The jejunostomy tube (JT) may be used to administer food and fluids directly into the jejunum. This method is used to bypass the usual route of feeding by mouth and stomach when there is blockage in the upper esophagus and/or stomach, your child is at risk for aspiration and gastroesophageal reflux disease, your child has difficulty taking enough food by mouth or gastrostomy feedings to maintain adequate nutrition, your child has intestinal pseudo-obstruction or short bowel syndrome, your child has had major stomach surgery or a problem with stomach emptying, or your child has a depressed gag reflex. Your child will receive jejunal feedings by a continuous drip method slowly over a period of hours. The continuous

This picture shows again the placement of a gastrostomy tube (GT) at skin level most likely a MIC-KEY tube, how it shows the balloon inside the stomach and the adaptable ports.
drip method is preferred over the bolus method to prevent giving a large volume of feeding over a short period of time. In addition to jejunostomy (JT), gastrostomy (GT) skin-level feeding devices and nasojejunal tubes are placed surgically to provide direct jejunal feedings. Factors affecting selection of these devices are your child’s age, the size of the device, and whether your child is allergic to the material of the device. Some children may have a gastrostomy/jejunostomy (GT/JT) tube in the same stoma (opening). There may be two distinctly separate tubes or one tube with several identified ports. Some children may have a gastrostomy device and a jejunostomy device and will have two distinct abdominal stoma sites. In most cases, the gastrostomy device will be vented for comfort, and in many situations, the venting is continuous. The gastrojejunal tube is a single tube with three limbs, including a jejunal feeding port (the opening of the tubing into the jejunum), a gastric port (the opening of the tubing into the stomach), and a balloon inflation limb (holds the tube in place).

This picture also shows the placement of a gastrostomy and a jejunostomy tube and the sphincters in the stomach. The upper sphincter is called the LES (lower esophageal sphincter) and the lower sphincter is called the pyloric sphincter.
There is one abdominal stoma (gastrostomy), and the device passes through the gastrostomy and stomach and into the jejunum. Other children may have a nasogastric (NG) tube or other small tube inserted through the gastrostomy (GT) opening alongside the gastrostomy and into the jejunum.

However, the gastrostomy/jejunostomy tube (GT/JT) offers some advantages to the continued use of the nasogastric tube (NG) - both esthetically and medically. Because we know that with the degenerative syndrome, tolerance of general anesthetics are decreased and that often there is an acceleration of loss under this type of stressful occurrence, many tubes are being done using the Percutaneous Endoscopic Gastrostomy (PEG tube) method. Following are different forms of tubes available:

- The MIC-KEY Skin Level Gastrostomy has safety plug, proximal anti-reflux valve, medication port and an external extension set that locks preventing accidental disconnection. It sits at 90 degrees to the skin.
- The Ross Abbott Stomate Low Profile Gastrostomy has a safety plug, anti-reflux valve, Y-port connector with right angle adapter.

These are pictures of gastrostomy (GT) and jejunostomy (JT) tube placements in the stomach. It also shows different gastrostomy and jejunostomy tubes.

These are different GT's and JT's and specific ports

- The MIC-KEY Skin Level Gastrostomy has safety plug, proximal anti-reflux valve, medication port and an external extension set that locks preventing accidental disconnection. It sits at 90 degrees to the skin.
- The Ross Abbott Stomate Low Profile Gastrostomy has a safety plug, anti-reflux valve, Y-port connector with right angle adapter.
- The Bard Button has safety plug, anti-reflux valve and venting (decompression) via a special additional venting tube
- The Corpak Low-Profile Gastrostomy Device (LPGD) has safety plug, anti-reflux valve and additional venting tubing
- A Foley tube which has a balloon in it where you inset water through a port into a balloon inside the stomach to prevent it from coming out

PEG tube (percutaneous endoscopic gastrostomy), which is put down through the mouth with the assistance of an endoscopy tube and pulled out through a small incision in the stomach, there is a plate inside the stomach which prevents it from coming out and a plate on the outside (some of them) as a device for security

For all tube feeding appliances

- Have 2 sets of tubing available to be cost effective
- Give water as ordered to maintain adequate hydration
- To decrease oral discomfort – brush teeth and give good oral care
- Clean nostrils, use Vaseline, watch for signs of skin breakdown
- Medications except enteric coated can be given per jejunostomy tube (JTube)
- Encourage ambulation to aid in absorption of the feeding, promote nutrient anabolic effects and foster a state of well-being
- Monitor intake and output – sudden change in weight indicates altered hydration and requires adjustment in feedings
- Check for tube obstruction and esophageal erosion, call if suspected
- Monitor hemoglobin if left upper abdominal pain is reported – rate of feeding may be too high or inadequate absorption
- Monitor tolerance by assessing diarrhea, cramping, nausea – tube feeding rate may be too fast
- Provide perineal care if diarrhea
- Check urine for glucose (sugar)
- Assess strep level – may experience a pseudo diabetic state
- Stress decreases lactose needed for lactose hydrolysis in the gastrointestinal tract (GI) – would order lactose free diet – if increase in glucose and increase of urine – would indicate an excessive carbohydrate levels
- To maintain a nitrogen balance level and promote healing and weight gain in children, who can not tolerate oral or gastrostomy feedings, continuous drip feedings are preferable because it ensures a reliable, stable blood sugar concentration. Tubing’s at risk should be changed on regular basis. Store at room temperature to discourage bacteria growth.
What Kind Of Formula
You will probably be working with a nutritionist to determine the calories that will be needed for your child. Calculation needs to be made on height and weight combined with the level of activity - not on age. A normally active nine years old may require over two thousand calories a day. Yet a child the same size that is confined to bed may only require a thousand calories. Some allowance must be made for an increase in tone, or if there is a lot of spasm or perspiration, adjust both calories and fluid amount.

Types of feedings available
Blended food - home made food which has been blended, seldom used as it is troublesome to prepare and there is a higher chance of causing blockage of the tube and also vomiting of your child, but certainly is an option. If your child is still permitted solid food, mix in a blender, the residue and fiber of a blended normal diet promotes bowel function and most children prefer it to a liquid formula.

Commercial food - can provide complete nutrition for the day, ready made liquid or powder form (cheaper form), additives are available like additional fiber, soy products, etc. There are many different brand names that are available today and you can get them through your health care provider. Some children do not require feedings at school but formulas are used to supplement their oral intake of food and fluids.

In the beginning, you may just want to use tube feeding as a supplement to the oral intake. So that if certain foods are still enjoyed, these can be fed orally - perhaps your child really enjoys ice cream or pudding, or is a mashed up spaghetti fan, then let him have what he can handle and make up the liquids and difference with tube feeding. You may consider making your own tube feeding and certainly this can be done. However, you risk a "lump" that can clog up the tube, you have to be careful to meet all the nutritional requirements, and you are adding additional demands to your time, which may be at a premium.

Very often, there has been a weight loss and some slight dehydration before the procedure is done, and with good intentions, those involved in your child's care will be very anxious to get things up to the maximum as quickly as possible. TAKE YOUR TIME!!! Advance slowly - let your child set the pace. Stomachs are touchy after being poked, particularly when they have not had much in them and when getting things in them has been rather stressful. Clear liquids, beginning with water and then advancing to diluted juices (cranberry or apple - stay away from orange juice because of the pulp) or punch combinations - hydration comes first, then calories. And usually with hydration comes an immediate weight gain, a change
in urinary output and sometimes a nice change in the consistency of bowel movements from hard and lumpy to soft, firm consistency. From juices begin at quarter to half to three quarter strength, then you can move to a full-strength formula. Recommended are those containing fiber if there are no dietary restrictions and again start slow with one quarter to one half and then three quarter strength formula. Some families alternate a fiber formula one day and a formula with no fiber the next day, or may use fiber 2-3/week and plain the other days.

**Medications Through A feeding tube**

In addition to using the tube for feedings, you will be using the tube to give medications. Medications may be administered through a feeding tube utilizing the bolus feeding method. The Physician or pharmacist should be asked for liquid medication where possible versus pills or capsules. Formula, juice or milk may be used if the medication does not dissolve in water, but most medications do fine dissolving in water, especially warm water. Even highly viscous liquids (sticky, gummy, gelatinous liquid like CO-Q10) should be diluted in water prior to administration. Always remember to flush the tube after inserting medications. Ask your Physician or pharmacist as to a certain medication being able to be crushed or dissolved or the compatibility with all of the medications you are dissolving at one time. Also giving bulk laxatives like Metamucil may present a problem. A few hints may help. DO NOT MIX THE MEDICATION INTO THE FEEDING. If there is a problem, then there is no way of knowing how much has been given and how much is left. MAKE SURE THAT TABLETS ARE CRUSHED WELL AND DISSOLVED IF AT ALL POSSIBLE. Often soaking the medications in water will soften the tablet so that it can be stirred into solution. Medications that are known for stopping or clogging up tubes include Tegretol and your bulk increasers such as Metamucil. Tegretol can be gotten as a liquid but has a short shelf life (check with your pharmacist). Any of the fiber additives need to be given immediately with plenty of rinse water afterward - in fact - you may want to draw these up in a syringe and push them slowly - with another syringe ready to follow with some more water to flush the tube and make sure that it all gets into the stomach.

Some medications may be irritating to the stomach, so you will want to given them diluted down or after a part or all of the feeding. Some antibiotics must be given on an empty stomach, so make sure that you check with your Doctor or pharmacist. And of course, some medications should not be given together. If you are using an oil, you will find that it settles out if mixed with formula, and if given through a syringe down the tube, it will leave a slippery residue. Oil, if aspirated into the lungs, causes the most difficult pneumonia to treat, so giving it needs to be done carefully.
Make sure that the medication schedule is complimentary to your feeding schedule. If there is difficulty with spasms or increased tone, then perhaps medication can be given 30 minutes prior to a meal so that your child is relaxed. Positioning is important. The head should be elevated (either sitting in a chair or with the head of the bed raised). If you do not have a hospital bed, roll up a blanket and stick it between the box spring and the mattress. This will give a nice slant to the mattress, and since having the head slightly elevated also helps to control gastrointestinal reflux, this can actually be in place 24 hours a day. Sitting in a chair (either straight up or reclined slightly) with the knees and hips bent, may help lessen some of the tone and control some of the clonus (rhythmic movement of a body part). Side lying, with legs bent and propped with pillows (particularly on the right side) is a good position. Some tolerate being fed in a prone position (lying on their tummies) – but it is important that your child be able to move their head from side to side. The one position that needs to be watched is for your child to lie on his back or being reclined to an almost flat position. If there is some gagging or vomiting in this position, it is very difficult to get the secretions up and out, and you risk having fluid getting back into the lungs causing aspiration pneumonia. If you use this position, make sure that someone is close by.

Different methods of tube feedings

- **Gravity** - using a bag - place a stethoscope over the stomach, just to the left of center, kink the feeding tube with your thumb and forefinger to prevent the stomach contents from flowing out, remove the cap and connect a syringe with plunger attached with 5-10c’s of air in it, unkink your tube, quickly insert the air while listening with the stethoscope, you should hear a pop sound which represents air entering the stomach, do not start the feeding if you do not hear the air rush into the stomach, add your formula to the bag and fill the tubing with formula before connecting it to the feeding tube, unclamp the tube, adjust the flow rate at the prescribed rate - usually 15-60 minutes unless otherwise directed, you may hold your child, sit your child in a chair, or place your child on his side in bed with his head elevated while the feeding is infusing, make so you rinse the feeding tube after the feeding is completed - usually 20-50cc’s or otherwise directed. Bolus feedings (food is poured into the tube slowly versus a machine), it allows for rapid feeding of formula over a relatively short period of time, can be instilled using a bulbed or piston syringe or through the use of gravity flow, and still get the required amounts of nutrition and fluids in for that day

- **Continuous feeding** - you will want to check placement as above before starting the feeding, fill your bag and tubing with formula before connecting it to the feeding tube, put the tubing with the cassette into the machine (pump), make so it is set at the proper rate and start your feeding. The
Bolus feedings – you will want to check for placement and residual as with
gravity feedings, you may also insert the plunger and gently push the formula
in slowly, make sure you pinch the tubing off before inserting another
syringe to avoid excess air getting into the stomach, make sure you rinse the
tube with water when the formula is finished. Never force fluids through a
tube. Infuse the feeding as slowly as you can to prevent abdominal
cramping, nausea, vomiting, gastric distention or diarrhea - if the formula is
not infused slowly they are at a higher risk of aspiration and the
complications of pneumonia. This method allows more freedom in that you
can give feedings anywhere, which is nice when you want to leave the house.
Medications are given by this method.

Guidelines for giving a tube feeding – make sure you wash your hands with soap
and water before feeding your child. Prior to each feeding, the tube must be
checked for patency (being free to move) of fluids through the tube and the
gastric contents measured (checking for residual) - the Doctor will tell you the
level he feels is appropriate for your child - but as a rule under 150cc's is
acceptable, if over that amount, withhold the feeding until the level goes down, you
must be certain to reinstall the withdrawn gastric (stomach fluid) contents, to
prevent loss of nutrients and electrolytes, and to check the markings (cm) on the
tube to be sure it has not moved. Formula should be given at room temperature (too
hot or cold could make your child uncomfortable), unused formula or blenderized
foods should be refrigerated and warmed to room temperature before feeding at
the next time, but never heat the solution as this could increase the growth of
bacteria. Your child should be fed in an upright position (at least 30 degrees) and
remain there for 30-60 minutes following the feeding to minimize the possibility of
aspiration and its complications.
The general guidelines for giving a feeding whether it is with a nasogastric (NG), gastrostomy (GT) or jejunostomy (JT) tube or whether it is the bolus, gravity or continuous method of feeding is basically the same.

- Do a health care assessment on your child daily or more frequent when needed. Any child with a feeding tube must receive a specific care guidelines and those individuals to assist with the care of that child need to have general training that covers the specific health care needs, potential problems and how to implement and establish an emergency plan.
- Allow your child to help as much as he is able to do, but not to the point of frustration and added stress.
- Be alert to any changes in your child's tolerance to the feedings, example - nausea, vomiting, abdominal cramping, diarrhea, too quick or too cold formula.
- Report to family any changes in child's usual patterns.
- If medications are prescribed, give before or after feedings according to your child's specific health care guidelines.
- Be sure to check the rate and flow periodically and adjust if needed, check residuals as ordered.
- Make sure you check for expiration dates of the formula (discard if one is not seen on the can or bottle), discard once tube feeding is opened after 24 hours, make so you date and time when you opened a new can or bottle of formula.

The actual procedure is as follows:

- Wash your hands and the hands of your child if he/she will be helping you to decrease chances of infection.
- Provide privacy.
- Sit down or in a semi-fowlers position (approximately 90 degree angle) to aid and promote in digestion and to help prevent esophageal reflux of the feeding solution.
- Insert a syringe to the clamped tube to reduce risk of introducing air into your child's gastrointestinal tract (GI) - causing distention and discomfort.
- Check the feeding tube for placement by injecting 5-10 cc's of air into the stomach and listen with a stethoscope for a whoosing sound - you will be listening just to the left of center under the sternum and ribs, also aspirate stomach contents and note color and amount, if residual are elevated, wait 30-45 minutes, check the residual again before starting the feeding.
- Once the tube feeding starts to infuse, tilt the syringe to allow for air bubbles to escape, always mix solutions well before starting your feeding to prevent your solution from separating, lower or raise the tubing to increase or decrease the rate of gravity flow - normal is approximately 6 inches.
Add more formula before the syringe or bag is completely empty to prevent air from entering the gastrointestinal system (GI) and causing abdominal bloating and or distention, never force a feeding through the tube.

If giving a bolus feeding, it will take 10-30 minutes (nasogastric feedings are usually given with the bolus method), if continuous, spread total amount of formula over the given number of hours to be infused, make sure the nasogastric tube (NG) is not pulling on the nose or causing discomfort.

After the feeding is completed, please make sure you flush the tubing with 30-50 cc's of water to prevent clogging or obstruction of the tube (to maintain patency by removing excess sticky formula to develop on the sides of the tube walls).

Clamp the tube, then remove the syringe to decrease the amount of air introduced into the gastrointestinal system (GI), to prevent leakage and contamination of the tube.

Instruct your child to remain in a sitting position for at least 30 minutes to prevent leakage and gastric reflux into the esophagus and to enhance the normal digestive process.

Rinse all reusable equipment with warm water, dry, store in convenient place for next feeding.

Monitor intake and output to detect fluid and electrolytes imbalances which can be easily be corrected if caught quickly.

Wash stoma daily and dry thoroughly.

If excessive skin irritation, rinse with 1/2 hydrogen peroxide and 1/2 saline, pat dry, apply ointment to prevent further skin breakdown.

Apply drain sponges around tube and tape with paper tape to again avoid skin breakdown.

Coil tube once and lay on top of dressing which reduces tension on suture line and helps prevent separation, also helping to prevent an accidentally pulled out tube.

Cover with larger bandages (ABD's) or montgomery straps (a large piece of tape on either side on the tube that has holes in it that are free and then you can take gauze or a string of some kind and tie the two sides together to reduce irritation of the skin, also helps to protect the tube if your child has a tendency to pull at the tube.

Listen for bowel sounds to check for abdominal distention by measuring abdominal girth.

If your child complains of thirst, provide in between feedings of extra water to maintain hydration. Provide oral care frequently.
The feeding schedule is probably one of the hardest things to come up with and will need to be adjusted from time to time to meet particular situations and needs. Rule of thumb: do what you would do if your child was a "normal" child. Right after surgery, you are going to do frequent small feedings, but within a matter of days you will be able to increase the amounts given at one time and begin toward a schedule of "meals" with some "snacks" in between. So that the goal may be to get in four cans; and you will work toward a schedule of four feedings - breakfast, lunch, dinner and bedtime. Some Doctors have the habit of ordering too much formula. If your child has any problems with vomiting - cut down the prescribed amount of formula in half and then slowly build back up to the prescribed amount as long as your child is tolerating it. In between feedings, you may give water or juice with medications or just extra free water. Each feeding will be about 10 ounces (8 of formula and 2 of water). To meet daily nutritional requirements you may be asked to crush up a one a day vitamin and give it in between a meal. If the protein is low, you might add a bit of powdered milk. If the calories are a little low you can add karo syrup, sugar or a tasteless sugar called polyose. There is always a need for "free" water/juices - more if the days are hot or if there is a lot of perspiring.

Feedings seem to go best when your child is relaxed, so if there is difficulty during the day, a recommendation may be made to feed slowly through the night. The big consideration is the chance of vomiting and not being heard. However, with careful positioning, and a monitoring system, sometimes it needs to be used. Stick with a schedule that meets your needs as well as your child's needs. Combine the feeding with some music, or a story, or perhaps some patting or touching. A normal meal usually lasts about 20 minutes (when using the gravity method), so this would be a minimum if you were pouring formula directly through a syringe and down the tube (a gravity feeding). Since this will be when the phone rings, or someone comes to the door, or something boils over on the stove, you will find that a feeding bag or pump, even though they will be slower, frees your hands (and may be better tolerated). You also need to have the formula at room temperature, since it is going directly into the stomach, rather than down the esophagus, which takes some of the chill off. Most insurance plans and medical assistance will pay for a pump and we recommend that you put in a request for one when your date for surgery is set. You may not need it in the beginning, but you will want it at some point. Just being able to put up a container of clear liquids on a day when things are not going well, or there is a fever, and being able to run it slowly over a 24 hour period, may prevent a hospitalization for dehydration.

We have talked a little bit about controlling gastrointestinal reflux with positioning and need to expand on this since an aspirational pneumonia is one of the most common problems. If you see or hear a gag, wretch, or there is formula coming out of your child's mouth, STOP THE FEEDING IMMEDIATELY. Allow some time for
things to calm down, and then resume. If it happens again, STOP. Note how much of the feeding is left and during the remainder of the day, try to make it up - if not the calories, then at least the amount of fluids by giving additional water a few ounces at a time. Try to intervene and stop the feeding before vomiting occurs since vomiting seems to become easier to do, the more it happens. If there is a lot of congestion or if there is some sinus congestion, the secretions may accumulate in the back of the throat and cause gagging. Think of yourself in the morning or when you have a cold, and try to think how you might get rid of it. Maybe a little chest percussion (PT) will help loosen things up before you start. Or maybe, the first feeding needs to be slower, or smaller. Each individual is different and with a little detective work you can often figure out what is making things worse.

If at all possible, keep a record of what you are doing and the reaction. Patterns may emerge that will be extremely useful to judge when changes need to be made. Total intake can be examined to see where caloric and fluid changes can be done. And you need to remember that things will need to be altered as time goes on. Do not be afraid to take the lead in requesting pumps and medication. You are there, you know your child, and it is far more important that what goes down, then to pour things down, only to have them come up.

Just one more thing about scheduling and amounts. If you are going from one amount to a higher one, do it gradually. Try adding an ounce or two to one of the feedings; if all goes well, to the next and so on. If you run into trouble, do the original amount for several feedings and then try again. It may take you a week to go from 32 ounces to 40 ounces; you may find that you can increase volume before you can increase calories. We often recommend that you begin by doing a day or two of increased volume before you even switch to increased volume.

All of this seems complicated, but just keep in mind that you are dealing with an individual and none of us are the same. You are first and foremost interested in maintaining hydration and comfort and then the calories. You do your best knowing what you know about your child and you look for people who will work with you.

Suggestions for environmental control

- Keep your dining room or the room where your child is pleasant, reduce glare of lights, play soft and relaxing music, be organized, meal time is a period of socializing and building trust, use a positive approach while feeding your child, keep distraction and noise to a minimum, be sensitive to any non-verbal communication that occurs during a meal
- Basic rules for positioning - hips flexed and firmly back in chair, hips, knees and ankles at 90 degree angles, feet supported by chair or footrest, if in a seat, body symmetrical and straight, shoulders and arms forward - elbows
Basic rules for feeding – place a small amount of food on a spoon, place food at the end of the spoon, do not overfill. When putting the spoon in your child’s mouth, keep the spoon in a horizontal position, place in the middle of his mouth - then move to the side, encourage your child to close his lips around the spoon, never scrape food off with the teeth, allow your child time to chew and swallow (may take 45-60 minutes for a meal)

Manual physical assistance - oral stimulation - improves applying deep pressure with a variety of textured objects in and around the mouth. This deep pressure applied directly over the muscles used in eating may also help normalize muscles and jaw control (physically assisting the child’s mouth to close): controlling from behind - place your thumb on his jaw joint to provide a point of control and to inhibit a jaw and/or tongue thrust, place your index fingers on his chin to assist him in jaw and lip usage, place your long finger under the chin to prevent jaw and tongue thrusting - be careful not to choke or gag your child; controlling from the front - place your thumb on his chin to assist him in jaw and lip usage, place your index finger under the chin to prevent jaw and tongue thrusting

Equipment
Pumps and tubings come in pretty standard sizes and shapes, with some variation in sophistication. There are several on the market that do not require a pole (Ross Companion and Ross II) and which are very portable. This may be important if you still enjoy getting out or your child is still involved in a program, since these can be hung across the back of the wheelchair and feedings can be done while on the bus or walking through a mall. Work with your health care provider and your Doctor to use equipment that will be suitable for the needs of your child. Pumps have alarms on them, become familiar with their meanings and how to respond to them.

Care Of A Feeding Tube (Gastrotomy or Jejunostomy Tube - (GT/JT)) - each Doctor probably has there own specific guidelines for care of the tube. What is listed below is just one possible method of treatment.

You will be taught how to care for a gastrostomy/jejunostomy (GT/JT) tube while in the hospital or if done as an outpatient - before you go home.

- Dressing changes should be done every 1-2 days (every day initially) and include cleansing around the tube with hydrogen peroxide, a cotton-tipped applicator or a cotton ball works well to remove any crusting or drainage, they need to be clean but not sterile, the hydrogen peroxide may be diluted up to one-half strength with water - just make sure that a fresh swab is
- Showers are recommended over tub baths to prevent infection at the site, cover the dressing with a double layer of plastic wrap and tape the edges, removing the plastic wrap and change the dressing after the shower
- Activities - there should not be any restrictions
- Feeding - use water to flush the tube after each feeding, use liquid forms of medications if possible, ask your Doctor or nurse to provide you with specific information about feedings or medications
- It does not hurt to lie on the tube after the initial healing takes place – in fact, you need to insist that some time be spent on lying prone, if at all physically possible
- Going swimming, getting in a hot tub, taking a shower and/or getting in the bath tub is ok with a gastrostomy/jejunostomy tube (GT/JT) tube

**Gastrostomy/Jejunostomy (GT/JT) Tube Site Care**
- Cleaning - the first week needs special attention to the dressing changes - the incision will heal, some physicians will allow you to not have a dressing around the tube, but it will still need to be cleaned daily
- Leakage - the tube may pull away from the abdominal wall resulting in leakage around the insertion site; it may also occur if the incision enlarges in your child with poor nutrition, excessive tension on the tube may cause the tube to be pulled out prematurely. Make sure that the anti reflux valve is not sticking or is broken - it may need replaced. The tube is marked (in cm) where it should be level with the incision and should be checked daily to make sure it has not moved, if it does, call your Doctor and he will advise you how to return it to its original position - some parents have said that they had more problems with leakage when a foley was used for the gastrostomy/jejunostomy (GT/JT) tube in children with Batten Disease
- Wound infection - purulent drainage (pus) around the tube is commonly seen but does not always represent a true infection. It may be the body's reaction to a foreign object, such as swelling, tenderness, redness, or drainage of pus around the tube - if an increase in redness occurs, apply an over the counter preparation such as Bacitracin and or Cortisone cream - if the redness continues to extend or there is a foul smelling thick drainage (pus), call your Doctor, clean the site more frequently for a few days, do not
- Skin irritation or excoriation (abrasion of the outer skin by trauma, chemicals, burns) is seen at the incision site apply a skin barrier for protection via a prescription.
- If the tube falls out completely - call your Doctor immediately. The tube usually can be easily replaced if it is done within 24 hours from the time it fell out. Waiting longer could mean that a separate new tube may have to be placed.
- Secretions from the stomach irritating the skin - apply an antacid such as Amphojel or Gelusil to prevent redness.
- A lot of movement of the tube, the tube has been pulled out, some bleeding - continue to treat with hydrogen peroxide but increase the number of times per day, use the ointments suggested.
- Pieces of tissue rising above the skin around the tube (granulation) - touch gently with silver nitrate sticks (have the home health nurse or your Doctor show you how), this cauterizes the tissue, it will turn black and then peel off, and eventually the opening should heal flat like a belly-button.
- The tube being pulled in by the tugging of the stomach (peristalsis) - pull the tube out to its proper position and secure by wrapping the tube with a piece of tape or slitting a nipple and taping it onto the tube so that the rounded end will pull against the skin.
- The tube can not be pulled back to the mark (at the cm mark) and there may be cramps, discomfort, etc. - the tube has probably worked its way into the small intestine, deflate the balloon (if one) using a syringe (unclamp the tube), pull the tube back to its correct position and then re-inflate the balloon - make so you take a magic marker and make a small mark on the tube or look at the number of centimeters as seen at the skin level when you get home from the hospital, check it daily for the correct position.
- Hissing or flow of liquid around the tube - hissing usually indicates a build up of gas, unclamp the tube and holding it up to prevent loss of fluid allow the gas to escape, constipation creates pressure also and can force the feeding back.

**Specific skin problems** surrounding the area can be kept to a minimum if they are recognized early and treated effectively.

- Folliculitis - which is inflamed and infected hair follicles usually caused by the traumatic removal of tape or other products used to anchor the tube - apply a topical antimicrobial powder and cover large lesions with non-adherent gauze or skin barrier paste and cover with a wafer, when the skin is completely healed you can prevent the recurrence by shaving the area.
- Mechanical trauma - a result of abrupt stripping of tape or other adhesives, using adhesive removers or solvents to loosen adhesives as well as gentle removal techniques can prevent skin damage
- Candidiasis - a fungal rash, can develop when skin is exposed to leakage around the tube, patchy red rashes and itching are common, treat with a topical antifungal powder, also remove the cause of moisture and maintain a dry intact area around the tube
- Chemical dermatitis - result of persistent leakage of stomach fluid, which is high in caustic enzymes and gastric contents. The skin will be red, moist, and painful. To treat the problem, you will need to correct the cause of the leakage and apply skin barrier protective powder to absorb excess fluid
- Allergic contact dermatitis - can occur when your child’s skin is sensitive to anchoring devices, tapes, soaps, or other commercial products, the area will appear red, swollen, eroded, weepy, or bleeding, at the first sign of irritation, attempt to figure out what the allergen is and then remove it.
- Cellulitis - is characterized by redness, erythema, intense pain, high white blood cell count, and fever, be careful not to confuse it with a topical skin problem, if you suspect cellulitis, call your Doctor

**Different products to stabilize Gastrostomy/Jejunostomy (GT/JT) tubes**
- Drain/tube attachment - provides a protective skin barrier, adhesive eliminates the need for tape, easy application, uses clamping mechanism to keep the tube in place, hypoallergenic, wear time 3-7 days minimum, but does protrude at some height from the skin and is unsuitable for kids with adhesive to latex sensitivities
- Elastic waistband - (gastrostomy - GT tube holder) - re-usable, one-time expense, adjustable, latex-free, eliminates discomfort and irritation caused by tape or adhesive-backed holders, but provides no absorbency at the gastrostomy (GT) tube insertion site
- Baby bottle nipple, 4 x 4 gauze, tape - inexpensive, readily available, easily applied, simply cut the end off of the nipple and slide it over the tube until the base is seated against the body, a split 4 x 4 (or cut a regular gauze pad 2-3 inches to slip around the tube) and tape to hold it in place but it does protrude at some height from the skin and unsuitable for some kids who may be allergic to tapes or latex sensitivities
- Semi permeable foam dressing and tape - highly absorbent, non-adherent, wear time 2-3 days but is unsuitable for patients who may be allergic to tapes
- Catheter tube holder - easily applied, tube can be repositioned but are variable wear time, no skin protection at insertion site, unsuitable for kids who may be allergic to tapes
- Abdominal binder - if your child has active hands and there is an increase of pulling the tube out, a binder would cover the entire abdomen and protect the tube and you may also want to use one of the holder's with the binder, but you need to assess the skin under the binder frequently.
- You can also a safety pin - put a piece of tape around the gastrostomy/jejunostomy (GT/JT) tubes, make it long enough so you can insert a safety pin to it and pin it to your child's nightgown or clothing.

Different devices as discussed in this section
Common tube feeding problems and what to do: this first group are symptoms that will require more immediate attention followed by those that do not:

- Respiratory distress – call for help, initiate emergency plan
- Color changes or changes in breathing – may be caused by increased airway secretions, may need suctioning or increase in suctioning. Stop the feeding immediately, check the tube for placement, assess for other problems – possibility of aspiration may have occurred, and follow your child’s specific guidelines set for him/her
- Color changes or changes in breathing when the feeding is not in progress – check for tube placement and assess for other problems
- Gagging/choking – most likely improper placement of tube
- If tube falls out – cover stoma (opening) and call family, school nurse, home health nurse and/or Doctor, the tube may need reinserted immediately if the tract closes quickly
- Diarrhea – cause may be too rapid feeding, too concentrated formula, intolerance to formula or medications – if diarrhea occurs, administer small, frequent, less concentrated feedings, make sure the tube feeding is not cold and that proper storage and sanitation procedures have been followed, Skin care may be necessary around perineal area depending on severity of diarrhea slow the feeding/flow rate, dilute the formula with water, gradually increase concentration over 3-5 days, may want to administer Reglan (Metopromide) to increase gastrointestinal (GI) motility if OK with your Doctor, warm the formula, for 30 minutes after feeding, position your child on his right side with his head elevated to facilitate gastric emptying, Call your Doctor – he may want to reduce the amount of formula being given during each feeding
- Cramping – formula may be too cold, tube in the wrong place, too fast feeding – use a formula at room temperature
- Constipation – inadequate fluid provided, low fiber diet, lack of activity – wash down all feedings with water, provide additional feedings of water if tolerated or prune juice; administer bulk laxatives; fruit, vegetable, or sugar content of feeding may be increased; consult your Doctor if constipation continues for more than 3 days
- Vomiting – too rapid feedings, tube too large, improper tube placement, large residual in stomach (remove residuals as ordered), formula too concentrated, medications given with feeding – slow the feeding; use smaller sized tube; reposition; monitor electrolyte levels if large amounts or continued vomiting, be sure to check your child’s specific guidelines, call your Doctor – he may want to adjust formula content, to correct deficiency, check for other problems which may contribute to vomiting
• Nausea – during feeding may indicate delayed gastric emptying, stomach distention, temperature of formula too cold, infusing too fast - stop the feeding, resume feeding when nausea subsides

• Gastrointestinal reflux – large residual in stomach, physiologic problem – elevate head before, during, and 30 minutes after feeding, thickened feedings, and/or giving medications

• Someone on continuous tube feedings can be in a state of chronic dehydration – make sure they get enough extra fluids

• Suctioning can cause depletion of electrolytes in the body adding to dehydration

• Aspiration of gastric secretions – discontinue feeding immediately; perform suctioning (nasally or tracheally) of aspirated contents, if possible; notify your Doctor – prophylactic antibiotics and chest physiotherapy may be ordered; check tube placement before feeding to prevent complication

• Tube obstruction – maybe due to inadequate flushing of the tube or very thick liquids (formulas) - flush tube with warm water or cranberry juice, if necessary, replace tube; flush tube with 50 ml of water after each feeding to remove excess sticky formula, which could occlude the tube

• Nasal or pharyngeal irritation or necrosis (injury or death of tissue) – provide frequent oral hygiene, using mouthwash or lemon and glycerin swabs, use Vaseline on cracked lips; change position of tube, if necessary, replace tube

• Redness, irritation, bleeding, drainage – check to be sure tubing is not being "tugged or pulled", may be leakage of stomach contents; check to be sure stoma (opening) is clean - could also be a leakage of food issue; food and medications coming in direct contact with skin; refer to child's specific guidelines; call the family, nurse and Doctor

• Hyperglycemia – (blood sugar levels increased due to high content of sugars in tube feeding formulas – monitor blood glucose levels; notify Doctor of elevated levels; administer insulin if ordered; Doctor may change formula to correct the sugar content

• Congestive heart failure – (increase of fluid in the lungs or swelling noted in the legs usually first then the arms) monitor your child's intake and output and respiratory status; reduce flow rate; call your Doctor; administer diuretics as ordered; decrease your child’s fluid intake and enforce bed rest

• One of the biggest problems why your child may be nauseated or begin to vomit, you might be over feeding your child. Sometimes, Doctors tell you to give your child too much formula. You know your child best. Just because the Doctor initially says to give your child 6 cans of formula a day - if he starts vomiting - try reducing the number of feedings or the amount of each feeding and see if the vomiting dissipates
Monitor blood and urine glucose (sugar) levels to assess glucose tolerance - monitor serum electrolytes and other blood studies to determine response to therapy

Assess dehydration - may cause constipation - increase fluid intake, may need laxatives or enema

Bloating and retention - may be caused by frequent and large volume of feeding at one time

Metabolic disturbances - can be caused by dehydration, diarrhea, or vomiting

Glycosuria, cramping, abdominal distention indicate intolerance of feedings

Dumping Syndrome - Definition of dumping syndrome is when the stomach contents empties too rapidly into the intestines causing symptoms. If the tube is placed directly into the jejunum (Jtube), the chance of dumping syndrome is increased due to the fact of the food already entering the body directly into the small intestine, and then the food goes too rapidly through the intestine where most of the absorption of nutrients takes place.

What causes dumping syndrome? After a gastrostomy tube (Gtube) or a Jejunostomy tube (Jtube) is inserted or your child might have any other kind of stomach surgery, food and fluids which the stomach can no longer store, enters the small intestine in large quantities and at an abnormally fast rate. In an attempt to accommodate this sudden on rush, large amounts of fluids are drawn from the vascular system into the bowel. As a result, the jejunum distends with foods and fluids and intestinal peristalsis and motility increase. This produces intestinal symptoms.

The major symptoms your child may experience with dumping syndrome will include nausea, vomiting, diarrhea, abdominal cramping, pallor, sweating, pale skin, and fainting. It can then be broken down into two main categories:

- **Early dumping syndrome** - which may be mild to severe, occurs a few minutes after eating and lasts up to 45 minutes. Onset is sudden with nausea, weakness, sweating, palpitations, dizziness, flushing, borborygmi (increased, hyperactive, intestinal peristalsis heard when you listen to bowel sounds of the abdomen - usually intense and episodic), explosive diarrhea, and increased blood pressure and pulse rate

- **Late dumping syndrome** - which is less serious, occurs 2-3 hours after eating. Similar symptoms include profuse sweating, anxiety, fine tremors of the hands and legs accompanied by vertigo, exhaustion, lassitude (weariness), palpitations, throbbing headache, faintness, sensation of hunger, glycosuria, and marked decrease in blood pressure and blood sugar
These symptoms may persist for a short period or for many years.

To minimize or eliminate dumping syndrome, teach your child or learn as parents:

- Eat 4-6 meals per day
- Maintain normal intake of foods containing fat and protein; they leave the stomach more slowly and attract less fluid into the intestine
- Avoid foods with concentrated carbohydrates and salt; they tend to attract more fluid into the intestine
- Avoid or limit foods high in fiber such as fresh fruits and vegetables and whole grain breads
- Avoid drinking fluids with meals to decrease the fluid in the intestine; drink fluids in between meals
- Avoid very hot or cold foods/liquids
- Lie down for 20-30 minutes up to a hour after eating
- Take anticholinergics to decrease motility and acid secretion and antispasmodics to slow intestinal motility if ordered (instruct to take 30 minutes to 1 hour before meals)
- Chew food thoroughly
- Try to avoid extra stress for your child by balancing activity and rest
- If your child has a gastrostomy/jejunostomy (GT/JT) and develops dumping syndrome, smaller, more frequent feedings and a longer period of post insertion (of the tube) adjustment may alleviate the problem. This syndrome seems to result from sudden duodenal or jejunal distention and rapid shifting of body fluids to make the intestinal contents isotonic (which means a balance in the pH of the fluids in the intestines)

Troubleshooting
If the formula is backing up and you are sure the entire formula feeding tube is above stomach level

- Raise the IV pole
- Change the position of the tubing
- Change your child’s position – should be in an upright position during the feeding and for 30-60 minutes after the feeding, if a continuous feeding, your child should have their head elevated at all times to prevent aspiration, which can occur following vomiting which could lead to pneumonia or life-threatening asphyxiation (watch for gagging, frothy or foamy white sputum, rapid pulse and respirations and/or any other signs of respiratory distress)
- Rinse the feeding tube with warm water, room temperature cranberry juice or coke
• Inevitably there will be drips and leaks on the floor - clean the floor drips away as quickly as possible, especially carpet, as an odor can develop and the feeding fluid can stain - a suggestion is to put a piece of plastic or a rug with a backing on it under where the bag with the formula is to be able to wipe it up from there or throw a towel, rug in the washer
• Tube blockage is often caused by the build up of formula residual in the lumen (internal space or opening that exists within the gastrostomy tube) - it can be prevented with the routine practice of flushing the tube after every use - if blockage occurs irrigate the tube with plenty of water, be careful not to use excessive force because the tube could rupture, milking the tube may help dislodge a clog
• If the tube is found out of the stoma or comes out of the stoma during a feeding, cover the stoma with sterile gauze pads, tape securely and call your health care nurse or Physician
• If your tube has a balloon in it, the balloon sometimes may rupture or the water inside the balloon may slowly leak out to where the tube may fall out. Periodically check to make sure that there is an adequate amount of water in the balloon by hooking a syringe on the end of the port and measuring the amount of water in the balloon. Usually, there are two sizes of balloons - a 5cc and a 30 cc balloon. Just remember, if you take the water out of the balloon for measurement, hang on to the tube at the skin level, so it does not fall out
• Check policies on changing a tube periodically, (mark on a calendar when the next date to change the tube will be) to prevent erosion of esophagus, trachea or nasal passages - if possible, use the newer, smaller lumen tubes to prevent such irritation

Common causes of feeding tube obstructions and how to prevent the problem
• A tube can become blocked or obstructed just because the tube is not flushed adequately enough following feedings or giving medications
• Tubing or delivery set kinked - examine the feeding tube and delivery system regularly to ensure that it’s stabilized, it’s anchored properly, and it has no kinks or twisted tubing
• A tube in the abdomen, whether it be a percutaneous endoscopic gastrostomy (Peg), a regular gastrostomy (GT), or a jejunostomy (JT) tube with the bumper becoming embedded - make sure the tube rotates freely, if the tube is immobile, call your Physician
• Inadequate or infrequent flushing of the feeding tube: formula residue adhering to the tube lumen - institute a routine flushing protocol, flush the tube with 30 cc’s of warm water every 4 hours during continuous feeding or before and after intermittent feedings
• Administration of inadequately crushed and dissolved pills – ask the pharmacist if a liquid form is available and appropriate, call your Physician to discuss any possible changes in medication

• Administration of viscous formula (those with higher calorie content or containing fiber) or medication, particularly medications known to cause clogging such as Antacids, Psyllium (Metamucil) or Sucralfate (Carafate) – flush the tube with 30 cc’s of water before giving medications, give each medication separately and flush with 10 cc’s of water between each, flush the tube with 30cc’s of water after you have given all medications, do not add medications directly to the feeding bag or container of formula, consult a nutritionist to evaluate the type of formula being administered

• Incompatibility between the formula and medications or incompatibility of medications given in the same syringe – consult your pharmacist to evaluate for incompatibilities, give medications as described above

• Formula coagulating when coming in contact with gastric secretions – flush the tube with 30cc’s of water before and after checking residual volumes

• Giving feeding by gravity (especially continuously) – consider using a pump to administer feeding if gravity feedings result in obstruction, some pumps automatically flush the tube

• Small tube lumen – flush routinely (every 4 hours) to avoid clogging small bore tubes tend to clog more easily

• Bacteria contaminating the formula leading to coagulation – wash your hands before handling the feeding equipment and minimize handling the formula, discard expired product, change the delivery system every 24 hours (or per manufacturers recommendation), follow recommended hang times for formula, store unopened cans of formula in a cool, dry place, mark opened cans of formula with date time and refrigerate, discard unused canned formula after 48 hours, refrigerate formula that is in powder form and reconstituted with water, discard unused reconstituted formula after 24 hours, do not dilute formula

• Yeast forming in the tube – observe for changes in the tube, such as dark discoloration, opaque tube, or nodules in the tube, an occluded tube probably will need to be replaced, call your Physician

• Squeeze or roll the tube with fingers moving slowly down toward child’s stomach. Try a catheter-tipped syringe filled with warm water, hold high to facilitate movement of fluid. Try to draw back on plunger of syringe. If blockage remains, consult family, nurse, and Doctor

**Documentation**

• Tube feeding sheet – to be completed after each feeding and indicate the date, time feeding began, rate, type and amount of feeding, and the flush, skin care, tube placement check and residual check
• Intake/output record - as indicated
• Weight record - weigh as ordered
• Vital signs sheet - as indicated
• Bowel movement chart/daily monitoring record
• Communication book - as indicated
• Notes - include events that occurred such as - any time a continuous pump feeding is shut off and the time that it is turned back on. Observation for placement and color/amount of aspirations, child's response (how tolerated), gastrostomy site care and mouth care, other observations such as more than allowed amount of residual volume, distention and/or discomfort during feeding, vomiting or diarrhea, any other unusual symptom for this particular child

I have at times duplicated specific statements in this book on the gastrointestinal system, but I feel it important enough to mention more than once. We sometimes are reading quickly and miss some points, but if we see it again, it gets our attention. Also, I have included specific issues for we as adults that our children can also have problems in the same areas.
Abdominal aorta – the portion of the descending aorta that passes from the aortic hiatus of the diaphragm into the abdomen, descending ventrally (anterior) to the vertebral column, and ending at the fourth lumbar vertebrae, where it divides into the two common iliac (and then into the femoral artery in the groin) arteries. It supplies blood to many different parts of the body

Abduction – movement of a limb away from the body

Abscess – a cavity containing pus and surrounded by inflamed tissue, formed as a result of suppuration (the process of pus formation) in a localized infection, healing usually occurs when the abscess is drained or is incised (lanced/cut)

Acetone – a colorless, aromatic, liquid found in small amounts in the urine and in larger quantities in the urine of diabetics

Acetylcholine – an acidic acid ester of choline, normally present in the body. It has important physiologic functions and is a neurotransmitter at the myoneural junction (pertaining to a muscle and its associated nerve)

Achalasia – an abnormal condition characterized by the inability of a muscle to relax, particularly the cardiac sphincter of the stomach

Acid-Base Balance – a condition existing when the net rate at which the body produces acids or bases equals the net rate at which acids or bases are excreted. The result of acid base balance is a stable concentration of hydrogen ions in the body fluids which is referred to as the pH and the concentration of oxygen and carbon dioxide

Adduction – movement of a limb toward the body

Adhesions – a band of scar tissue that binds together two anatomical surfaces, which are normally separate from each other. Adhesions are most commonly found in the abdomen when they form following abdominal surgery, inflammation, or injury. A loop of intestines may adhere to unhealed areas and cause an intestinal obstruction if scar tissue develops and constricts the lumen (diameter) of the bowel, blocking the intestinal flow. The condition is characterized by abdominal pain, distention, nausea, vomiting, and an increase in pulse rate, without a rise in temperature. Inserting a NG (nasogastric tube) and suction may relieve the blockage, if not, surgery may be necessary to separate the adhering surfaces

Adipose – fatty, adipose tissue is composed of fat cells arranged in soft lobes

Adrenal gland – either of two secretory organs perched atop the kidneys. Each consists of two parts having independent functions: the cortex and the medulla. The adrenal cortex secretes cortisol and androgens (in response to adrenocorticotropic hormones secreted by the anterior pituitary). Adrenal androgens serve as precursors that are converted by the liver to testosterone and

GASTROINTESTINAL SYSTEM GLOSSARY
estrogens. Renin from the kidney controls adrenal cortical production of aldosterone. The adrenal medulla manufactures the catecholamines epinephrine and norepinephrine

**Adrenal Insufficiency** – this disease is the result of chronic adrenal cortical insufficiency called Addison's disease, brought about by an invasion of the cortex by chronic infectious diseases such as Tuberculosis or fungus diseases. Commonly idiopathic atrophy (shrinkage) of the adrenals is the cause. Signs and symptoms include: increased pigmentation of the skin, weakness, fatigue, hypotension (low blood pressure), nausea, vomiting, anorexia, weight loss, and occasional hypoglycemia (low blood sugar)

**Afferent** – proceeding toward a center, as applied to arteries, veins, lymphatics, and nerves

**Alkaline** – a compound with the chemical characteristics of a base instead of an acid. Alkaline solutions combine with fatty acids to form soaps, turn red litmus paper blue, and enter into reactions that form water-soluble carbonates

**Amenorrhea** – the absence of menstruation, may be caused by dysfunction of the pituitary gland (in the brain), hypothalamus (in the brain), ovary, uterus, by the congenital absence or surgical removal of both ovaries and the uterus, or by medication

**Anal** – of or pertaining to the rectum, the portion of the large intestine approximately 4-5 inches long, continuous with the descending sigmoid colon (intestine) which ends at the anal canal and the opening to the outside of the body

**Anal stenosis** – one of several congenital, developmental malformations of the rectal portion of the gastrointestinal tract, the opening to the anal canal is small and could lead to an obstruction, surgery may be necessary to correct the problem

**Anemia** – a disorder characterized by a decrease in hemoglobin (red blood cells) in the blood levels below the normal range, according to the pathophysiological classification, anemia is a reflection of any one or more of three basic processes: decreased hemoglobin or red blood cell production, increased red blood cell destruction, or blood loss. Symptoms of anemia include fatigue, exertional dyspnea, dizziness, headache, insomnia, and pallor; anorexia, dyspepsia, palpitations, tachycardia, cardiac dilatation and systolic murmurs may also occur. If anemia occurs, you need to be aware of adequate diet to supply blood building components, adequate rest, adequate time for recovery, and repeated blood tests to evaluate the progress of therapy. You also need to be alerted to signs of blood loss should there occur again and if transfusions are given, to be aware of blood (transfusion) reactions

**Anorexia** – loss of appetite, resulting in the ability to eat, the condition may result from poorly prepared food or unattractive surroundings, unfavorable company, or psychological causes, which may lead to prolonged refusal to eat, resulting in emaciation (excessive leanness caused by disease or lack of nutrition), amenorrhea
(absence of monthly menstrual periods), emotional disturbance concerning body image

**Antacids** – opposing acidity, a drug or dietary substance that buffers, neutralizes or absorbs hydrochloric acid in the stomach. Most antacids are not absorbed systemically. Antacids containing aluminum or calcium are constipating; those containing magnesium have a laxative effect

**Antibacterial or antimicrobial** – of or pertaining to a substance that kills bacteria or inhibits their growth or replication, an antibacterial agent, antibiotics synthesized chemically or derived from various microorganisms exert their bactericidal or bacteriostatic effect by interfering with the production of the bacterial cell wall, by interfering with protein synthesis, nucleic acid synthesis, or cell membrane integrity, or by inhibiting critical biosynthetic pathways in the bacteria

**Anticholinergics** – of or pertaining to a blockade of acetylcholine receptors, which results in the inhibition of the transmission of parasympathetic nerve impulses. This group of drugs reduces spasms of smooth muscle in the bladder, bronchi, and intestine; relax the iris sphincter; decrease perspiration; and accelerate impulse conduction through the myocardium (heart muscle) by blocking vagal impulses; can also reduce Parkinsonian symptoms. This group of drugs can also be used to treat spastic disorders of the gastrointestinal tract, to reduce salivary and bronchial secretions preoperatively, or to dilate the pupil

**Anticoagulant toxicity** – an anticoagulant pertains to a substance that prevents or delays coagulation of the blood. If there is toxicity, that means that there is too much of the anticoagulant and the blood will be too thin and can cause bleeding, usually of the nose, stomach, kidneys, or intestines, in which case, immediate treatment would need to be initiated

**Antidiarrheal** – medications or foods that help stop or slow down diarrhea

**Antihypertensive** – of or pertaining to a substance or procedure that reduces blood pressure, diuretics can cause a decrease in blood pressure by decreasing blood volume

**Antiinflammatory** – of or pertaining to a substance or procedure that counteracts or reduces inflammation by killing the bacteria (infection)

**Antispasmodics** – a group of medications that control or prevent an involuntary muscle contraction of sudden onset, as habit spasms, hiccups, stuttering, or a tic, a convulsion or seizure, a sudden transient constriction of a blood vessel, bronchus, esophagus, pylorus, ureter, or other hollow organ

**Apathy** – an absence or suppression of emotion, feeling, concern, or passion, an indifference to things generally found to be exciting or moving. The condition is commonly seen in patients with neurosis or schizophrenia

**Aspiration** – the act of taking a breath, inhaling into the lungs, the act of withdrawing a fluid, as in mucus or serum from the body by a suction device

**Asymptomatic** – without having any symptoms
Atrophy - a wasting or diminution of size or physiological activity of a part of the body owing to disease or other influences. A skeletal muscle may undergo atrophy because of lack of physical exercise or as a result of neurological or musculoskeletal disease. Cells of the brain and central nervous system may atrophy (shrink) in old age because of restricted blood flow to those areas.

Attention Deficit Disorder - a syndrome affecting children, adolescents, and rarely adults, characterized by learning and behavior disabilities. The symptoms may be mild or severe and are associated with functional deviations of the central nervous system without signs of major neurological or psychiatric disturbance. The people affected are usually of normal or above average intelligence. Symptoms include impairment in perception, conceptualization (the process of creating an idea or notion), language, memory, and motor skills, decreased attention span, increased impulsivity and emotional lability (unstable), and usually but not always, hyperactivity. The condition is 10 times more prevalent in boys than in girls and may result from genetic factors, biochemical irregularities, or prenatal injury or disease. There is no known cure, and symptoms often subside or disappear with time. Medication is frequently prescribed for children with hyperactive symptoms, and some form of psychotherapeutic counseling is often recommended.

Auscultation - the act of listening for sounds within the body to evaluate the condition of the heart, lungs, pleura, intestines, or other organs or to detect the fetal heart sound (during pregnancy). Auscultation may be performed directly, but most commonly, a stethoscope is used to determine the frequency, intensity, duration, and quality of the sounds.

Autonomic Nervous System - the part of the nervous system that regulates involuntary vital function, including the activity of the cardiac muscle, smooth muscle, and the glands. It has two divisions: the sympathetic nervous system accelerates heart rate, constricts blood vessels, and raises blood pressure; the parasympathetic nervous system slows heart rate, increases intestinal peristalsis and gland activity, and relaxes sphincters (a circular band of muscle fibers that constricts a passage or closes a natural opening of the body).

Aversion - a form of behavior therapy in which punishment or unpleasant or painful stimuli, like electric shock or drugs that induce nausea, are used in the suppression of undesirable behavior. The procedure is used in such conditions as drug abuse, alcoholism, gambling, overeating, or smoking.

Bacteria - any of a small unicellular microorganism - may be spherical (cocci), rod-shaped (bacilli), spiral (spirochetes), or comma-shaped (vibrios). The nature, severity, and outcome of any infection caused by a bacterium are characterized of that species.
Barium – is used as a contrast medium (to help visualize) in radiography of the gastrointestinal tract as a barium swallow to evaluate the upper portion of the GI tract or a barium enema to evaluate the lower portion of the intestinal tract.

Bile – a bitter, yellowish-green secretion of the liver, stored in the gallbladder; bile receives its color from the presence of bile pigments, as bilirubin. Bile passes from the gallbladder through the common bile duct in response to the presence of a fatty meal in the duodenum. Bile emulsifies (liquefies) these fats, preparing them for further digestion and absorption in the small intestine. Any interference in the flow of bile will result in the presence of unabsorbed fat in the stool and in jaundice (yellow color to the skin, or eyes).

Bilirubin – the orange yellow pigment of bile, formed principally by the breakdown of hemoglobin in red blood cells after termination of their normal lifespan. Water-soluble, unconjugated bilirubin, normally travels in the blood stream to the liver, where it is converted to a water-soluble, conjugated form and excreted into the bile. In a healthy person the majority of bile produced is excreted in the stool. The characteristic yellow pallor of jaundice is caused by the accumulation of bilirubin in the blood and in the tissues of the skin. Testing for bilirubin in the blood provides valuable information for diagnosing and evaluating liver disease, biliary obstruction, or anemia.

Biopsy – the removal of a small piece of living tissue from an organ or other part of the body for microscopic examination to confirm or establish a diagnosis, estimate prognosis, or follow the course of a disease.

Bolus – a dose of a medication or a contrast material, radioactive isotope, injected orally or intravenously to be used in evaluating or diagnosing; a bolus of food ready to be swallowed; or as a feeding by the bolus method.

Botulism – an often fatal form of food poisoning caused by a toxin (a poison) – it differs from most other forms of food poisoning in that it develops without gastric distress and may not occur for from 18 hours to 1 week after the contaminated food has been ingested. Symptoms may include by a period of lassitude (weariness, exhaustion) and fatigue followed by visual disturbances, as double vision, difficulty in focusing of the eyes, and loss of ability of the pupil to accommodate to light. Muscles may become weak, and the patient often develops dysphagia (difficulty in swallowing). Nausea and vomiting occur in less than half of the cases. Hospitalization is required and antitoxins are administered. Sedatives are given, mainly to reduce anxiety. Approximately two thirds of the cases are fatal, usually because of respiratory complications. For those who survive, recovery is slow.

Bradycardia – an abnormal circulatory condition in which the heart muscle contracts steadily, but at a heart rate that is slow, usually below 60 beats per minute. The heart rate is usually slower during sleep, and in those who are physically fit, the pulse rate may be extremely slow (40-50 beats per minute). Symptoms include: the cardiac output (the amount of blood that is pushed through the circulatory system with each beat) is decreased causing faintness, dizziness,
chest pain, and eventually syncope (lightheadedness which may result in fainting), and circulatory collapse. Treatment will include the administration of Atropine to stimulate the heart rate to increase, implantation of a pacemaker, or it may be due to medication such as Digoxin.

**Bronchiectasis** – an abnormal condition of the bronchial tree, characterized by irreversible dilatation and destruction of the bronchial walls. The condition is sometimes congenital, but it is more often a result of bronchial infection or of obstruction by a tumor or an aspirated foreign body. Symptoms include a constant cough production of copious (large amount) purulent (pus) sputum, hemoptysis (coughing up of blood from the lungs), chronic sinusitis, clubbing of the fingers, and persistent moist, coarse rales (fluid in the lungs). Complications include pneumonia, lung abscess, empyema (pus in the lining around the lungs), and brain abscess. Treatment includes frequent postural drainage, antibiotics, and rarely surgical resection of the affected part of the lung.

**Bulbous** – bulb-shaped, swollen, terminating in an enlargement

**Bulky** – used as in bulky foods, roughage, to add bulk to the stool for gastrointestinal function, as in colon transit time, water absorption, and fat metabolism

**Calculus** – a pathological stone formed by mineral salts, calculi are usually found within hollow organs or ducts and can cause obstruction and inflammation. Kinds of calculi include gallbladder stones or kidney stones

**Cardiac** – of or pertaining to the heart. Possibly heart disease or heart muscle

**Cardiovascular** – of or pertaining to the heart and the blood vessels of the heart – an evaluation of the condition, function, and abnormalities of the heart and circulatory system. The cardiovascular system pumps and conveys the blood throughout the body – numerous control mechanisms of the system assure that the blood is delivered to the structures where it is most needed and at the proper rate. The system delivers nutrients and other essential materials to the fluids surrounding the cells and removes waste products which are conveyed to excretory (wastes) organs as the kidneys and intestines

**Caustic enzyme** – an agent that is corrosive (an agent that eats away at a tissue) and burning and that will destroy living tissue

**Cecum** – a cul-de-sac (blind pouch) constituting the first part of the large intestine, located below the entrance of the ileum (the lower portion of the small intestine), usually where the appendix is located

**Cellulitis** – an infection of the skin characterized most commonly by local heat, redness, pain, swelling, Occassionally fever, malaise (weakness), chills, and headache. Abscess and tissue destruction usually follow if antibiotics are not taken. Damaged skin, poor circulation, and diabetes favor the development of cellulitis (an infection
of the skin – will see redness, swelling, heat at the site). Treatment, in addition to appropriate antibiotics, includes warm soaks and avoidance of pressure of the affected areas.

Central Nervous System – CNS – of the two main divisions of the nervous system of the body, consisting of the brain and the spinal cord. The CNS processes information to and from the peripheral nervous system and is the main network of coordination and control the entire body. The brain controls many functions and sensations. As sleep, muscular movement, hunger, thirst, memory, and the emotions. The spinal cord extends various types of nerve fibers from the brain and acts as a switching and relay terminal for the peripheral nervous system. The 12 pairs of cranial nerves emerge directly from the brain. Sensory nerves and motor nerves of the peripheral system leave the spinal cord separately between the vertebrae but unite to form 31 pairs of spinal nerves containing sensory fibers and motor fibers

Cheek biting – usually seen in neurological cases when the patient does not realize that they are doing it. Small bites located on the insides of the lips that become sore, may bleed, and usually slows eating due to the discomfort.

Chemoreceptor trigger – a sensory nerve cell activated by chemical stimuli as a chemoreceptor in the carotid (main artery that goes to the brain – one on either side) that is sensitive to the PCO2 (carbon dioxide) in the blood, signaling the respiratory center in the brain to increase or decrease respiration.

Cholecystitis – acute or chronic inflammation of the gallbladder. Acute cholecystitis is usually caused by a gallstone that cannot pass through the cystic duct.

Cholecystokinin – a hormone produced by the mucosa of the upper intestine, which stimulates contraction of the gallbladder and the secretion of pancreatic enzymes.

Cholelithiasis – the presence of gallstones in the gallbladder. The condition causes unlocalized abdominal discomfort, eructation (belching) and intolerance to certain foods, or no symptoms at all. In patients with severe attacks, cholecystectomy (removal of the gallbladder) is recommended to prevent such complications as cholecystitis (acute or chronic inflammation), cholangitis (inflammation of the bile ducts), and pancreatitis (inflammation of the pancreatitis).

Cholesterol – a fat-soluble crystalline steroid alcohol found in animal fats, oils, egg yolk, and widely distributed in the body, especially in the bile, blood, brain tissue, liver, kidneys, adrenal glands, and myelin sheaths (containing fatty laminations) of nerve fibers. It facilitates the absorption and transport of fatty acids, acts for the synthesis of Vitamin D at the skin surface, and facilitates the synthesis of various steroid hormones, including adrenal cortisols. Cholesterol is the chief element in most gallstones. Increased levels of serum cholesterol may be associated with the pathogenesis of atherosclerosis (hardening of the arteries).

Chronic – of a disease or disorder: developing slowly and persisting for a long period of time, often for the remainder of a lifetime of the patient.
**Chyme** - the viscous, semi fluid contents of the stomach present during digestion of a meal. It then passes through the pylorus (the portion of the lower stomach just before it enters into the small intestine) into the duodenum (the shortest, widest and most fixed portion of the small intestine), where further digestion occurs.

**Cirrhosis** - a chronic degenerative disease of the liver in which the lobes are covered with fibrous tissue, the parenchyma (the tissue of an organ as distinguished from supporting or connective tissue) degenerates, and the lobules are infiltrated with fat. Functions of the liver deteriorate, blood flow through the liver is obstructed, causing back pressure and leading to portal hypertension (an increased venous pressure associated with the liver) and esophageal varices (a dilated vein in the esophagus). Unless the cause of the disease is removed, hepatic coma (liver), gastrointestinal hemorrhage and kidney failure will eventually occur. Symptoms of cirrhosis include nausea, flatulence (gas), anorexia, weight loss, and ascites (abdomen filling up with fluid caused by the liver's inability to process the amount of fluids it normally did). Light colored stools, weakness, abdominal pain, varicosities (an abnormal condition, usually of a vein, characterized by swelling and twisting), and spider angiomas (small clumped areas of blood and lymph vessels). Definite diagnosis is made by biopsy, but x-ray, physical examination, and several blood tests of liver function are preformed to monitor the course of the disease. Treatment usually includes a balanced diet (rich in proteins as can be tolerated), vitamins (especially folic acid), and rest. The liver has remarkable ability to regenerate, but recovery may be very slow.

**Clubbing of the fingers** - an abnormal enlargement of the distal phalanges (fingers and toes), usually associated with cyanotic heart disease, but sometimes because of cirrhosis, colitis, chronic dysentery (an inflammation of the intestine, especially of the colon, that may be caused by chemical irritants, bacteria or parasites, characterized by frequent and bloody stools, abdominal pain, and tenesmus - spasms of the bowel or bladder, accompanied by the desire to empty the bowel or bladder), the mechanism whereby diminished oxygen tension in the blood causes clubbing is not understood. It occurs in all digits but most easily seen in the fingers.

**Cognitive function** - an intellectual process by which one becomes aware of, perceives, or comprehends ideas. It involves all aspects of perception, thinking, reasoning, and remembering.

**Colic** - sharp visceral pain resulting from torsion (the process of twisting or turning away from the normal position - it may be positive - clockwise or negative - counter clockwise), obstruction, or smooth muscle spasm of a hollow or tubular organ, as a ureter (kidney) or the intestines (stool).

**Collagen** - a substance consisting of bundles of tiny reticular fibrils (having a netlike pattern or structure of veins), which combine to form the white, glistening, inelastic fibers of the tendons, ligaments, and the fascia (the fibrous connective tissue in the body).
tissue of the body that may be separated from other specifically organized structures, as the tendons and ligaments)

**Colonic** – relating to the colon or the large intestine

**Colonic inertia** – an abnormal condition characterized by a general inactivity or sluggishness of the lower intestine

**Colonies** – in bacteriology: a mass of microorganisms in a culture that originates from a single cell. Some kinds of colonies, according to different configurations are smooth, rough or dwarf colonies; in biology, a mass of cells in a culture or in certain experimental tissues, as a spleen colony

**Colonscopy** – examination of the upper portion of the rectum with an elongated speculum (an instrument for examining canals as in the colon or large intestine)

**Colostomy** – surgical creation of an artificial rectum on the abdominal wall by incising the colon and bringing it out to the surface of the abdomen for stool to be excreted as waste

**Complex partial seizure** – symptoms include a change in awareness, confused, dream-like, usually unable to respond appropriately to questions or commands, often performs unusual behaviors such as fumbling, picking at clothes, grunting, or repeating words or phrases, chewing, tasting, or swallowing movements, may also scream, run, or some other dramatic behavior. They usually last from 30 seconds to 3 minutes. The person may have an aura which would tell him that a seizure may be coming, or a partial seizure may develop into generalized seizures

**Conduit** – a urinary suprapubic or conduit where the ureter is brought out from the bladder to the surface of the abdomen for the urine to be collected in a bag

**Congenital Anomalies** - any abnormality present at birth, particularly a structural one, which may be inherited genetically, acquired during gestation, or inflicted during parturition (birth), also called birth defect

**Congestive heart failure** – CHF – an abnormal condition characterized by circulatory congestion caused by cardiac disorders, especially myocardial infarction of the ventricles (a heart attack). This condition usually develops chronically in association with the retention of sodium (salt) and water by the kidneys. If the right heart pump becomes defective, you will see swelling of the lower legs first then it will eventually creep up to the thighs, if the left heart pump becomes defective, you will see lung congestion (increased shortness of breath, fluid in the lungs). Treatment includes prolonged rest, administration of oxygen, medications such as Digoxin (to slow the heart rate down and to give each beat a more forceful push), diuretics such as Lasix, and vasodilators to reduce blood pressure

**Conjunctiva** – the mucous membrane lining the inner surfaces of the eyelids and anterior part of the sclera (white part of the eye)

**Consistency** – being able to be consistent in giving feedings, medications, doing dressings, turning your child every one to two hours, etc., the same time each day

**Contractures** – an abnormal, usually permanent condition of a joint, characterized by flexion (a movement allowed by certain joints of the skeleton that decreases the
angle between two adjoining bones as bending the wrist) and fixation (a muscle that acts to hold a part of the body in appropriate position) and caused by atrophy and shortening of muscle fibers or by loss of the normal elasticity of the skin, as from the formation of extensive scar tissue over a joint

**Cornea** - the convex, transparent, anterior part of the eye, comprising one sixth of the outermost tunic (an investing membrane) of the eye bulb. It is a fibrous structure with five layers; it is dense, uniform in thickness, nonvascular, and projects like a dome beyond the sclera, which forms the other five sixths of the eye’s most outermost tunic

**Corticosteroids** - any one of the natural or synthetic (manmade) hormones associated with the adrenal cortex, which influences or controls key processes of the body, as carbohydrate and protein metabolism, electrolyte and water balance, and the functions of the cardiovascular system, skeletal muscle, kidneys, and other organs. The corticosteroids synthesized by the adrenal glands include the glucocorticoids, the mineral corticoids, and the adrenogenital corticoids. The principle glucocorticoid is cortisol; also known as hydrocortisone, the mineral corticoid is aldosterone and the adrenogenital corticoids are androgen, estrogen, and progesterone. Cortisol and its synthetic analogs can prevent or reduce inflammation by inhibiting edema, leukocytic (white blood cells) migration, disposition of collagen (a substance which combine to form the fibers of tendons, ligaments, and the fascia), and other complications associated with the inflammatory processes

**Cyanosis** - bluish discoloration of the skin and mucous membranes caused by an excess of deoxygenated hemoglobin (red blood cells) in the blood or a structural defect in the hemoglobin molecule, will be seen in respiratory problems when severe issues become apparent

**Cystic fibrosis** - an inherited disorder of the exocrine glands (secreting outwardly through a duct to the surface of an organ or tissue or into a vessel, as a gland that secretes through a duct) causing those glands to produce abnormally thick secretions of mucous. The glands most affected are those in the pancreas, the respiratory system, and the sweat glands. It is usually recognized in infancy or early childhood, occurring usually in Caucasians. Early signs of the disease are a chronic cough, frequent, foul-smelling stools, and persistent upper respiratory infections. The most reliable diagnostic tool is the sweat test, which shows elevations of both sodium and chloride. There is no known cure, so treatment is directed at prevention of respiratory infections. Mucolytic agents (capable of dissolving mucus), bronchodilators (relaxes the muscles) and mist tents (to provide moisture) are used to help liquefy the thick, tenacious mucus. Physical therapy measures, as postural drainage and breathing exercises, can also dislodge secretions. Broad spectrum antibiotics may be used prophylactically (as a preventative agent)
Cytology - the study of cells, including their formation, origin, structure, function, biochemical activities, and pathology

Decompensation - failure of the heart to maintain adequate circulation, characterized by dyspnea (shortness of breath), venous engorgement, and edema. Failure of the defense system mechanism as seen in progressive personality disintegration

Decompression - the removal of pressure, as from gas in the intestinal tract by inserting a nasogastric tube for a period of time (a day or so)

Defecation - the elimination of feces (stool) from the digestive tract through the rectum

Dermatology - the study of the skin, including anatomy, physiology, and pathology and the diagnosis and treatment of skin disorders

Detoxify - to remove the toxic quality of a substance as in possibly too much medication in one's system by checking blood levels

Diabetes - a clinical condition characterized by the excessive excretion of urine. The excess may be caused by a deficiency of antidiuretic hormone (ADH), as in diabetes insipidus, or it may be the result of the hyperglycemia (high sugar levels) as seen in diabetes mellitus

Diaphoresis - the secretion of sweat, especially the profuse secretion associated with an elevated body temperature, physical exertion, exposure to heat, and mental or emotional stress. Sweating is centrally controlled by the sympathetic nervous system and is primarily a thermoregulatory mechanism, but the sweat glands on the palms and soles respond to emotional stimuli and do not participate in thermal sweating

Diaphragm - in anatomy, a dome-shaped, musculofibrous partition that separates the thoracic and the abdominal cavities. The convex cranial surface of the diaphragm forms the floor of the thoracic cavity, and the concave surface forms the roof of the abdominal cavity. This partition is pierced by various openings through which pass different structures, as the aorta, esophagus, and vena cava (one of the two large veins returning blood from the peripheral circulation to the right side of the heart to be reoxygenated). The diaphragm aids respiration by moving up and down. During inspiration it moves down and increases the volume of the thoracic cavity; during expiration it moves up, decreasing the volume

Disaccharides - a group of sugars in carbohydrates

Disimpaction - removing an impaction (hard stool) manually if necessary

Distention - the state of being distended, or to become stretched or inflated

Diverticulitis - inflammation or an abscess of diverticula, which is an out-pouching in the colon or intestine, causing stagnation (stoppage of motion) of feces (stool) in little distended sacs in the colon. With repeated inflammations, the lumen (the
diameter or opening) of the colon narrows and may cause an obstruction. During periods of inflammation, the patient will experience cramping pain, particularly over the sigmoid (lower rectal) area and fever. The need for bed rest, IV’s, antibiotics, and to eat nothing by mouth for a few days may be necessary during an acute phase.

**Down’s syndrome** – a congenital condition characterized by varying degrees of mental retardation and multiple defects. It is the most common chromosomal abnormality of a generalized syndrome and is caused by the presence of an extra chromosome.

**Duodenal Contractions** – the shortest, widest, and most fixed portions of the small intestine, taking an almost circular course from the pyloric valve of the stomach so that its termination is close to the starting point. It plays a key role in digestion, because the common bile duct and pancreatic duct empty into it, by the peristaltic waves that are present during digestion.

**Dysarthria** – difficult, poorly articulated speech, resulting from interference in the control over the muscles of speech, usually because of damage to a central or peripheral motor nerve.

**Dyspepsia** – a vague feeling of gastric discomfort felt after eating. There is an uncomfortable feeling of fullness, heartburn, bloating and nausea. Dyspepsia is not a distinct condition, but it may be a sign of underlying intestinal disorder, as peptic ulcer, gallbladder disease, or chronic appendicitis.

**Dysphagia** – difficulty in swallowing commonly associated with obstructive or motor disorders of the esophagus. Patients with obstructive disorders, as esophageal tumor or lower esophageal ring, are unable to swallow solids but can tolerate liquids. Persons with motor disorders, as achalasia (an abnormal condition characterized by the inability of a muscle to relax, particularly the cardiac sphincter of the stomach), are unable to swallow solids or liquids. Diagnosis of the underlying condition is made through barium studies, the observed clinical signs, and evaluation of the patient’s symptoms.

**Dysplasia** – a combining form of a condition of abnormal development of tissue.

**Dyspnea** – a shortness of breath or a difficulty in breathing that may be caused by certain heart conditions, strenuous exercise, or anxiety.

**Dysrhythmia** – an abnormal heart rhythm.

**Edema** – the abnormal accumulation of fluid in the interstitial (spaces between tissues) tissues, in the pericardial sac (space around the heart), intrapleural space (within the pleural cavity around the lungs), peritoneal cavity (which covers the abdominal intestines), or joint capsule. Edema may be caused by increased capillary (the tiny vessels that join the arterioles and the venules) fluid pressure; venous (vein) obstruction, as in varicosities, thrombophlebitis (inflammation of a vein), or pressure from casts, tight bandages, or garters; congestive heart failure;
overloading with parenteral fluids (not in or through the digestive system); renal (kidney) failure; cirrhosis (liver), and inflammatory reactions. Diuretics (water pills) are usually given to reduce the swelling or an elastic stocking and elevation of the extremity can be helpful

**Effector organ** - a structure which when stimulated produces an effect, specifically muscles and glands - one of the nerve endings having the efferent process end in a gland or muscle cell. The terminal arborizations (like a tree - interlacing) of efferent or motor nerves

**Electrocautery snare** - the application of a needle or snare heated by electrical current for the destruction of tissue, as for the removal of warts

**Emesis** - to expel the contents of the stomach through the esophagus and out of the mouth, vomiting

**Encephalopathy** - any abnormal condition of the structure or function of tissues of the brain, especially chronic, destructive, or degenerative conditions

**Encopresis** - incontinence of fecal (stool) material (wastes)

**Endocrine gland** - pertaining to an organ, gland, or structure that secretes a substance, as a hormone, into the blood or lymph for specific effect on another organ or part, pertaining to internal secretion; hormonal

**Enzymes** - a protein produced by living cells that catalyzes chemical reactions in organic matter. Most enzymes are produced in minute quantities and catalyze reactions within cells. Digestive enzymes, however, are produced in relatively large quantities and act outside the cells in the lumen (diameter) of the digestive tube

**Epiglottis** - the cartilaginous structure that overhangs the larynx like a lid and prevents food from entering the larynx or the trachea while swallowing, to prevent aspiration

**Epiglottitis** - an inflammation of the epiglottis, acute epiglottitis is a severe form of the condition, affecting primarily children. It is characterized by fever, sore throat, stridor (heard during inspiration - a high pitched musical respiratory sound caused by an obstruction in the trachea or larynx), croupy cough, and an erythematous (reddened), swollen epiglottis. The child may become cyanotic (blue lips and/or fingers) and require an emergency tracheostomy (opening into the neck to be able to continue respirations) to maintain respiration. The causative organism is usually Haemophilus haemolyticus. Antibiotics, rest, oxygen, and supportive care are usually included in the treatment plan

**Erythema** - redness or inflammation of the skin or mucous membranes that is the result of dilatation and congestion of superficial capillaries. Examples of erythema are nervous blushes and mild sunburn

**Esophageal** - pertaining to the esophagus, which is the muscular, canal, about 9 inches long, extending from the pharynx to the stomach. It begins in the neck at the inferior border of the cricoid cartilage, opposite the sixth cervical vertebra, and descends to the cardiac sphincter of the stomach in a vertical path with two slight curves. It is the narrowest part of the digestive tube and is most constricted
at its origin and at the point where it passes through the diaphragm. The esophagus is composed of fibrous, muscular, and submucous coats, and is lined with mucous membrane.

**Esophagitis** - inflammation of the mucosal lining of the esophagus, caused by infection, irritation from a nasogastric tube, or most commonly, from backflow of gastric juice from the stomach.

**Euphoria** - a feeling or state of well-being or elation, an exaggerated abnormal sense of physical and emotional well-being not based on reality or truth, disproportionate to its cause, and inappropriate to the situation, as commonly seen in the manic stage of bipolar disorder (manic-depressive), in some forms of schizophrenia, in organic mental disorders, and in toxic and drug-induced states.

**Exacerbation** - an increase in the seriousness of a disease of the patient's signs or symptoms, after the symptoms have subsided or lessened.

**Excoriation** - an injury to the surface of the skin or other part of the body caused by scratching or abrasion (scraping of the skin).

**Extrapyramidal** - of or pertaining to the tissues and structures of the brain that are associated with movement of the body, excluding motor neurons, the motor cortex, and the corticospinal and corticobulbar tracts, of or pertaining to the function of these tissues and structures; any of a large group of conditions characterized by involuntary movement, changes in muscle tone, and abnormal posture, as in tardive dyskinesia (an abnormal condition characterized by involuntary, repetitious movements of the muscles of the face, limbs and trunk), chorea (a condition characterized by involuntary, purposeless, rapid motions, as flexing and extending the fingers, raising and lowering the shoulders, or grimacing), athetosis (a neuromuscular condition characterized by slow, writhing, continuous, and involuntary movement of the extremities) and Parkinson's disease (a slowly progressive, degenerative neurologic disorder characterized by resting tremor, pill rolling of the fingers, a mask-like face, shuffling gait, forward flexion of the trunk, muscle rigidity and weakness); a reaction to a treatment or a drug characterized by the signs of extrapyramidal disease. The reaction may persist or regress after discontinuation of the treatment or drug; the part of the nervous system that includes the basil ganglia (the islands of gray matter in the brain), part of the midbrain (one of three parts of the brain stem), and the motor neurons of the spine. The extrapyramidal system controls and coordinates the motor activities required for locomotion and for stasis (to stand), body support, and posture; the tracts of motor nerves from the brain to the anterior horns of the spinal cord, except for the fibers of the pyramidal tracts (a pathway comprised of groups of nerve fibers in the white matter of the spinal cord through which motor impulses are conducted). Within the brain, extrapyramidal tracts comprise various relays of motor neurons between motor areas of the cerebral cortex, the basil ganglia, the thalamus, the cerebellum, and the brain stem (all parts of the brain). Research into the precise functions of these networks continues, and it is not yet known how some
of them work. The extrapyramidal tracts are functional rather than anatomical (standard position – not movable) units, comprising the nuclei (the controlling body with each particular cell) and the fibers (a strand of nerve, muscle or connective tissue) and excluding the pyramidal tracts. They especially control and coordinate the postural, static, supporting, and locomotor mechanisms and cause contractions of muscle groups in sequence or simultaneously.

**F**

**Fatty acid** – any of several organic acids produced by the hydrolysis (the chemical alteration or decomposition of a compound with water) of neutral fats. In a living cell, a fatty acid occurs in combination with another molecule, rather than in a free state. Essential fatty acids are unsaturated molecules that cannot be produced by the body and must therefore be included in the diet. Kinds of essential fatty acids are arachidonic, linoleic, and linolenic.

**Fecal impaction** – an accumulation of hardened feces in the rectum or sigmoid colon that an individual is unable to move. Diarrhea may be a sign of fecal impaction, since only liquid material is able to pass around the obstruction. Occasionally, fecal impaction may cause urinary incontinence due to pressure on the bladder. Treatment includes oil and cleansing enemas and manual breaking up and removal of the stool by a gloved finger. Persons who are dehydrated, nutritionally depleted, on prolonged bed rest, receiving such constipating medications as iron or opiates, or undergoing barium x-rays are at risk of developing fecal impactions.

**Feces** – stool.

**Femoral artery** – an extension of the external iliac artery into the lower limb, starting just distal to the inguinal ligament and ending at the junction of the middle and lower third of the thigh (in the groin). It divides into seven branches and supplies parts of the lower limb and trunk.

**Fiber** – a slender, elongated thread or filament; a strand of nerve, muscle, or connective tissue.

**Fistula** – an abnormal passage from an internal organ to the body surface or between two internal organs, caused by a congenital defect, injury, or infection. Fistulas may be created for therapeutic purposes or to obtain body secretions for physiology studies. An arteriovenous fistula is commonly created to gain access to the patient’s bloodstream for dialysis. Anal fistulas resulting from rupture or drainage of abscesses may be treated by fistulectomy (removal of) or fistulotomy (opening into).

**Flatus** – air or gas in the intestine that is passed through the rectum.

**Fluid Retention** – an abnormal involuntary accumulation of fluid, usually in the bladder or in the lungs usually due to cardiovascular deficits (where you could see swelling in the extremities, usually of the lower extremities, or extra fluid in the lungs causing increased shortness of breath).
**Fluoroscopy** - a technique in radiology (x-rays for visually examining a part of the body) or the function of an organ using a fluoroscope. The technique offers immediate, serial images in many clinical situations, as in cardiac catheterization

**Forceps** - a pair of any of a large variety and number of surgical instruments, all of which have two handles or sides, each attached to a blade. The handles may be joined at one end, as a pair of tweezers, or the two sides may be separate to be conjoined in use. Forceps are used to grasp, handle, compress, pull, or join

**Fourth ventricle** - term used of the brain, a cavity filled with cerebrospinal fluid

**Functional** - as in a functional disease that affects function or performance, a condition marked by signs or symptoms of an organic disease or disorder although careful examination fails to reveal any evidence of structural or physiological abnormalities. Headache, certain heart murmurs, and constipation may be symptoms of either organic disease or functional disease

**Fungi** - a simple parasitic plant that, lacking chlorophyll, is unable to make its own food and is dependent on other life forms. A simple fungus reproduces by budding and multicellular fungi reproduce by spore formation. Of the 100,000 identified species of fungi, 100 are common in man and 10 are pathogenic

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**G**

**Galactose** - a simple sugar found in lactose (sugar milk), nerve cell membranes, sugar beets, gums, seaweed and in flaxseed. Prepared galactose, a white crystalline substance, is less sweet and less soluble in water than glucose but is similar in other properties

**Gastritis** - inflammation of the lining of the stomach. Acute gastritis may be caused by the ingestion of aspirin or other medications or by the presence of viral, bacterial, or chemical toxins. The symptoms including anorexia, nausea, vomiting, and discomfort after eating, usually abate the causative agent is removed. Chronic gastritis is usually a sign of underlying disease, as peptic ulcer. Diagnosis is by endoscopy with biopsy

**Gastroenteritis** - inflammation of the stomach and intestine accompanying numerous gastrointestinal disorders. Symptoms are anorexia, nausea, vomiting, abdominal discomfort, and diarrhea. The condition may be attributed to bacterial enterotoxins, bacterial, or viral invasion, chemical toxins, or to miscellaneous conditions, as lactose intolerance. The onset may be slow, but more often it is abrupt and violent, with rapid loss of fluids and diarrhea. Hypokalemia (low potassium in the blood) and hyponatremia (low sodium/salt in the blood) acidosis, or alkalosis (acid-base balance) may develop. Treatment is supportive, employing bed rest, sedation, intravenous replacement of electrolytes, and antispasmodic medication to control vomiting and diarrhea

**Gastroschisis** - a congenital defect characterized by incomplete abdominal wall closure and protrusion of the viscera (internal organs)
**Genetic predisposition** – the chance fluctuations in gene frequencies that may occur within a given population, due to a given genetic predisposition you or your children may acquire a specific trait or disorder

**Gingival** – the gums of the mouth, a mucous membrane with supporting fibrous tissue that overlies the crowns of unerupted teeth and encircles the necks of those teeth that have erupted

**Gingivitis** – a condition in which the gums are red, swollen, and bleeding. Most gingivitis is the result of poor oral hygiene and of the accumulation of bacterial plaque on the teeth, but it may be a sign of another condition

**Globus hystericus** – a transitory sensation of a lump in the throat that cannot be swallowed or coughed up, which often accompanies an emotional conflict or acute anxiety. The condition is thought to be due to a functional disturbance of the ninth cranial nerve and spasm of the inferior constrictor muscle that encircles the lower part of the throat. The physical examination tends to be normal, as does the barium swallow x-rays

**Glottis** – a split-like opening between the true vocal cords, also called the true glottis

**Gluteal** – pertaining to the buttocks, the main muscles of the buttocks

**Gluttony** – over indulgence of food, "stuffed feeling"

**Glycogen** – a polysaccharide that is the major carbohydrate stored in animal cells. It is formed from glucose and stored chiefly the liver. Glycogen is depolimerized to glucose and released into circulation as needed by the body

**Guarding** – some conditions (example – appendicitis) you will see the patient hold his side as if by doing that, helps to relieve the pain

**Heavy metal ingestion** – an occupational disorder caused by the inhalation of fumes of metallic oxides and characterized by symptoms similar to those of influenza. The condition occurs most among workers engaged in welding and other occupations dealing with the manipulation of metals. Access to fresh air and treatment of the symptoms usually alleviate the condition

**Hematemesis** – vomiting of bright, red blood, indicating rapid upper gastrointestinal bleeding, commonly associated with esophageal varices, or peptic ulcer. The rate and the source of bleeding are determined by endoscopic examination. Treatment requires replacement of blood by transfusion and administration of intravenous fluids and electrolyte balance. Vasoconstrictors may sometime be infused at the site of the bleeding to help reduce the amount of bleeding. Surgery may be necessary

**Hemorrhoids** – a varicosity in the lower rectum owing to congestion in the veins. Internal hemorrhoids originate above the internal sphincter of the rectum. If they become large enough to protrude from the rectum, they become constricted and
are painful. Small internal hemorrhoids may bleed with having a stool. External hemorrhoids appear outside the rectum. They are usually not painful and bleeding does not occur unless a hemorrhoidal vein ruptures. Treatment includes local application of a topical medication to lubricate, anesthetize, and shrink the hemorrhoid, sitz baths (sitting in a pan of warm water) and cold or hot compresses are also soothing. The hemorrhoids may require sclerosing by injection, ligation, or excision by a surgical procedure. Ligation is increasingly the preferred method, it is simple, effective, and does not require anesthesia. In this operation, the hemorrhoid is grasped with a forceps and a rubber band is slipped over it causing tissue necrosis and sloughing of the hemorrhoid usually occurs within 1 week. Straining to defecate, constipation, and prolonged sitting contribute to the development of hemorrhoids

Hernia – protrusion of an organ through an abnormal opening in the muscle wall of the cavity that surrounds it. A hernia may be congenital, may result from the failure of certain structures to close after birth, or may be acquired later in life, owing to obesity, muscular weakness, surgery or illness. Common kinds of hernias include femoral, hiatal, incisional, inguinal, umbilical or ventral

Hiatal hernia – protrusion of a portion of the stomach upward through the diaphragm. The condition occurs in about 40% of the population and most people display few, if any symptoms. The major difficulty in symptomatic patients is gastroesophageal reflux, the backflow of the acid contents of the stomach into the esophagus

Hirschsprung’s – the congenital absence of autonomic ganglia in the smooth muscle wall of the colon, resulting in poor or absent peristalsis in the involved segment of colon, accumulation of stool, and dilation of the bowel (megacolon). Symptoms include intermittent vomiting, diarrhea, and constipation. The abdomen may become distended to several times the normal size. The condition is usually diagnosed in infancy, but it may not be recognized until much later in childhood. Diagnosis is confirmed by barium enema, biopsy of the affected tissue shows the absence of ganglia. Surgical repair in early childhood is usually successful. A temporary colostomy is performed and the portion affected is removed. The colostomy is almost always reversed a few months later (12 weeks)

Histamine – a compound, found in all cells, produced by the breakdown of histidine. It is released in allergic, inflammatory reactions and caused dilation of capillaries, decreased blood pressure, increased secretion of gastric juice, and constriction of smooth muscles of the bronchi and uterus

Hydrochloric Acid – a compound consisting of hydrogen and chlorine. It is secreted in the stomach and is a major component of gastric juice

Hyperactive – excessive, above, or beyond, as in a hyperactive child, or hyperactive accumulation of gastric juices

Hypercalcemia – greater than normal amounts of calcium in the blood, most often resulting from excessive bone reabsorption and release of calcium, as occurs in
thyroid disorders. Symptoms may be confusion, anorexia, abdominal pain, muscle pain and weakness. Extremely high levels of blood calcium may result in shock, kidney failure, and death

Hyperextension - of a joint, a position of maximum extension

Hypermagnesium - a greater than normal amount of magnesium in the plasma, found in people with kidney failure and in those who use a large quantity of drugs containing magnesium, as antacids. Toxic levels can cause heart irregularities and depression of deep tendon reflexes and respiration. Treatment often includes intravenous fluids, a diuretic and hemodialysis

Hypersalivation - excess secretion of saliva

Hypersomnia - sleep of excessive depth or abnormal duration, usually caused by psychological rather than physical factors and characterized by a state of confusion upon awakening, extreme drowsiness, often associated with lethargy, a condition characterized by periods of deep long sleep, also called narcolepsy

Hypoaactive - slower than normal level of activity or a lesser amount of gastric juices produced are two examples

Hypokalemia - a condition in which an inadequate amount of potassium, the major intracellular cation (inside the cell), is found in the circulating blood stream. Hypokalemia is characterized by abnormal EKG's, weakness, and flaccid paralysis and may be caused by starvation, treatment of diabetes, adrenal problems or diuretic therapy

Hypotension - an abnormal condition in which the blood pressure is not adequate for normal perfusion and oxygenation of the tissues. An expanded intravascular space, a decreased intravascular volume or a diminished cardiac thrust may be the cause, low blood pressure

Hypothyroidism - a condition characterized by severe, congenital hypothyroidism and often associated with other endocrine abnormalities. Typical signs include dwarfism, mental deficiency, puffy facial features, dry skin, a large tongue, umbilical hernia, and muscular incoordination. This disorder usually occurs in areas where the diet is deficient in iodine and where goiter is endemic. Early treatment with thyroid hormone generally promotes normal physical growth but may not prevent mental retardation

Hypotonicity - pertaining to defective muscular tone or tension, a solution of lower osmotic pressure than another

I

Idiosyncratic - a physical or behavioral characteristic or manner that is unique to an individual or a group, an individual's unique hypersensitivity to a particular drug, to a food, or another substance

Iliac - one of the three bones that make up the pelvis, the wide upper portion of the pelvis
**Immunosuppressive** - of or pertaining to a substance or procedure that lessens or prevents an immune system, an immunosuppressive agent

**Impaction** - a condition of being tightly wedged into a part, overloading of an organ, as the stool in the confine, as a loop of intestine in an inguinal hernia

**Increased Intracranial Pressure** - increased or a buildup of pressure in the head caused usually by trauma or injury, other causes can be stroke or aneurysm, needing immediate treatment; a severe headache is the first and most severe symptom

**Incarcerated** - to trap, confine or constriction

**Infarction** - the development of a localized area where the tissue, organ, vessel, dies or (necrosis) resulting from tissue anoxia (no oxygen) caused by the interruption in the blood supply to the area, or less frequently by circulatory stasis produced by the occlusion of a vein that ordinarily carries blood away from the area, an example is a myocardial infarction (heart attack)

**Inflammation** - the protective response of the tissues of the body to irritation or injury. It may be acute or chronic; its cardinal signs are redness, heat, swelling, and pain, accompanied by loss of function. The process begins with a brief increase in vascular permeability. The second stage is prolonged and consists of sustained increase in vascular permeability, exudation of fluids from the vessels, clustering of leukocytes along the vessel walls, phagocytosis (break down) of microorganisms, deposition of fibrin in the vessel, disposal of the accumulated debris by macrophages (cleaning up), and finally the migration of fibroblasts (to support the tissues around the area of inflammation) to the area and the development of new, normal cells

**Insomnia** - chronic inability to sleep or to remain asleep throughout the night, wakefulness, sleeplessness, the condition is caused by a variety of physical and psychological factors, including emotional stress, physical pain and discomfort, disturbances in cerebral function, like toxic delirium and senile dementia, drug abuse and drug dependence, psychosomatic disorders, neuroses, psychoses, and psychological problems that produce anxiety, irrational fears, and tensions

**Intraluminal** - within the interior of any tubular structure, the diameter

**Intussusception** - prolapse of one segment of bowel into the lumen (diameter) of another segment of bowel. This segment of intestinal obstruction may involve segments of the small intestine, the colon, or the terminal ileum and cecum. It occurs most often in infants and small children and is characterized by abdominal pain, vomiting and bloody mucus in the stool. Surgery is usually necessary to correct the obstruction

**Irritable colon** - (irritable bowel syndrome) - abnormally increased motility of the small and large intestine generally associated with emotional stress. Most of those affected are young adults, who complain of diarrhea, or small, scanty, hard stools and occasionally abdominal pain. The pain is usually relieved by moving of the bowels. In the diagnosis of irritable bowel syndrome, more serious conditions (dysentery), lactose intolerance, and the inflammatory bowel diseases must be ruled
Although this is a functional disorder, patients experience pain and discomfort and need emotional support.

**Ischemia** – decreased blood supply to a body organ or part. Some causes are embolism (obstruction of a vessel by a blood clot), atherosclerosis (hardening of the arteries), thrombosis (the formation of a blood clot), and vasoconstriction (constriction of a blood vessel).

**Jaundice** – a yellow discoloration of the skin, mucous membranes, and sclera (the white part of the eye) of the eyes, caused by greater than normal amounts of bilirubin in the blood. Persons with jaundice may also experience nausea, vomiting, and abdominal pain and may pass dark urine. Jaundice is a symptom of many disorders, including liver disease, biliary obstruction and anemias.

**Jejunum** – one of the three portions of the small intestine, connecting proximally with the duodenum and distally with the ileum (the third portion of the small intestine). It has a slightly larger diameter, a deeper color, and a thicker wall than the ileum and contains heavy, circular folds that are absent in the lower part of the ileum. It also has larger villi than the ileum.

**Jugular vein distention** – there are two jugular veins: an external and an internal – the external receives the blood from the cranium and the deep parts of the face. It lies superficial to the sternocleidomastoid muscle as it passes down the neck to join the subclavian vein (major vein that takes blood back to the heart and lungs for reoxygenation). The internal jugular receives blood from the brain and superficial parts of the face and neck. It is directly continuous with the transverse sinus, accompanying the internal carotid as it passes down the neck and joins with the subclavian vein to form the innominate vein. They are more pronounced during expiration than during inspiration and also during heart problems such as congestive heart failure.

**Ketoacidosis** – acidosis accompanied by an accumulation of ketones in the body, resulting from faulty carbohydrate metabolism. It occurs primarily as a complication of diabetes and is characterized by a fruity odor of acetone on the breath, mental confusion, dyspnea, nausea, vomiting, dehydration, weight loss, and if untreated, coma. Emergency treatment includes the administration of insulin (secreted by the pancreas) and IV fluids and the evaluation and correction of electrolyte imbalance.

**Ketone level** – normal metabolic products from which acetone may arise spontaneously. Excessive production of these bodies leads to their excretion in urine as in diabetes, which can be measured.
Ketosis – the abnormal accumulation of ketones in the body as a result of a deficiency or inadequate use of carbohydrates. Fatty acids are metabolized instead, and the end products, ketones, begin to accumulate. This condition is seen in starvation, and most frequently in diabetes. It is characterized by ketonuria (ketones in the urine), loss of potassium in the urine, and a fruity odor of acetone on the breath. Untreated ketosis may progress to ketoacidosis, coma and death

Kussmaul's respiration – abnormally deep, very rapid, sighing respirations, resulting from air hunger characteristic of diabetes

Lacteal blockage – a blockage of one of the many central lymphatic capillaries in the villi of the small intestine. It opens into the lymphatic vessels in the submucosa. The capillary is filled with chyme that turns milky white during the absorption of fat

Lactose Intolerance – a sensitivity disorder resulting in the inability to digest lactose owing to a deficiency of or defect in the enzyme lactase. Symptoms of the disorder are bloating, flatus, nausea, diarrhea, and abdominal cramps. The diet is adjusted according to the tolerance level, restricting such foods as milk, cheese, butter, margarine, and any products containing milk, as cakes, ice cream, cream soups, and sauces

Laryngoscopy – an examination of the interior of the larynx, the instrument should be warmed and parts should be sprayed with cocaine, to observe with the aid of a small long handled mirror for reflecting the interior of the larynx

Larynx – the organ of voice, the enlarged upper end of the trachea; musculocartilaginous structure lined with mucous membrane, it consists of nine cartilages bound together by an elastic membrane and moved by muscles

Lavage – the process of washing out an organ, usually the bladder, bowel, paranasal sinus, or stomach for therapeutic purposes, to perform a lavage, kinds of lavage are blood, gastric, peritoneal dialysis lavages

Lethargy – the state or quality of being indifferent, apathetic, or sluggish, stupor or coma resulting from disease or hypnosis

Level of Consciousness – the degree of awareness of one's surroundings, this may be affected by a neurologic injury or from nonneurologic causes such as electrolyte imbalance, hepatic coma (liver), hypoglycemia (low blood sugar), hypoxia (low oxygen), or sedative overdose

Lithotripsy – a procedure where an instrument is used for crushing a stone in the urinary bladder, a kidney stone

Localize – limited to one place or part, limitation to a definite area, determination of the seat of an infection, relation of a sensation to its point of origin

Lumbar vertebrae – one of the five largest segments of the movable part of the vertebral column, distinguished by the absence of a foramen in the transverse
process and by vertebral bodies without facets. The body of each lumbar vertebra is flattened or slightly concave superiorly and inferiorly and is deeply constricted ventrally at the sides. The spinous process of each is thick, broad, and somewhat quadrilateral; the body of the fifth lumbar vertebra is much deeper ventrally than dorsally.

**Lymphadenopathy** - a disease of the lymph nodes, which is a body of alkaline fluid found in the lymphatic vessels that has a clear, transparent, colorless fluid, however, in vessels draining the intestines it may appear milky owing to presence of absorbed fats.

**Lymphatic** - of or pertaining to the lymphatic system of the body, consisting of a vast network of tubes transporting lymph, a lymph vessel conveys toward the heart; contains valves like the veins; like plasma in the blood but lymph contain no red blood cells, acts as a filter of bacteria in the body, example in the intestine.

\[ \text{Malabsorption} \ - \text{impaired absorption of nutrients from the gastrointestinal tract, it occurs in celiac disease (dilatation of the small and large intestines, a chronic intestinal disorder) sprue (a malabsorption problem in tropical areas), dysentery (one of a number of intestinal disorders), diarrhea, and other disorders and may result from an inborn error in metabolism, malnutrition, or any chemical or anatomic condition of the digestive system that prevents normal absorption.} \]

**Malaise** - a vague feeling of bodily weakness or discomfort, often marking the onset of a disease.

**Mallory Weiss syndrome** - a condition characterized by massive bleeding following a tear in the mucous membrane at the junction of the esophagus and the stomach, the laceration is usually caused by protracted vomiting in those with pylorus (at the bottom of the stomach) obstruction or by endoscopy, can be seen with arteriography (putting dye in the vein) and surgery is usually need to stop the bleeding.

**Mechanical obstruction** - is an obstruction that is not a part of the body such as a piece of meat causing an obstruction in the throat.

**Medulla oblongata** - the most vital part of the brain, continuing as the swollen portion of the spinal cord just above the foramen magnum (the spinal cord passes through it from the occipital bone in the brain) and separated from the pons (a process of tissue connecting two or more parts) by a horizontal groove, it is one of three parts of the brain stem and contains mostly white substance with some mixture of gray substance. The medulla contains the cardiac, vasomotor, and the respiratory centers of the brain, and medullary injury or disease often proves fatal.

**Mesentery** - a peritoneal fold that attaches the stomach, small intestine, pancreas, and other abdominal organs to the dorsal body wall, commonly, the term refers to the membranous folds, which invest the small intestine.
**Mesothelium** - a layer of cells derived from the mesoderm lining of the primitive body cavity, in the adult it becomes the epithelium covering the serous membranes

**Metabolic** - the aggregate of all chemical processes that take place in living organisms, resulting in growth, generation of energy, elimination of wastes, and other bodily functions as they relate to the distribution of nutrients in the blood. After digestion, metabolism takes place in two steps: anabolism, the constructive phase, in which smaller molecules (as amino acids) are converted to larger molecules (as proteins); and catabolism, the destructive phase, in which larger molecules (as glycogen) are converted to smaller molecules (as pyruvic acid). The metabolic rate is customarily expressed (in calories) as the heat liberated in the course of metabolism.

**Microbes** - a pathogenic microorganism, a small living microorganism.

**Minor motor seizures** - a transitory disturbance in brain function caused by abnormal neuronal discharges that arise initially in a localized motor area of the cerebral cortex, the manifestations depend on the site of the abnormal electrical activity, as tonic contractures of the thumb, caused by excessive discharges in the motor area of the cortex controlling the first digit. The disturbance may spread, or it may end in a shower of clonic movements or a generalized convulsion also called focal motor seizures.

**Molecules** - the smallest unit of matter that can exist alone and exhibit the characteristic chemical properties of an element or compound. A molecule is composed of two or more atoms held together by chemical forces.

**Motility** - the capability of spontaneous but unconscious or involuntary movement, the condition of being capable of movement.

**Motor Impairment** - the inability for motor movement.

**Mucopurulent** - characteristic of a combination of mucus and pus.

**Mucosa** - is a mucous membrane, which is any one of four major kinds of thin sheets of tissue that cover or line various parts of the body. They line cavities or canals of the body that open to the outside, as the linings of the mouth. They consist of a surface layer of epithelial tissue covering a deeper layer of connective tissue and protect the underlying structure, secrete mucus, and absorb water, salts, and other solutes.

**Myocardial** - of or pertaining to the heart, a thick, contractile, middle layer of uniquely constructed and arranged muscle cells that form the bulk of the heart wall, it contains a minimum of other tissue, except for the blood vessels, and is covered interiorly by the endocardium (a layer of heart muscle).

**Myoclonic** - a condition of intermittent clonic spasm or twitching of a muscle or muscles, twitching or clonic spasm of a muscle or group of muscles.

**Myopathy** - an abnormal condition of skeletal muscle characterized by muscle weakness, wasting, and histological changes within muscle tissue, as seen in any of the muscular dystrophies. A myopathy is distinct from a muscle disorder caused by
nerve dysfunction. The specific diagnosis of any myopathy is made using tests of serum enzymes, electromyography and muscle biopsy

Myotomy – the cutting of a muscle, performed to gain access to underlying tissues or to relieve constriction in a sphincter, as in severe esophagitis

N

Neurological – a systematic examination of the nervous system, including an assessment of mental status, the function of each of the cranial nerves, sensory and neuromuscular function, the reflexes, and other cerebellar functions

Neuromuscular – of or pertaining to the nerves and the muscles

Neuropathies – any abnormal condition characterized by inflammation and degeneration of the peripheral nerves

Nocturnal – pertaining to or occurring during the night, describing an individual that is active at night and sleeps during the day

O

Obstipation – a condition of extreme and persistent constipation caused by intestinal or eliminatory obstruction, a process of blocking

Obstructive bowel disorder – a blockage of the lumen of the intestinal tract which causes enlargement of a loop of bowel, abdominal distention, and if large enough can cause pain and absence of stool

Oliguria – diminished amount of urine formation, usually seen after profuse perspiration, bleeding or diarrhea

Opiates – a narcotic drug containing opium, its derivatives, or any of several semisynthetic or synthetic drugs with opium like activity, a substance that causes sleep or the relief of pain

Osmosis – the movement of a pure solvent as water through a semipermeable membrane from a solution that has a lower solute concentration to one that has a higher solute concentration

Oxidized – of an element of compound, to combine or cause to combine with oxygen, to remove hydrogen, or to increase the valence of an element, any process in which the oxygen content of a compound is increased

P

Pallor – lack of color, paleness of the skin

Palpitation – to examine by touch, to feel, process of examining by application of the hands to the external surface of the body to detect evidence of disease in the various organs
Pancreatic juice – its secretion is brought about by two hormones, secretin and pancreozymin, which are secreted by the duodenal mucosa, pancreatic juice begins to flow when the acid contents of the stomach pass through the pylorus. It is a clear, viscid, alkaline fluid resembling saliva in consistency. It contains water, protein, inorganic salts, and enzymes, from 500-800cc are secreted every 24 hours and discharged through the duodenum

Paralytic ileus – concerning paralysis, one afflicted with paralysis; as in a paralytic ileus which involves the intestinal wall with distention and symptoms of acute obstruction and prostration, it may occur after any abdominal operation

Paralyze – to cause temporary or permanent loss of muscular power or sensation, to render effective

Parasitic infection – like, caused by, or concerning a parasite, an organism that lives within, upon, or at the expense of another organism known as the host

Parasympathetic – of or pertaining to the craniosacral division of the autonomic nervous system – they originate in the nuclei (cell portion that controls its function) in the midbrain, medulla, and the sacral portion of the spinal cord, some effects of the parasympathetic stimulation are constriction of the pupil, contraction of smooth muscle in the stomach (alimentary tract), constriction of the bronchioles, slowing of the heart rate, and increased secretion by glands, except sweat glands, parasympathetic effects are specific rather than general

Parenteral – situated or occurring outside of the intestines; digestive – of foreign substances by body cells as opposed to enteral digestion, which occurs in the alimentary canal; injection – of substances into the body through any route other than via alimentary canal, as subcutaneous, IV, IM, or intrathecal injection; therapy – introduction of a substance, especially by means other than the intestinal tract

Paresthesia – abnormal sensation without an objective cause, such as numbness, prickling, and tingling, heightened sensitivity

Parietal cell receptor – pertaining to or forming the wall of a cavity, large cells on margin of the peptic glands of the stomach, which supposedly secrete hydrochloric acid

Parotid – one of the largest pairs of salivary glands that lie at the side of the face just below and in front of the external ear

Paroxysmal – a marked, usually episodic increase in symptoms, a convolution, fit, seizure, or spasm, a sudden, periodic attack or recurrence of symptoms of a disease, an exacerbation of the symptoms of a disease, sudden emotional state as of fear, grief or joy

Pathologic – pertaining to that branch of medicine that studies the nature and cause of disease, indicative of or caused by disease

Pepsin – an enzyme secreted in the stomach that catalyzes the hydrolysis of protein. Preparations of pepsin obtained from pork and beef stomachs are sometimes used as digestive aids
**Peridex** - a solution used in oral care especially when a toothbrush can no longer be used due to gingivitis as an example. It is comprised of hydrogen peroxide, saline and water in equal parts

**Peridontal disease** - surrounding a tooth or part of one with a problem such as the tissues or possibly a nerve

**Peripheral edema** - swelling of an outer part or a surface of the body, a part away from the center, as in the lower legs and feet

**Peritoneum** - an extensive serous membrane that covers the entire abdominal wall of the body and is reflected over the contained viscera (the internal organs). It is divided into the parietal peritoneum and the visceral peritoneum. In men, it is a closed membranous sac. In women, it is perforated by the free ends of the uterine tubes. The free surface of the peritoneum is smooth mesothelium (layer of tissue) lubricated by serous fluid, which permits the viscera to glide easily against the abdominal wall and against one another. The mesentery (a peritoneal fold of tissue) of the peritoneum fans out from the main membrane to suspend the small intestine.

**Peritonitis** - an inflammation of the peritoneum produced by bacteria or irritating substances introduced into the abdominal cavity by a penetrating wound or perforation of an organ in the gastrointestinal or reproductive tract. The major cause is usually appendicitis but may also be caused by intestinal diverticuli, peptic ulcers, gangrenous gallbladder, hernias, or ruptured spleen, liver, or ovarian cyst. The patient has chills, fever, breathes rapidly and shallowly, anxious, dehydrated, and unable to have a stool and may vomit fecal material. A high white cell count is usually indicative of the problem and is usually treated with surgery to correct the rupture or perforation

**Periumbilical** - around the umbilicus or "belly-button"

**Pharyngitis** - inflammation or infection of the pharynx, usually causing symptoms of a sore throat; some causes may be the herpes simplex virus, infectious mononucleosis, and a strep infection; symptoms may be relieved by analgesic medications, drinking warm or cool liquids, or saline irrigation of the throat

**Pharynx** - a tubular structure about 5 inches long that extends from the base of the skull to the esophagus and is situated just in front of the cervical vertebrae. It serves as a passageway for the respiratory and digestive tracts and changes shape to allow the formation of various vowel sounds. It is composed of muscle, is lined with mucous membranes and is divided into the nasopharynx, the oropharynx and the laryngopharynx. It contains the openings of the right and the left auditory tubes, the nares (nose) and the tonsils

**Phenothiazines** - a group of medications that exert significant influence on many organ systems of the body at once such as Compazine or Thorazine which produce antiadrenergics, anticholinergic, and antihistaminic activity

**Phobia** - abnormal fear of an object, experience or place specified

**Photophobia** - abnormal sensitivity to light, especially by the eyes. It is prevalent in diseases of the conjunctiva and the cornea
**Phrenic nerve** – one of a pair of muscular branches of the cervical (neck) plexus, arises from the fourth cervical nerve. It contains about half as many sensory as motor fibers and is generally known as the motor nerve to the diaphragm.

**Plaque** – a flat, often raised, patch on the skin, or any other organ of the body, a patch of atherosclerosis, a thin film on the teeth made up of mucin and colloidal material found in saliva and often secondarily invaded by bacteria.

**Plasma** – the watery, colorless, fluid portion of the lymph and blood in which the leukocytes (white blood cells), erythrocytes (red blood cells) and platelets are suspended. It contains no cells and is made up of water, electrolytes, proteins, glucose, fats, bilirubin, and gases. It is essential for carrying the cellular elements of the blood through the circulation, transporting nutrients, maintaining the acid-base balance of the body and transporting wastes from the tissues. Plasma and interstitial fluid correspond closely in content and protein concentration; therefore, plasma is important in maintaining the osmotic pressure and exchange of fluids and electrolytes between capillaries and tissues.

**Pleuritic chest pain** – pain associated with the inflammation of the pleura of the lungs (the lining surrounding the lungs), characterized by dyspnea, and stabbing pain, leading to restriction of ordinary breathing with spasm of the chest on the affected side. A friction rub may be heard on auscultation, simple pleurisy with undetectable exudate is called fibrinous or dry; pleural effusion indicates extensive inflammation with considerable amounts of exudate in the pleural spaces. Common causes include lung or chest abscess and pneumonia; the condition may result in permanent adhesions between the pleura and the adjacent surfaces. Treatment consists of relief of pain and therapy for the primary disease.

**Postganglion** – situated behind a ganglion, which is a knot or knot-like mass of nerve cells, chiefly, collected in groups outside the central nervous system. Individual cells and very small groups abound in association with alimentary organs. The two types of ganglia in the body are the sensory ganglia on the dorsal roots of spinal nerves and on the sensory roots of the trigeminal, facial, glossopharyngeal, and vagus nerves and the autonomic ganglia of the sympathetic and parasympathetic systems.

**Projectile** – vomiting not preceded by nausea in which the stomach contents are forcibly ejected.

**Prone** – lying with the face downward, referring to the hand with the palm facing downward.

**Proprioception** – sensation pertaining to stimuli originating from within the body regarding spatial position and muscular activity or to the sensory receptors that they activate.

**Propulsive** – a tendency to push or fall forward in walking, a condition seen in neurological disorders.

**Protrusions** – state or condition of being forward or projecting, a part that is prominent beyond a surface, like a knob.
**Pruritus** – the symptom of itching, an uncomfortable sensation leading to the urge to scratch, which often results in secondary infection, jaundice, lymphoma, and skin irritation, treatment depends on the cause, symptomatic relief may be obtained by antihistamines, starch baths, topical corticosteroids, cool water, or alcohol applications

**Psoriasis** – a common chronic skin disorder characterized by circumscribed red patches covered by thick, dry, silvery adherent scales that are the result of excessive development of epithelial cells, exacerbations and remissions are typical, lesions may be anywhere on the body but are more common on extensor surfaces, bony prominences, scalp, ears, genitalia, and the perianal area, treatment includes topical corticosteroids, ultraviolet light, tar solution baths, crams and shampoos and photochemotherapy

**Psychogenic** – originating within the mind, any physical symptom, disease process, or emotional state of psychological rather than physical origin

**Pulmonary** – of or pertaining to the lungs

**Purulent** – producing or pertaining containing pus

**Pyloric Obstruction** – (or stenosis) is a narrowing of the pyloric sphincter at the outlet of the stomach, causing an obstruction that blocks the flow of food into the small intestine. The condition occurs as a congenital defect in 1 of 200 newborns and, occasionally, in older adults secondary to an ulcer or fibrosis at the outlet. Diagnosis is made in infants by the presence of forceful projectile vomiting and palpitation of a hard, prominent pylorus, and in adults by x-ray following barium ingestion, after surgery, a stomach tube remains in place and observation is maintained for signs

**Pyloroplasty** – a surgical procedure performed to relieve pyloric stenosis resulting from chronic gastric ulcer, before surgery, any electrolyte imbalance or fluid deficiencies needs to be corrected, sodium chloride and potassium chloride solutions may be given to correct ion imbalances from vomiting, which is a characteristic of the condition. The passageway is dilated. The operation allows the alkaline secretions of the duodenum to flow back into the stomach, branches of the vagus nerve that supply the acid-secreting portion of the stomach may be cut, reducing the acidity of the stomach contents; diarrhea is a common postoperative complication

**Pylorus** – a tubular portion of the stomach that angles to the right from the body of the stomach toward the duodenum, it is marked by the thickening of the pyloric sphincter and its lining is composed of an intestinal kind of epithelium rather than the gastric kind common to the body of the stomach

**Pyrosis** – a percordial, substernal or epigastric burning sensation, often associated with the eructation (vomiting) of acid contents from the stomach, it may be a symptom of esophagitis
Rales – a common abnormal respiratory sound heard on auscultation of the chest during inspiration, characterized by discontinuous bubbling noises. Fine rales have a crackling sound produced by air entering distal bronchioles or alveoli that contain serous secretions, as in congestive heart failure, medium rales are medium pitched bubbling or gurgling sounds caused by air passing through secretions in the bronchioles or by separation of bronchiolar walls previously adhered by exudate, coarse rales originate in the larger bronchi or trachea and have a lower pitch.

Rectal – the portion of the large intestine, about 5 inches long between the sigmoid colon and the anal canal which ends up to the opening to the outside of the body

Reflux – an abnormal backward or return flow of a fluid, usually associated with gastroesophageal - meaning the stomach contents are regurgitated back into the esophagus and out the mouth

Regurgitation – the return of swallowed food into the mouth, the backward flow of blood through a defective heart valve, named for the affected valve such as aortic regurgitation

Remission – the partial or complete disappearance of the clinical and subjective characteristics of a chronic disease, it may be spontaneous or the result of therapy, in some cases, remission is permanent and the disease is cured

Repulsion – the act of repelling, disjoining, a force that separates two bodies or things

Rhinorrhea – thin, watery discharge from the nose

Rigidity – a condition of hardness, stiffness, or inflexibility

Salivary – of or pertaining to saliva or its formation, which is a clear, viscous fluid secreted by the salivary and mucous glands in the mouth. It contains water, mucin, organic salts and the digestive enzyme ptyalin. It moistens the oral cavity to initiate the digestion of starches and to aid in chewing and swallowing

Scleroderma – a relatively rare autoimmune disease afflicting the blood vessels and connective tissue, characterized by fibrous degeneration of the connective tissue of the skin, lungs, and internal organs, most common in middle aged women, signs include skin changes, joint deformity, and pain on movement, a biopsy may be done to diagnose the condition, x-ray will diagnose it if systemic, corticosteroids may help treat the symptoms, and salicylates and mild analgesics may ease joint pain

Scoliosis – lateral curvature of the spine, a common abnormality in childhood. Causes include congenital malformations of the spine, poliomyelitis, skeletal dysplasias, spastic paralysis, and unequal leg length. Early recognition and
orthopedic treatment may prevent progression. Treatment includes braces, casts, exercises, and corrective surgery.

**Sigmoidoscopy** – an endoscope used to examine the lumen (diameter) of the sigmoid colon. It allows for direct visualization of the mucous membrane lining the colon.

**Sinusitis** – inflammation of the sinus tracts. It may be a complication of an upper respiratory infection, dental infection, allergy, a change in atmosphere, or a structural defect of the nose. With swelling of the nasal mucous membranes the openings from sinuses to the nose may be obstructed, resulting in an accumulation of sinus secretions, causing pressure, pain, headache, fever, and local tenderness. Treatment includes steam inhalations, nasal decongestants, analgesics, and if infection is present, antibiotics.

**Skin turgor** – the normal resiliency of the skin caused by the outward pressure of the cells and interstitial fluid. Dehydration results in decreased skin turgor, manifested by lax skin, which when grasped and raised between two fingers, slowly returns to a position level with the adjacent tissue or may appear wrinkled. Marked edema or ascites results in increased turgor manifested by smooth, taut, shiny skin that cannot be grasped and raised. An elevation of the turgor of the skin is an essential part of the physical assessment.

**Spasm** – an involuntary muscle contraction of sudden onset, as habit spasms, hiccups, stuttering, or a tic. A convulsion or a seizure, a sudden transient constriction of a blood vessel, bronchus, esophagus, pylorus, ureter, or other hollow organ.

**Spina bifida** – a relatively common congenital neural tube defect characterized by a developmental anomaly in the posterior vertebral arch. It may occur with only a small deformed lamina separated by a midline gap, or it may be associated with the complete absence of laminae surrounding a large area.

**Spinal cord trauma** – any one of the traumatic disruptions of the spinal cord, often associated with extensive musculoskeletal involvement. Common spinal cord injuries are spinal fractures and dislocations. Such trauma may cause varying degrees of paraplegia and quadriplegia (the inability to move either two limbs or four). Injuries to spinal structures below the first thoracic vertebra may produce paraplegia. Injuries to the spine above the first thoracic vertebra may cause quadriplegia. Injuries that completely transect the spinal cord causes permanent loss of motor and sensory function.

**Staphylococci** – a bacteria normally found on the skin and in the throat; certain species cause severe, purulent infections, which may cause nausea, vomiting or diarrhea. Staph aureus is a species frequently responsible for abscesses, endocarditis (inflammation of the lining of the heart), impetigo (skin infection), osteomyelitis (inflammation of the bones), pneumonia, and septicemia (infection in the blood stream).

**Sternum** – the elongated, flattened bone forming the middle portion of the thorax. It supports the clavicles, articulates with the first seven pairs of ribs, and
comprises the xiphoid process. It is composed of highly vascular tissue covered by a thin layer of bone. The sternum is longer in men than in women.

**Stomatitis** – inflammation of the mouth. It may result from infection by bacteria, viruses or fungi, from exposure to certain chemicals or drugs; from vitamin deficiency; or from a systemic inflammatory disease.

**Strangulated** – the constriction of a tubular structure of the body, as the trachea, that impedes circulation or prevents function.

**Stricture** – any abnormal narrowing of the lumen of a hollow organ, as the esophagus, ureter or urethra, owing to inflammation, external pressure, or scarring. Treatment varies depending on the cause.

**Suprarenal** – situated above the kidney.

**Symmetrical** – of the body or parts of the body: equal in size or shape, different in placement or arrangement about an axis.

**Sympathetic** – the same as autonomic nervous system - refer to it above.

**Sympathomimetics** – noting a pharmacological agent that mimics the effects of stimulation of organs and structures by the sympathetic nervous system by occupying adrenergic receptor sites and acting as an agonist or by increasing the release of the neurotransmitter norepinephrine at postganglionic nerve endings. Various agents are used as decongestants of nasal and ocular mucosa and used for maintaining blood pressure during surgery under spinal anesthesia. Side effects may include nervousness, headache, anxiety, vertigo, nausea, vomiting, dilated pupils, glycosuria (sugar in the urine), and dysuria (painful urination).

**Symptomatology** – the science of symptoms and indications, all of the symptoms of a given disease as a whole.

**Systemic** – of or pertaining to the whole body rather than to a localized area or regional portion of the body.

**Systemic Inflammatory Disease** – an infection that would involve all body systems such as bacteria in the blood or possibly a disease such as lupus.

**T**

**Tachycardia** – a circulatory condition in which the myocardium (heart rate) contracts regularly but at an accelerated rate of 100-150 beats per minute. Pathologic tachycardia accompanies anoxia, as caused by anemia, congestive heart failure, hemorrhage or shock.

**Tachypnea** – an abnormally rapid rate of breathing as seen with possibly a high fever.

**Tenesmus** – persistent, ineffectual spasms of the rectum or bladder, accompanied by the desire to empty the bowel or bladder. Intestinal tenesmus is a common complaint in inflammatory bowel disease and irritable bowel disease.

**Thoracic** – of or pertaining to the thorax, which is the cage of bone and cartilage containing the principal organs of respiration and circulation and the covering part.
of the abdominal organs. It is formed by the sternum, the 12 thoracic vertebra and the 12 ribs.

**Thoracic vertebrae** - one of the 12 bony segments of the spinal column of the upper back, designated T1 to T12. T1 is just below the seventh cervical vertebra (C7) and T12 is just above the first lumbar (L1). The thoracic portion of the spine is flexible and has a concave ventral curvature. Each vertebrae becomes thicker and heavier in descending order from T1 to T12.

**Thyroid gland** - a highly vascular organ at the front of the neck, consisting of bilateral lobes connected in the middle by a narrow isthmus. It is slightly heavier in women than in men. The gland secretes the hormone thyroxin directly into the blood and is part of the endocrine system of the ductless glands. It is essential to normal body growth in infancy and childhood, and its removal greatly reduces the oxidative processes of the body, producing a lower metabolic rate characteristic of hypothyroidism. The thyroid is activated by the pituitary hormone and requires iodine to elaborate thyroxin.

**Tonically** - pertaining to or characterized by tension or contraction, especially muscular tension, restoring tone, or a medicine that increases strength and tone.

**Tonic-clonic** - both tonic and clonic, said of muscular spasms or seizures.

**Toxemia** - distribution throughout the body of poisonous products of bacteria growing in a focal or local site, thus producing generalized symptoms (constitutional disturbances, rigors, increased temperature, diarrhea, vomiting, pulse and respiration quickened or depressed prostration.

**Toxin** - a poisonous substance of animal or plant origin.

**Tracheostomy** - an operation of cutting into the throat to the trachea usually for insertion of a tube to overcome tracheal obstruction or the inability to breathe through the nose or mouth.

**Tricyclic antidepressants** - (same as anti depressant) - of or pertaining to a substance or a measure that prevents or relieves depression, a mood disturbance characterized by feelings of sadness, despair, and discouragement resulting from and proportionate to some personal loss or tragedy, an abnormal emotional state characterized by exaggerated feelings of sadness, melancholy, dejection, worthlessness, emptiness, and hopelessness that are inappropriate and out of proportion to reality.

**U**

**Ulcerations** - of the nature of an ulcer or affected with one - an open sore or lesion of the skin or mucous membrane of the body, with loss of substance, sometimes accompanied by formation of pus, simple ulcers may result from trauma, caustics, or intense heat or cold.

**Ulcerative colitis** - a chronic, episodic, inflammatory disease of the large intestine and rectum, characterized by profuse watery diarrhea containing varying amounts
of blood, mucous, and pus, and easily confused with Crohn’s disease. The attacks of diarrhea are accompanied by tenesmus, severe abdominal pain, fever, chills, anemia, and weight loss. Children with the disease suffer retarded physical growth. Diagnosis is aided by x-ray and biopsy. Treatment includes use of corticosteroids, or other anti-inflammatory agents, and surgery

**Umbilicus** – the point on the abdomen at which the umbilical cord joined the fetal abdomen, marked in the adult by a depression but sometimes by a protrusion

**Ureter** – one of a pair of tubes, that carry the urine from the kidney into the bladder, they are thick walled and are divided into an abdominal portion and a pelvic portion

**Uveitis** – inflammation of the uveal tract of the eye, including the iris, ciliary body, and choroid. It may be characterized by an irregularly shaped pupil, inflammation around the cornea, pus, opaque deposits on the cornea, pain, and lacrimation. Causes include allergy, infection, trauma, diabetes, collagen diseases, and skin diseases. A major complication may be glaucoma

**Uvula** – the small, cone-shaped process suspended in the mouth above the root of the tongue from the middle of the posterior border of the soft palate

**V**

**Vagotomy** – the cutting of certain branches of the vagus nerve, performed with a gastric surgery, to reduce the amount of gastric acid secreted and lessened the chance of recurrence of a gastric ulcer. Since peristalsis will be diminished, a pyloroplasty or an anastomosis of the stomach to the jejunum is done to assure proper emptying of the stomach

**Vagus nerve** – either of the longest pair of cranial nerves essential for speech, swallowing, and the sensibilities and functions of many parts of the body, it is the 10th cranial nerve arising in the medulla in the brain. Vagus means “wanderer” – that they are the only nerves that extend beyond the region of the head and neck. The vagus nerves supply most of the nerves in the neck, thorax and abdomen

**Valsalva** – a method for testing the patency of the eustachian tubes. With mouth and nose held tightly closed, a forced expiratory effort is made; if the eustachian tubes are open, air will enter into the middle ear cavities and the subject will hear a popping sound

**Varices** – a tortuous, dilated vein, an enlarged, tortous artery or a distended twisting lymphatic, seen frequently in the esophagus or in the intestine

**Ventricular gallop** – an abnormal cardiac rhythm in which a low-pitched extra heart sound is heard early in diastole on auscultation of the heart, when heard in a healthy young child or young adult, it is called a physiologic third heart sound and will usually disappear as he ages

**Vertebral column** – the flexible structure that forms the axis of the skeleton and are arranged in a straight line from the base of the skull to the coccyx. The
vertebrae are separated by intervertebral discs. They provide attachment for various muscles, which give the column strength and flexibility

**Vestibular** – of or pertaining to a vestibule. As the vestibular portion of the mouth, which lies between the cheeks and the teeth, a space or cavity that serves as an entrance to a passageway

**Videofluoroscopy** – video taping of an x-ray process

**Viral** – any of the diseases caused by 1 of approximately 200 viruses pathogenic to humans, some are the most communicable and dangerous diseases known; some are mild and transient conditions that pass virtually unnoticed. If cells are damaged by the viral attack, disease exists. The signs of infection reflect the anatomic location in the damaged cells. Viruses are introduced in the body through a break in the skin, a blood transfusion, droplet infection through the respiratory tract, or by ingestion through the digestive tract into the gastrointestinal system

**Viruses** – a minute microorganism much smaller than a bacterium, having no independent metabolic activity, may only replicate within a cell of a living plant or animal host, a virus consists of a core of nucleic acid (DNA or RNA) surrounded by a coat of protein

**Visceral** – any one of the large internal organs contained in the abdominal, the thoracic, or the pelvic cavities of the body

**Vitamin D intoxicification** – a disease when too much vitamin D is ingested

**Vomitus** – same as emesis, look above for definition

**W**

**Widened Pulse Pressure** – when the difference between the systolic and diastolic pressures, normally 30-40 mm Hg becomes greater than the normal as in 100/60 versus 150/60

**X**

**Y**

**Z**

**Zenker's diverticulum** – a circumscribed herniation of the mucous membrane of the pharynx as it joins the esophagus. Food may become trapped in the diverticulum and may be aspirated. Diagnosis is confirmed by x-ray studies. In most cases it is small, causes no dysfunction, is not diagnosed, and requires no treatment
BIBLIOGRAPHY

GASTROINTESTINAL SYSTEM

Acid Reflux and Heartburn, Dr. Minocha, Professor of Medicine and Director, Division of Digestive Diseases, University of Mississippi Medical Center, Jackson, MS. 2002

Assessments, Chapter 11, Pages 384 - 431, Nurses Reference Library, Springhouse Publishing Company, 1986


Choosing Feeding Equipment, Suzanne Evans Morris, PhD., Speech-Language Pathologist, New Visions, 1997

Chronic Constipation and Encopresis in Children, Dr. Stephen M. Borowitz, January 22, 2002, Children’s Medical Center of the University of Virginia


Constipation: A Guide for Patients, James A. Clifton, Center for Digestive Diseases Iowa Health Book: Internal Medicine, University of Iowa Hospitals and Clinics, November, 1994

Constipation in Children, Colin D. Rudolph MD, PhD., Children’s Center for Motility Disorders, Children’s Hospital Medical Center, Cincinnati, Ohio 45229 at the 1998 International Family Conference

Definitions, Nurses Reference Library, Springhouse Publishing Company, 1986

Diagnostics, Chapter 27, Pages 809 - 887, Nurses Reference Library, Springhouse Publishing Company, 1986

Diseases, Chapter 10, Pages 648 - 718, Nurses Reference Library, Springhouse Publishing Company, 1986
Duodenal Ulcer, U. S. National Library of Medicine, 8600 Rockville Pike, Bethesda MD, 20894, September, 2002

Emergencies, Chapter 7, Pages 296 - 337, Nurses Reference Library, Springhouse Publishing Company, 1986

Enteral Feeding, Abdullah Abdulaziz Al Zaben, February 16, 2002

Expanding Children’s Diets, Susanne Evans Morris, PhD., Speech-Language Pathologist, New Visions, 1999


Feeding And Speech Relationships, Suzanne Evans Morris, Ph D., Speech-Language Pathologist, New Visions, 1998

Feeding Tube, Tips For Daily Living With Huntington’s Disease, Jean Miller, April 19, 2000

Feeding Tubes, Jean Miller, Huntington’s Disease Advocacy Center

Food Progressions For Biting And Chewing, Suzanne Evans Morris, PhD., Speech-Language Pathologist, New Visions, 2000


For People In Pain, American Pain Society, 1996-2002

Gastroenteritis, Vinay N. Reddy, MD, May 12, 2001

Gastroenterology and Hepatology: Peptic Ulcer Disease, Jatinder P.S. Ahluwalia, MD, Mark A. Graber, MD, William B. Silverman, MD, Division of Gastroenterology and Hepatology and Department of Internal Medicine, Family Medicine, and Emergency Medicine, University of Iowa Hospitals and Clinics and College of Medicine, 2002

Gastroesophageal Reflux Disease (Hiatal Hernia and Heartburn), the National Digestive Diseases Information Clearing house, NIH Publication No. 94-882, April, 2000


Heartburn and Hiatus Hernia, by Dr. Matin D. Smith, University of Iowa Medical Center, 2002

Hiatus Hernia, Jackson Gastroenterology, 423 North 21st Street, Suite 100, Camp Hill, Pa. 17011, 2002

Hiccups, Dr M. P. Churchill, 2001

Hiccups, Safe Natural Cures

How I Do It - Laparoscopic Anterior Fundoplication by A. Munro, Department of Surgery, Raigmore Hospital, Inverness, UK, J.R. Coll.Surg.Edinb, 45, April, 2000, Pages 93-98

How To Care For Your Feeding Tube (Gastrostomy Tube). Dr. Mel Sharafuddin, Iowa Endovascular Department, University Of Iowa Health Care


Implantable Therapies For Chronic Pain And Neurological Disorders, Advanced Neuromodulation Systems, Inc. 2001-2002

Infections - Appendicitis, Dr. Winston Greene, Kid’s Health, November, 2002

Introductory Anatomy: Digestive System, Dr. D. R. Johnson, Centre for Human Biology

Irritable Bowel Syndrome, Keith D. Lindor, MD, Department of Internal Medicine, Division of Gastroenterology, Mayo Clinic, Rochester, Minnesota

Lactose Intolerance, the National Digestive Diseases Information Clearinghouse, NIH Publication No. 02-2751, May, 2002

Management of Constipation in the Terminally Ill Patient, Ken MacKinnon, October 14, 1997

Managing PEG Tubes And Feeding Tubes, Theresa M. Ortega and Marcella F. Harb-Hauser, Max's House

Mouth Stuffing, Suzanne Evans Morris PhD., Speech-Language Pathologist, New Visions, 1998

Nasal Gastric Bolus Feeding, Cincinnati Children's Hospital Medical Center, 1999-2002

Nausea and Vomiting as Symptoms and Side Effects, Power-Grape – a Digest of Disease Management News, February 1999 Volume 3, Number 2

Oncology - Percutaneous Endoscopic Stomas For Enteral Feeding and Drainage, Moshe Shike, MD, Gastroenterology - Nutrition Service, Memorial Sloan-Kettering Cancer Center, New York, Volume 9, No 1, January 1995

Parenteral Feeding Administration and Dosage, Patient Teaching, Chapter 8, Pages 204 - 253, Nurses Reference Library, Springhouse Publishing Company, 1986


Questions and Answers About Hiccups, Larry R. Nolan, President of Nolan Research Inc, U.S. Food and Drug Administration

Refusal Of First Foods, Suzanne Evans Morris PhD., Speech-Language Pathologist, New Visions, 1997


Swallowing Disorders, by Peter J. Casano, MD, American Academy of Otolaryngology – Head and Neck Surgery, One Prince Street, Alexandria, VA 22314-3357, 1-800-836-4444, 2002

Taber's Cyclopedic Medical Dictionary, Edition 11, FA Davis Company

Tube Feeding, Betsy Gettig, MS, CGC & Toni Finney, BS, Department Of Human Genetics, University of Pittsburgh, September 5, 2000

Tube Feeding In Degenerative Syndromes, Polly Green, B.S., M.S., Kennedy Krieger Institute, Baltimore, Maryland

Tube Feeding Management

Tube Feeding: Medical Treatment or Basic Care? Adrian Treoloar & Philip Howard, August 1998, CMQ

Tube Feeding With Gravity Feeding Set- Home Care, Cincinnati Children's Hospital Medical Center, 1999-2002

Vomiting and Diarrhea - Caring For A Child With Vomiting And Diarrhea, Dr. Suser, Surge Electronics Media, Inc.


Your Feeding Tube Placement, Wake Forest University School of Medicine, Wake Forest University Baptist Medical Center