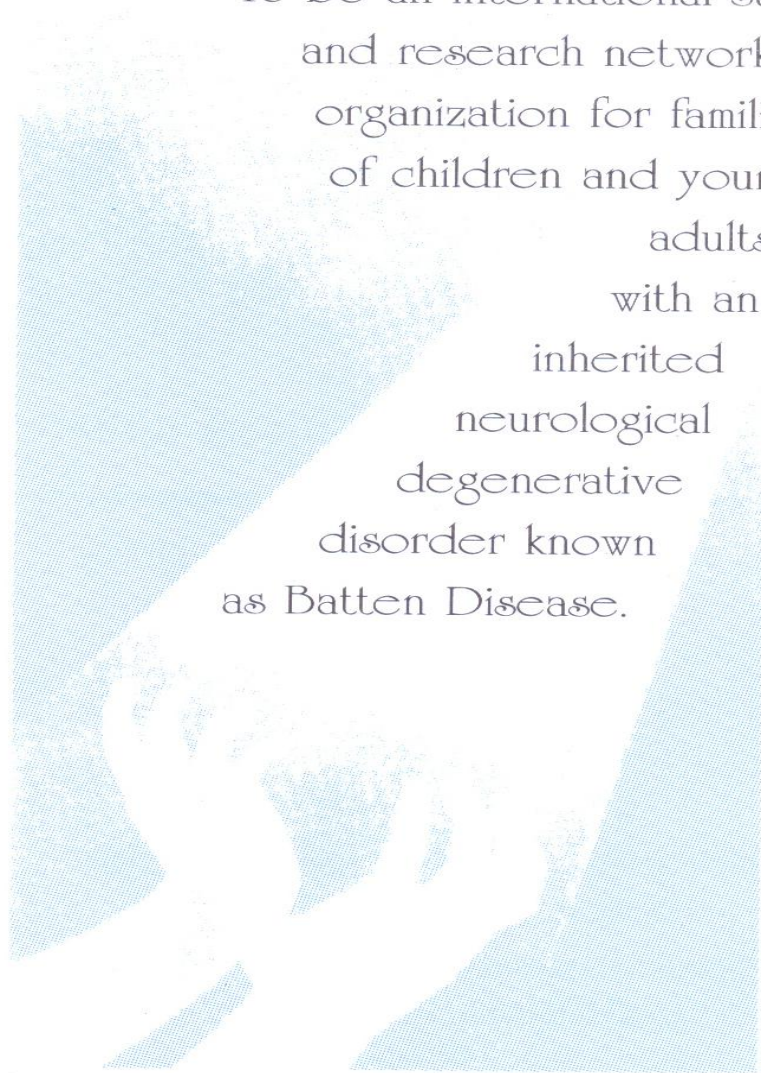


The mission of BDSRA is:

To be an international support
and research networking
organization for families
of children and young
adults
with an
inherited
neurological
degenerative
disorder known
as Batten Disease.



“A light in a world of darkness...”

BDSRA NOVEMBER 2000

DENTAL ISSUES & MOUTH CARE

WELCOME

NOTICE TO THE READER

This Batten Disease Handbook is compiled with information from many sources concerning the topics included. Families in the organization have also contributed their specific situations that have been helpful in their own battle with Batten Disease. All material in this book is provided for information purposes only. Although Batten Disease Support and Research Association (BDSRA) has made every reasonable effort to assure the accuracy of the information contained in this book, BDSRA is not engaged in rendering medical or other professional services and advice. BDSRA does not guarantee or warrant that the information in the book is complete, correct, current, or applicable to every situation. BDSRA disclaims all warranties express or implied, concerning this book and the information contained herein. If medical or other expert assistance is required, the services of a competent professional should be attained.

Nancy Carney, RN
Batten Disease Support and Research
Updated December 2011

DENTAL ISSUES AND MOUTH CARE

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Dental Issues And Mouth Care

In communities and states across the country, Americans with developmental disabilities are experiencing significant difficulty in gaining access to quality medical and dental care. In order to see any betterment in this issue there are two crucial issues. First, clinicians need to advocate on a national level to create a national dialogue between the Physicians and Dentists who care for these special children. Second, there will be no change until medical and dental schools begin to be responsible to educate and train the next generation of caregivers. If we are to be successful, two components must be met, clinical experience and educational commitment must be adjoined.

Oral health is an integral part of total health. If you do not have good oral health, you are not healthy. In spite of continuing scientific evidence linking periodontal disease to cardiovascular disease, Physicians often ignore doing an oral exam as part of their routine physical examination. They rarely, if ever, concern themselves with oral conditions unless your child presents with a specific complaint. As a matter of fact, when it comes to oral examinations, the universal term WNL (within normal limits) has come to mean "we never look". Individuals with disabilities have poorer overall oral health and oral hygiene than the general population, and there is evidence that your children with special needs, experience significant disparities in their access to quality dental services. The reasons for this health disparity are complex and include lack of caregiver support, Dentist reimbursement issues, genetic and other physiological disorders, medication toxicity, cultural and environmental factors, coexisting psychiatric or behavioral disorders and others.

A. Medical Management Considerations - Special Care in Oral Health

What is special care? It is an approach to oral health management tailored to your child's needs who has a variety of medical conditions or limitations that require more than routine delivery of oral care. Special care encompasses preventive, diagnostic and treatment services.

Standard treatment procedures can be adapted to fit most children's needs and abilities. While some children require more specialized care, most can be treated successfully in general dental practices.

Why do children need special care?

Some children need routine oral health care, but have medical conditions or limitations that require delivery beyond the routine. The dental team, for example, may need to learn to transfer a child from a wheelchair to the dental chair, to uses of sign language to communicate, or to adapt oral hygiene devices so that a child/parent or caregiver can use them.

Other children have medical and oral conditions that call for extraordinary care and require oral health professionals to have specialized knowledge.

The oral health of special care children may be neglected because of a demanding disease, a disabling condition, or limited access to oral health care. The coordination of care and an understanding of special care issues in oral health are essential for all members of your child's health care team, including medical and dental professionals and caregivers.

B. Vital Functions of the Mouth

The tongue, teeth, and lips modify sound for speech. The nearly oval oral cavity at the anterior end of the digestive tube, bounded anteriorly by the lips and containing the tongue and the teeth, lie between the cheeks communicating with the pharynx. 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. We have to be careful not to give our children with disabilities too hot of food or it may burn the tongue and then we also loose our taste buds (we all have experienced this in our lifetimes). This may happen more frequently with our disabled children, so we need to be extra careful to avoid this problem.

Diseases of the mouth cavity may be indications of purely local disease (involving only the mouth) or they may be symptoms of systemic disturbances such as dehydration, anemia, or nutritional deficiencies (which may involve the entire body by getting into the blood stream, where it becomes a much more serious problem). The mouth can be a minor problem one day and a major problem the next day if not treated. If too serious, your child may stop eating and drinking due to the pain involved with certain diseases like thrush. Then many other problems can become a result, such as dehydration. If your child is a toddler, a couple of days of dehydration and they will be in a hospital replenishing their fluids.

People with developmental disabilities are at an increased risk for both dental malformation and dental disease. The increased risk is partly attributable to underlying disorders, congenital infections, malformations of the jaw and/or mouth, behavioral problems, differences in eating patterns or diet, and the use of certain medications. Oral health is important for adequate nutrition, speech, and aesthetics (a condition of feeling, sensation or perception). Despite the increased risk of disease and the importance of good health, dental care has historically been one of the greatest unmet needs of people with developmental disabilities. It is often totally overlooked unless the patient specifically complains about something in particular. What about patients like children with Batten Disease who many cannot talk - even some parents are not aware of their mouth issues that are arising, because their children cannot talk to them. Doctors just "assume" that the mouth is OK unless otherwise specified. They are more interested in more "major" problems that the disabled child may be having. It is thus important for the primary care Physician to play an active role in preventing dental problems and making referrals for oral health. By being familiar with the dental problems associated with developmental disabilities, primary care Physicians will be able to recommend preventive measures, monitor for the onset of

USUAL SEQUENCE OF TOOTH ERUPTION

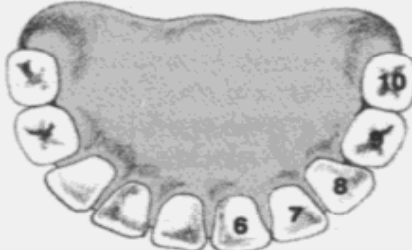
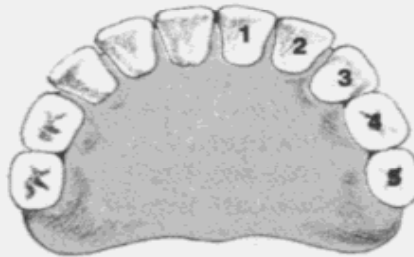
PRIMARY DENTITION

Maxillary

- 1 Central incisor: 8 to 12 months
- 2 Lateral incisor: 10 to 12 months
- 3 Cuspid: 18 to 24 months
- 4 First molar: 12 to 15 months
- 5 Second molar: 24 to 30 months

Mandibular

- 6 Central incisor: 5 to 9 months
- 7 Lateral incisor: 12 to 15 months
- 8 Cuspid: 18 to 24 months
- 9 First molar: 12 to 15 months
- 10 Second molar: 24 to 30 months



CHILD

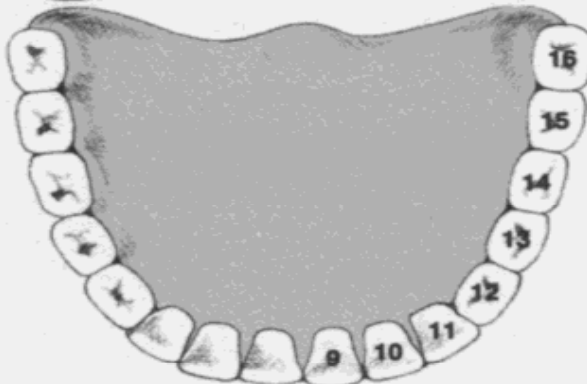
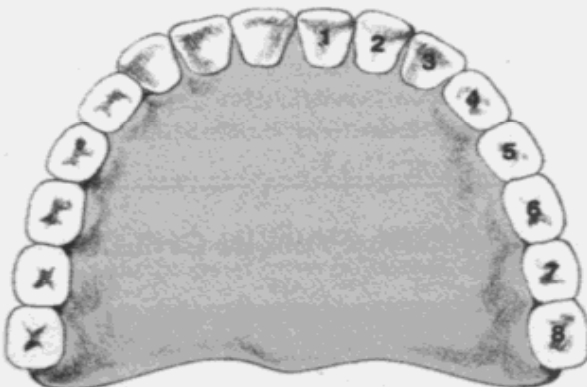
PERMANENT DENTITION

Maxillary

- 1 Central incisor: age 7 to 8
- 2 Lateral incisor: age 8 to 9
- 3 Cuspid: age 11 to 12
- 4 First bicuspid: age 10 to 11
- 5 Second bicuspid: age 10 to 12
- 6 First molar: age 6 to 7
- 7 Second molar: age 12 to 13
- 8 Third molar: age 17 to 21

Mandibular

- 9 Central incisor: age 6 to 7
- 10 Lateral incisor: age 7 to 8
- 11 Cuspid: age 9 to 10
- 12 First bicuspid: age 10 to 12
- 13 Second bicuspid: age 11 to 12
- 14 First molar: age 6 to 7
- 15 Second molar: age 11 to 13
- 16 Third molar: age 17 to 21



ADULT

problems, make appropriate referrals to oral healthcare providers, and alert oral healthcare providers of the increased risk for certain dental problems. Primary care Physicians need to make it a practice to briefly take a look at the disabled child's mouth, teeth, tongue, etc. to look for any obvious problems. How long would this take? Probably not more than 20-30 seconds. But as stated above, unless Doctors in training are taught to make the mouth part of their primary assessment and this is where it needs to be started, it will not happen. This is where the changes need to be met.

C. Types of Dental Problems

1. Dental Decay (caries and cavities)

- This is an erosive process that results from the action of bacteria on fermentable carbohydrates in the mouth, which in turn produces acids that dissolve tooth enamel.
- The extent of damage to the teeth depends on several factors, the most significant of which are: the presence of dental plaques, the strength of the acids and the ability of the saliva to neutralize them, the length of time the acids are in contact with the teeth, and susceptibility of the teeth to decay.
- Dental plaques are gluey, gelatin-like substances that adhere to the teeth and afford protection for the bacteria. The initial action that causes damage to a tooth occurs under a dental plaque.
- Dental decay begins with a small hole, usually in a fissure or flaw of the enamel, or in an area that is hard to clean. Left unchecked, it penetrates the enamel into the dentin. Because the dentin is not as hard as the enamel, decay progresses somewhat more rapidly and in time reaches the pulp.

The following picture shows the progression of dental decay.

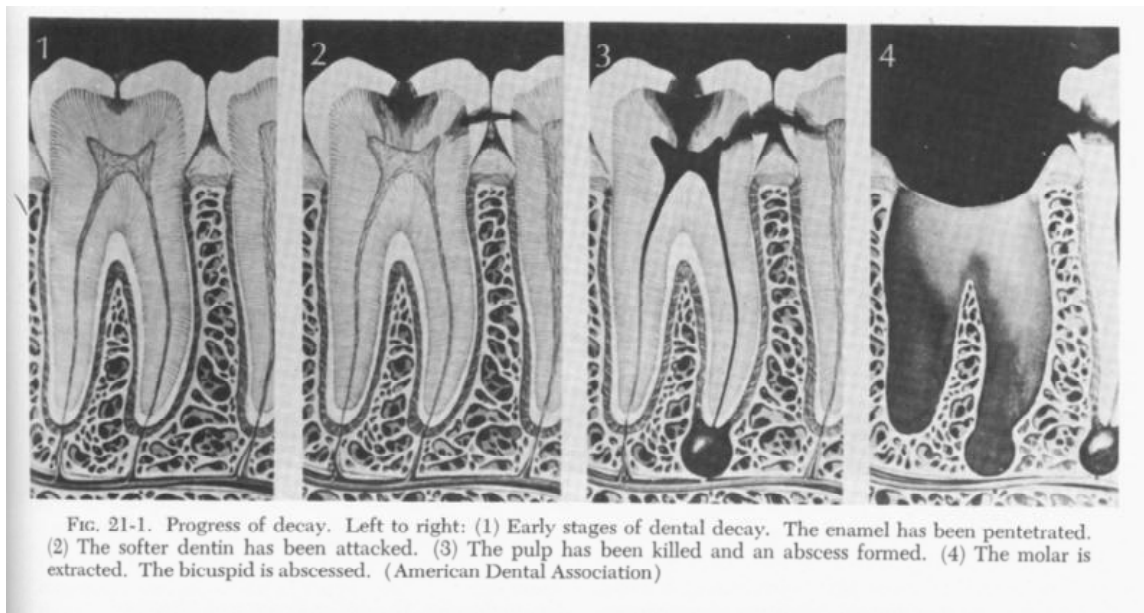


FIG. 21-1. Progress of decay. Left to right: (1) Early stages of dental decay. The enamel has been penetrated. (2) The softer dentin has been attacked. (3) The pulp has been killed and an abscess formed. (4) The molar is extracted. The bicuspid is abscessed. (American Dental Association)

- When the blood, lymph vessels and nerves are exposed, they become infected, and an abscess may form either within the tooth or at the tip of the root. Soreness and pain usually accompany the abscess. As the infection increases, the face may become swollen and there may be pulsating pain.
- The Dentist can determine by x-ray pictures the extent of damage and the type of treatment needed. It may be necessary to extract the tooth .
- Possible complications: tartar formation may cause tenderness and swelling of gums.
- Prevention: daily teeth brushing and flossing; fluoride water and toothpaste; no bottles after 12 months of age; sealants.
- Treatment: cavity fillings, tooth crowns, and/or dental sealants.
 - a. **Cavity Fillings** - most of us have had a cavity filled, the decayed part is drilled out and a white or silver fillings is put in its place.

b. **Tooth Crowns** - also are done quite frequently, an artificial covering over the natural crown of a tooth.

c. **Dental Sealants** - What are dental sealants? Sealants are thin, plastic coatings painted on the chewing surfaces of the back teeth (molars). Sealants are put on in the dental offices, clinics, and sometimes in the schools. Getting sealants put on is simple and painless. Sealants are painted on as a liquid and quickly harden to form a shield over the tooth. Sealants are clear or tinted. Tinted sealants are easier to see.

Are sealants new? No, sealants are not new. They have been around for along time! Research led to the development of sealants in the early 1960"s. But many people still do not know what sealants are. In fact, fewer than 20 percent of children in the United States have sealants.

How long do sealants last? Sealants can last up to 10 years. But they need to be checked at regular-dental check-ups to make sure they are not chipped or worn away. The Dentist can repair sealants by adding more sealant material. How much do sealants cost? Sealing one tooth usually costs less than filling one tooth. Having sealants put on healthy teeth now will save you money in the long run by avoiding fillings, crowns, or caps used to fix decayed teeth. *But the most important reason for getting sealants is to avoid tooth decay. Healthy teeth can last a lifetime!*

Does insurance pay for sealants? Many insurance companies pay for sealants. Check with your insurance company for details.

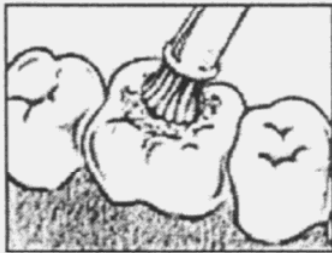
Why get sealants? By covering the chewing surfaces of the molars, sealants keep out the germs and food that cause decay.

What causes decay? Germs in the mouth change the sugar in food to acid. The acid can eat a cavity in the tooth. The decay has to be cleaned out by drilling and then the tooth has to be filled. Of course a healthy tooth is the best tooth. So it is important to prevent decay. That is why sealants are so important.

Why do back teeth decay so easily? The chewing surfaces of back teeth are rough and uneven because they have small pits and grooves. Food and germs can get stuck in the pits and stay there a long time because toothbrush bristles cannot brush them away.

Who should get sealants? Children should get sealants on their permanent molars as soon as the teeth come in - before decay attacks the teeth. The first permanent molars - called "6 year molars" - come in between the ages of 5 and 7.

The process for applying sealants to the teeth is as follows below:



The tooth is cleaned.



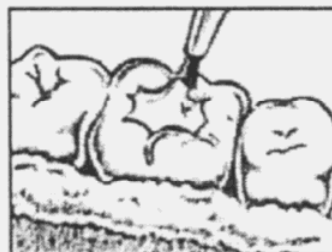
The tooth is dried, and cotton or other material is put around the tooth so it stays dry.



A solution is put on the tooth surface that makes the tooth a little rough. (It is easier for the sealant to stick to a slightly rough tooth.)



The tooth is rinsed and dried. Then new cotton is put around the tooth so it stays dry.



The sealant is applied in liquid form and hardens in a few seconds.



The sealant in place

The second permanent molars - "12 year molars" - come in when a child is between 11 and 14 years old. The other teeth with pits and grooves - called "premolars" or "bicuspid" -

right in front of the molars, also may need to be sealed. Teenagers and young adults without decay or fillings in their molars also may get sealants.

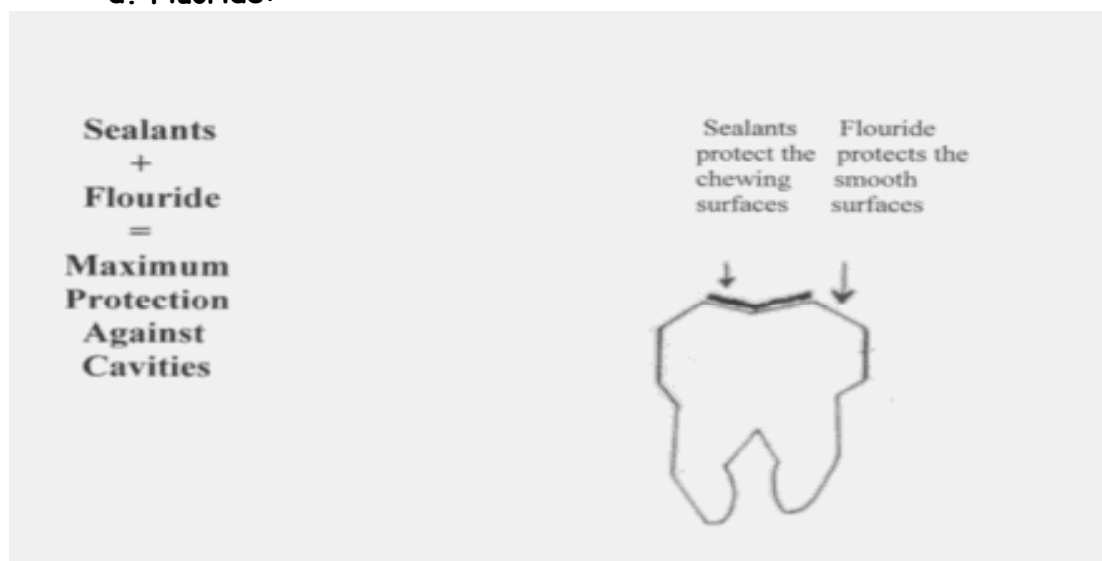
Should sealants also be put on baby teeth? Your Dentist might think it is a good idea, especially if your child's baby teeth have deep pits and grooves. Baby teeth play an important role in holding the correct spacing for permanent teeth - so it is important to keep baby teeth healthy so they do not fall out early.

How are sealants put on? The tooth is cleaned. The tooth is dried, and cotton or other material is put around the tooth so it stays dry. A solution is put on the tooth surface that makes the tooth a little rough. (It is easier for the sealant to stick to a slightly rough tooth). The tooth is rinsed and dried. Then new cotton is put around the tooth so it stays dry. The sealant is applied in liquid form and hardens in a few seconds. Then the sealant is in place.

What if a small cavity is accidentally covered by a sealant? The decay will not spread because it is sealed off from its food and germ supply.

Besides sealants, are there other ways to prevent tooth decay? Yes. The best way you can help prevent tooth decay is to brush your teeth and your child's teeth with a fluoride toothpaste and drink fluoridated water (water is fluoridated in about half the cities and towns in the United States). If your water is not fluoridated or if your teeth need more fluoride to stay healthy, your Dentist can prescribe it in the form of a gel, mouth rinse or tablet. If you have a baby or a young child that needs fluoride and do not have fluoride in your water, your Physician (Pediatrician) or Dentist can prescribe fluoride drops or tablets. Fluoride is the best defense against tooth decay!

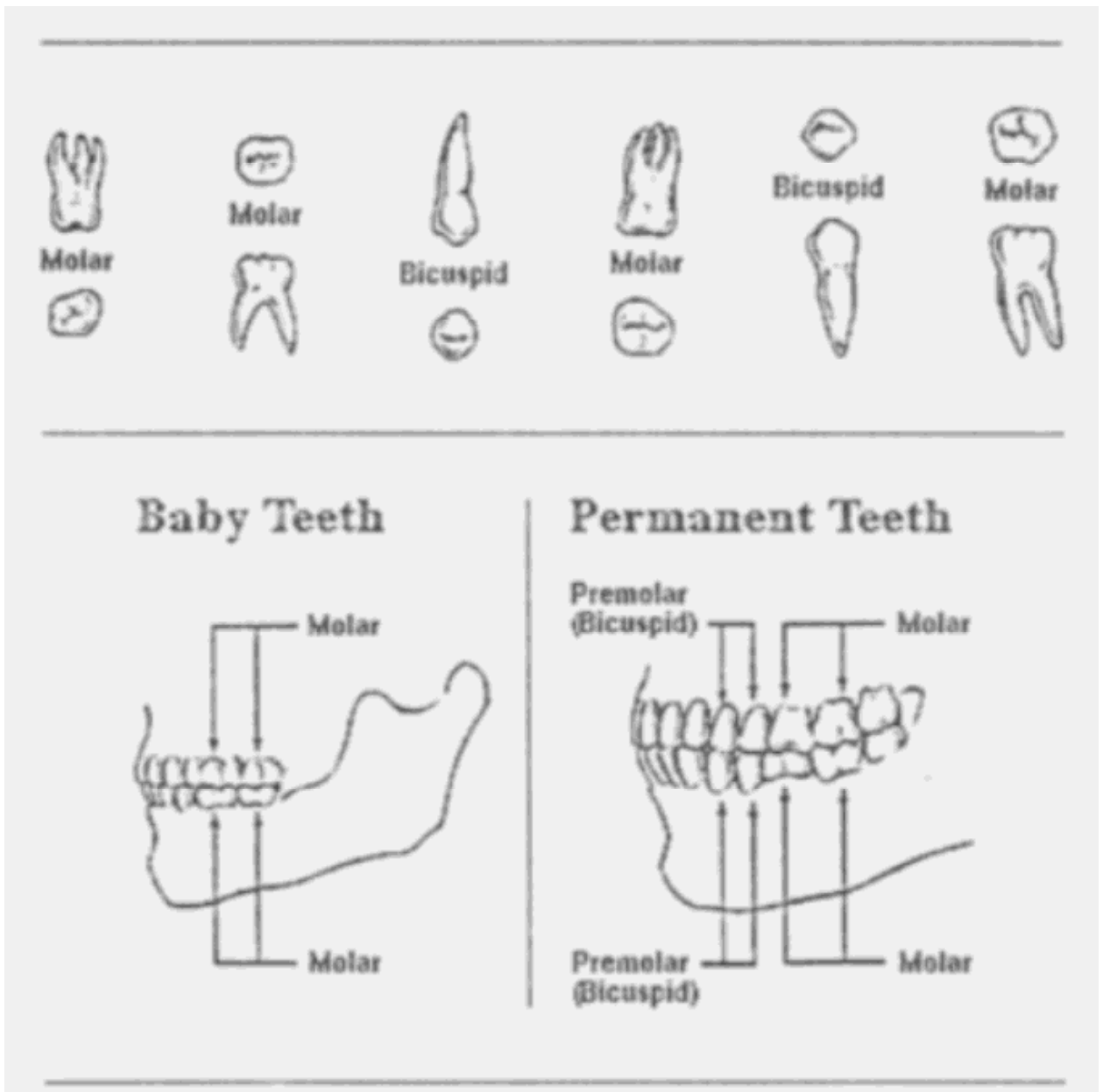
d. Fluoride:



- Makes teeth more resistant to decay.
- Repairs tiny areas of decay before they become big cavities.
- Makes germs in the mouth less able to cause decay.

Fluoride helps the smooth surfaces of the teeth the most. It is less effective on the chewing surfaces of the back teeth (molars). Regular brushing - with fluoride toothpaste - and flossing also help prevent tooth decay. *Sealants and fluoride together can prevent almost all tooth decay.*

The picture below shows the different teeth and baby teeth versus adult teeth.



e. A healthy mouth for your baby.

1. Protect your baby's teeth with fluoride - which protects teeth from tooth decay and helps heal early decay. Fluoride is in the drinking water of most towns and cities. Ask your Dentist or Doctor if your water has fluoride in it. If it does not, talk to your Dentist or Doctor about giving you a prescription for fluoride drops for your baby.

2. Check and clean your baby's teeth - healthy teeth should all be one color. If you see spots or stains on the teeth, take your baby to your Dentist. Clean your baby's teeth as soon as they come in with a clean soft cloth or a baby's toothbrush. Clean the teeth at least once per day. It is best to clean them right before bedtime. At about age 2, most of your child's teeth will be in. Now you can start brushing them with a small drop of fluoride toothpaste. Use a drop of toothpaste about the size of a large pea. As your child gets older, let him use his own toothbrush but you put the toothpaste on the toothbrush until about age 6. Very young children cannot get their teeth clean by themselves. Until your children are about age 7 years old, you should brush their teeth after they do.

3. Feed your baby healthy food. Choose foods that do not have a lot of sugar in them. Give your child fruits and vegetables instead of candy and cookies.

4. Prevent baby bottle tooth decay. Do not put your baby to bed with a bottle at night or at naptime. (If you put your baby to bed with a bottle, fill it only with water). Milk, formula, juices, and other sweet drinks such as soda all have sugar in them. Sucking on a bottle filled with liquids that have sugar in them can cause tooth decay. Decayed teeth can cause pain and can cost a lot to fill. During the day, do not give your baby a bottle filled with sweet drinks to use like a pacifier. If your baby uses a pacifier, do not dip it in anything sweet like sugar or honey. Near his first birthday, you should teach your child to drink from a cup instead of a bottle.

5. Take your child to the Dentist. Ask your Dentist when to bring your child in for his first visit. Usually, the Dentist will want to see your child between ages 1 and 2. At this first visit, your Dentist can quickly check your child's teeth.

2. Periodontal (Gum) Disease

If you have been told you have periodontal (gum) disease, you are not alone. An estimated 80% of American adults currently have some form of the disease. Periodontal diseases range from simple gum inflammation to serious disease that results in major damage to the soft tissue and bone that support the teeth. In the worst cases, teeth are lost. Gum disease is a threat to your oral health. Research is also pointing to possible health effects of periodontal diseases that go well beyond your mouth (more about this later). Whether it is stopped, slowed, or gets worse depends a great deal on how well you care for your child's teeth and gums every day, from this point forward.

a. What causes periodontal disease?

Our mouths are full of bacteria. These bacteria, along with mucus and other particles, constantly form a sticky, colorless "plaque" on teeth. Brushing and flossing help get rid of

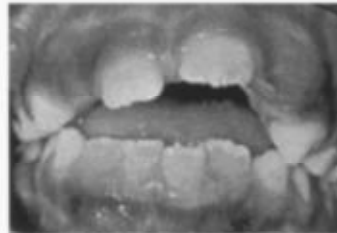
The picture below shows some of the developmental diseases that can occur.

Oral Development

Tooth eruption may be delayed, accelerated, or inconsistent in children with growth disturbances. Gums may appear red or bluish-purple before erupting teeth break through into the mouth. Eruption depends on genetics, growth of the jaw, muscular action, and other factors. Children with Down syndrome may show delays of up to 2 years. **Offer information about the variability in tooth eruption patterns and refer to an oral health care provider for additional questions.**



Malocclusion, a poor fit between the upper and lower teeth, and crowding of teeth occur frequently in people with developmental disabilities. Nearly 25 percent of the more than 80 craniofacial anomalies that can affect oral development are associated with mental retardation. Muscle dysfunction contributes to malocclusion, particularly in people with cerebral palsy. Teeth that are crowded or out of alignment are more difficult to keep clean, contributing to periodontal disease and dental caries. **Refer to an orthodontist or pediatric dentist for evaluation and specialized instruction in daily oral hygiene.**



Tooth anomalies are variations in the number, size, and shape of teeth. People with Down syndrome, oral clefts, ectodermal dysplasia, or other conditions may experience congenitally missing, extra, or malformed teeth. **Consult an oral health care provider for dental treatment planning during a child's growing years.**

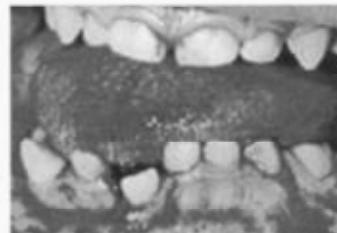


Developmental defects appear as pits, lines, or discoloration in the teeth. Very high fever or certain medications can disturb tooth formation and defects may result. Many teeth with defects are prone to dental caries, are difficult to keep clean, and may compromise appearance. **Refer to an oral health care provider for evaluation of treatment options and advice on keeping teeth clean.**



Oral Trauma

Trauma to the face and mouth occur more frequently in people who have mental retardation, seizures, abnormal protective reflexes, or muscle incoordination. People receiving restorative dental care should be observed closely to prevent chewing on anesthetized areas. **If a tooth is avulsed or broken, take the patient and the tooth to a dentist immediately. Counsel the parent/caregiver on ways to prevent trauma and what to do when it occurs.**



plaque. Plaque that is not removed can harden and form bacteria-harboring "tartar" that brushing does not clean. Only a professional cleaning by a Dentist or dental

hygienist can remove tartar.

b. Genetic Disorders - Many genetic disorders manifest themselves with different expressions of oral disease. This may include a high frequency of dental decay, susceptibility to periodontal (gum) disease, premature loss of teeth, delayed eruption of teeth or congenitally missing or malformed teeth. The mouth will offer the Dentist important clues. The types of genetic disorders can be single locus, chromosomal abnormalities, or multifactorial disorders. Then there are anomalies of the lips, gums, and the tongue. Children with Batten Disease frequently have gum problems. Several disorders may affect the gums and also the bony sockets of the teeth. The gum diseases may range from gingivitis (inflammation of the gums) to periodontal disease, which involves destruction of the bone and may lead to loss of teeth. Gingivitis is the inflammation of the marginal surface of the gums. The gums are enlarged, reddish in appearance and may bleed when touched or when using a toothbrush. Gingivitis is usually caused by poor oral hygiene, but mouth breathing may also be a factor. Oral hygiene at home will prevent most gingivitis. Periodontitis is a progressive deterioration of the support system of the tooth. A tooth may have more mobility than others and become loose. With the use of radiographs, the Dentist can see the bone loss that eventually will lead to lost teeth unless opportune periodontal treatment is provided.

1. **Gingivitis** - Inspect a child's gums carefully. Gingivitis, a common condition among children, usually results from a combination of such factors as:
 - Mouth breathing (often associated with nasal insufficiency from such problems as enlarged adenoids or allergies) in which constant passage of air dries out the gums and inflames the anterior labial gingiva.
 - Tooth eruption (the presence of both primary and permanent teeth commonly causes abnormal gingival stimulation from chewing and from food impaction).
 - Puberty (hormonal stimulation, especially in girls, contributes to gingivitis).
 - Poor hygiene
 - Crooked teeth
 - Retained primary roots
 - Poor diet

The longer plaque and tartar are on teeth, the more harmful they become. The bacteria cause inflammation of the gums that is called "gingivitis". In gingivitis, the gums become red, swollen, and can bleed easily. Gingivitis is a mild form of gum disease that can usually be reversed with daily brushing and flossing, and regular cleaning by a Dentist or dental hygienist. This form of gum disease does not include any loss of bone and tissues that hold teeth in place. Refer to the picture on gingival hyperplasia on page 22.

2. Periodontal Disease

Healthy teeth are set firmly within the jawbone and attached by periodontal fibers. Gingiva (gum tissue) surrounds the neck of the tooth, leaving a shallow crevice. Oral bacteria from food particles, tissue cells and saliva get into the gingival crevice. If these bacteria are not removed by cleaning, they form colonies called plaque. Dental plaque is the main cause of periodontal disease. When allowed to build up, plaque produces toxic-by-products that inflames and infects the gums. This early condition is called gingivitis. If dental plaque continues to build up, the irritated gums pull away from the tooth, forming pockets that trap more plaque. The process may be speeded up by the presence of tartar, which is formed when plaque combines with minerals to create a barnacle-like white or yellowish deposit. Although tartar is inert, it harbors surface bacteria and worsens the disease below the gum line. As the process accelerates, more tissue becomes diseased and more plaque accumulates. If it is not stopped, the inflammation will affect the underlying bone structure and cause its destruction. Once the bone is destroyed, there is loosening and, ultimately, loss of the teeth.

When gingivitis is not treated, it can advance to "periodontitis" (which means inflammation around the tooth". In periodontitis, gums pull away from the teeth and form "pockets" that become infected. The body's immune system fights the bacteria as the plaque spreads and grows below the gum line. Bacterial toxins and the body's enzymes fighting the infection actually start to break down the bone and connective tissue that hold teeth in place. If not treated, the bones, gums, and connective tissue that support the teeth are destroyed. The teeth may eventually become loose and have to be removed.

a. What might affect periodontal disease?

The following pictures are of progressing periodontal disease.

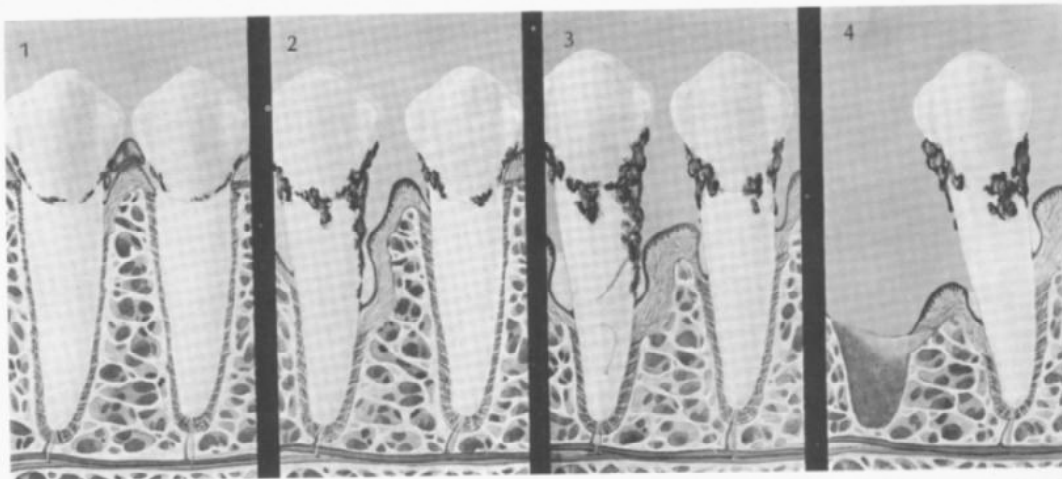


FIG. 21-2. Progress of periodontal disease. Left to right: (1) Irritations cause gums to withdraw from teeth. (2) Further destruction. (3) Most of the tissues have been destroyed. (4) One tooth is lost—the other weakened. (American Dental Association)

- Increased plaque
- A change in the composition of plaque and other microorganisms
- Loss of collagen in the gum tissue
- Vascular disorders

Things that can be done to prevent periodontal disease.

- Six-month check-ups
- Brushing and flossing
- Antibacterial plaque treatments
- Self-examination
- Watch for warning signs and call your Dentist if noticed
 1. Bleeding gums - may notice during eating or brushing your teeth.
 2. Abnormal changes - possibly tenderness, sores, bright red color on your child's Gums.
 3. White patches - may indicate the presence of thrush, a fungus infection requiring treatment.
- Dental treatment
 1. Scaling and Root planning
 2. Gum Surgery
 - A. Flap surgery
 - B. Bone and tissue grafts

b. Risk Factors

- Hormonal changes in girls/women - these changes can make the gums more sensitive and make it easier for gingivitis to develop.
- Stress - research shows that stress can make it more difficult for our bodies to fight infection, including periodontal disease.
- Medications - some drugs, such as antidepressants and some heart medications, can affect oral health because they lessen the flow of saliva. (Saliva has a protective effect on teeth and gums.)
- Genetic susceptibility - some children are more prone to severe periodontal disease than others.

c. Who gets periodontal disease?

Although teenagers rarely develop periodontal disease they can develop gingivitis, the milder form of the disease. Gum disease will develop when plaque is allowed to build up along and under the gum line.

d. What can I do to prevent gum disease?

Here are some things you can do to prevent periodontal diseases.

- Brush your teeth twice a day (with a fluoride toothpaste)
- Floss every day

- Visit the Dentist routinely for a checkup and professional cleaning
- Eat a well balanced meal

e. How do I know if my child has periodontal disease?

Symptoms are often not noticeable until the disease is advanced. They include:

- Bad breath that will not go away
- Red or swollen gums
- Tender or bleeding gums
- Painful chewing
- Loose teeth
- Sensitive teeth
- Cause: gum inflammation due to poor dental/oral care
- Influencing factors: malformed or poorly arranged teeth; bruxism; poor health; medication side effects

Any of these symptoms may signal a serious problem, which should be checked by your Dentist. At your dental visit:

- The Dentist will ask about your medical history to identify underlying conditions or risk factors that may be contributing to periodontal disease.
- The Dentist or dental hygienist will examine your child's gums and note any sign of inflammation.
- The Dentist or dental hygienist will use a tiny ruler called a "probe" to check any periodontal pockets and to measure any pockets. In a healthy mouth, the depth of these pockets is usually between 1 and 3 millimeters (very small).
- The Dentist or dental hygienist may take an xray to see whether there is any bone loss (normally an x-ray is taken once every two years unless otherwise indicated).
- The Dentist may refer you to a Periodontist, a specialist who treats gum diseases.

f. How is periodontal disease treated?

The main goal of treatment is to control the infection. The number and types of treatment will vary, depending on the extent of the gum disease.

- **Deep cleaning (scaling and root planning)** - the Dentist, Periodontist, or dental hygienist removes the plaque through a deep-cleaning method called scaling and root planning. Scaling means scraping off the tartar from above and below the gum line. Root planning gets rid of rough spots on the tooth root where the germs gather, and helps remove bacteria that contributes to the disease.
- **Surgical treatments**
 1. **Flap Surgery** - surgery may be necessary if inflammation and deep pockets remain following treatment with deep cleaning and medications. A Periodontist may perform flap surgery to remove tartar deposits in deep pockets or to reduce the

periodontal pocket, and make it easier for the child, Dentist and hygienist to keep the area clean. This common surgery involves lifting back the gums and removing the tartar. The gums are then sutured back in place so that the tissue fits snugly around the tooth again.

2. Bone And Tissue Grafts - In addition to flap surgery, your Periodontist may suggest bone or tissue grafts. Grafting is a way to replace or encourage new growth of bone or gum tissue destroyed by periodontitis. A technique that can be used with bone grafting is called guided tissue regeneration, in which a small piece of mesh-like fabric is inserted between the bone and the gum tissue. This keeps the gum tissue from growing into the area where the bone should be, allowing the bone and connective tissue to regrow. Since each case is different, it is not possible to predict with certainty which grafts will be successful over the long-term. Treatment results depends on many things, including severity of the disease, ability to maintain oral hygiene at home, and certain risk factors, which may lower the chances of success. Ask the Periodontist what the level of success might be in your particular case.

- **Medications** - medications may be used with treatment that includes scaling and root planning, but they cannot always take the place of surgery. Depending on the severity of gum disease, the Dentist or Periodontist may still suggest surgical treatment. Long-term studies will be needed to determine whether using medications reduces the need for surgery and whether they are effective over a long period of time. Here are some medications that when used correctly can be helpful.

1. Prescription antimicrobial mouth rinse - contains an antimicrobial called **Chlorhexidine** - to control the bacteria when treating gingivitis and other gum surgery. It is used like a regular mouthwash.

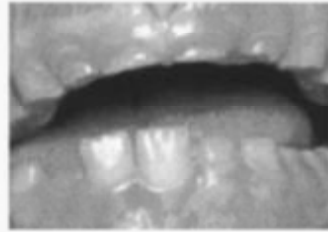
2. Antiseptic "chip" - a tiny piece of gelatin filled with the medicine **Chlorhexidine** - to control bacteria and reduce the size of periodontal pockets. After root planning, it is placed in the pockets where the medicine is slowly released over time.

3. Antibiotic gel - a gel that contains the antibiotic **Doxycycline** - to control bacteria and reduce the size of periodontal pockets. The Periodontist puts it in the pockets after scaling and root planning. The antibiotic is released slowly over a period of about seven days.

4. Antibiotic microspheres - tiny, round particles that the antibiotic **Minocycline** - to control bacteria and reduce the size of periodontal pockets. The Periodontist puts the microspheres into the pockets after scaling and root planning. The particles release Minocycline slowly over time.

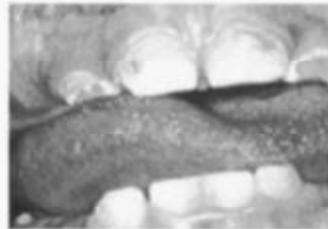
Bruxism

Bruxism, the habitual grinding of teeth, is a common occurrence in people with cerebral palsy or severe mental retardation. In extreme cases, bruxism leads to tooth abrasion and flat biting surfaces. **Refer to a dentist for evaluation; behavioral techniques or a bite guard may be recommended.**

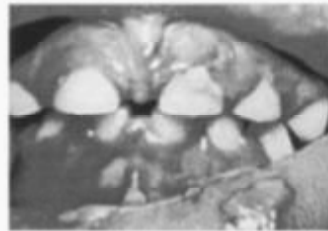


Oral Infections

Dental caries, or tooth decay, may be linked to frequent vomiting or gastroesophageal reflux, less than normal amounts of saliva, medications containing sugar, or special diets that require prolonged bottle feeding or snacking. When oral hygiene is poor, the teeth are at increased risk for caries. **Counsel the parent/caregiver on daily oral hygiene to include frequent rinsing with plain water and use of a fluoride-containing toothpaste or mouth rinse. Explain the need for supervising children to avoid swallowing fluoride. Refer to an oral health care provider and/or gastroenterologist for prevention and treatment. Prescribe sugarless medications when available.**



Viral infections are usually due to the herpes simplex virus. Children rarely get herpetic gingivostomatitis or herpes labialis before 6 months of age. Herpetic gingivostomatitis is most common in young children, but may occur in adolescents and young adults. Viral infections can be painful and are usually accompanied by a fever. **Counsel the parent/caregiver about the infectious nature of the lesions, the need for frequent fluids to prevent dehydration, and methods of symptomatic treatment.**



Early, severe periodontal (gum) disease can occur in children with impaired immune systems or connective tissue disorders and inadequate oral hygiene. Simple gingivitis results from an accumulation of bacterial plaque and presents as red, swollen gums that bleed easily. Periodontitis is more severe and leads to tooth loss if not treated. Professional cleaning by an oral health care provider, systemic antibiotics, and instructions on home care may be needed to stop the infection. **Explain that the parent/caregiver may need to help with daily toothbrushing and flossing and that frequent appointments with an oral health care provider may be necessary.**



Gingival Overgrowth

Gingival overgrowth may be a side effect from medications such as calcium channel blockers, phenytoin sodium, and cyclosporine. Poor oral hygiene aggravates the condition and can lead to superimposed infections. Severe overgrowth can impair tooth eruption, chewing, and appearance. **Refer to an oral health care provider for prevention and treatment. A preventive regimen of antimicrobial rinses and frequent appointments may be needed. Consider alternative medications if possible.**



5. Enzyme suppressant - a low dose of the medication **Doxycycline** that keeps destructive enzymes in check. To hold back the body's enzyme response - if not controlled, certain enzymes can break down gum tissue. This medication is in pill form. It is used in combination with scaling and root planning.

Second Opinion -

When considering any extensive dental or medical treatment options, you should think about getting a second opinion. To find a Dentist or Periodontist for a second opinion, call your local Dental Society. They can provide you with names of practitioners in your area. Additionally, dental schools may sometimes be able to offer a second opinion. Call the dental school in your area to find out whether it offers this service.

g. Can periodontal disease cause health problems beyond the mouth?

Maybe. But so far the research is inconclusive. Studies are ongoing to try to determine whether there is a cause and effect relationship between periodontal disease and heart attack and stroke, preterm delivery of babies, and controlling blood sugar in diabetics. In the meantime, it is a fact that controlling periodontal disease can save your teeth - a very good reason to take care of your teeth and gums.

3. Dental Injury

- Signs or symptoms: chipped tooth, tooth fractures; tooth loss
- Cause: chewing hard items, falls or blows to the mouth
- Treatment: tooth repair or replacement if possible

a. Signs And Symptoms of Dental Problems

1. Physical Signs

- Pain or discomfort of mouth or jaw
- Headache
- Unusual mouth odor
- Discoloration or other unusual appearance of teeth

b. Behavioral Signs

- Refusal to eat or drink
- Hand or fingers in mouth
- Head banging or rocking

c. Dental Issues In Developmental Disabilities - Causes or Influencing Factors

- **Physical Disabilities** - difficulty brushing teeth and flossing can lead to poor dental hygiene. People with physical disabilities may be more trauma-prone (especially

those with epilepsy and motor dysfunction syndromes), which increases the risk of tooth damage from falls.

- **Medications** - Dilantin is likely to cause gingival hyperplasia (overgrowth of gums) which makes the gums more vulnerable to infection, trauma, and bleeding. Muscle control medications may decrease the production of saliva, which compromises tooth protection. Excessive syrup medications can cause tooth decay.
- **Oral Motor disorders** - abnormal function of the tongue, lips, and cheek may adversely affect the mouth's natural cleaning process. Poor suck may affect feeding. Abnormal patterns of swallowing may cause food to linger in the mouth, increasing the risk for tooth decay. Pouching (holding foods in the mouth like chipmunk's) increases bacteria that may cause tooth decay and gum disease.
- **Common secondary conditions** - gastroesophageal reflux disease introduces higher levels of acids to the mouth, which can damage tooth enamel and lead to tooth decay.
- **Diet differences** - low fluid intake and pureed diets reduce the natural cleansing action of the tongue. Soft diets rich in carbohydrates can increase tooth decay. Inadequate nutritional intake can lead to dental and other health problems. Tube-feeding can create calcium deposits on the teeth.
- **Common behaviors** - Bruxism (tooth grinding) is very common among children with developmental disabilities, and may lead to enamel and dental abrasion, fracture, abnormal mobility of the teeth, or temporomandibular joint disorder (TMJ). Self-injurious behavior (head banging, gum picking, lip biting) may lead to tooth loosening or fracture and gingival disease. Excessive drooling or tongue thrusting decreases the amount of saliva in the mouth, which is necessary for natural cleansing. Pica may introduce sharp, toxic, or otherwise harmful materials to the mouth.
- **Epilepsy** - gingival hyperplasia from Dilantin and/or increased risk of dental injury from falls.
- **Other** - caregivers often focus on health and daily living needs but neglect the importance of dental care. Children with disabilities may feed from bottles longer and more often, which can lead to malocclusion and increased tooth decay as liquids pool around the teeth.

4. Dry Mouth

What do I need to know about dry mouth? Everyone has a dry mouth once in a while - if they are nervous, upset, or under stress. But if you have a dry mouth all or most of the time, it can be uncomfortable and can lead to serious health problems.

a. Dry mouth causes:

- Can cause difficulties in tasting, chewing, swallowing, and speaking.
- Can increase your chance of developing dental decay and other infections in the mouth.
- Can be a sign of certain diseases and conditions.
- People get dry mouth when the glands in the mouth that make saliva are not working properly. Because of this, there might not be enough saliva to keep your mouth wet (called salivary glands).
- Side effects from some medications. More than 400 medications can cause the salivary glands to make less saliva. Medicines for high blood pressure and depression often cause dry mouth like cotton, as well as anesthetics.
- Disease. Some diseases affect the salivary glands. Parkinson's disease can cause dry mouth.
- Radiation therapy. The salivary glands can be damaged if they are exposed to radiation during treatment.
- Chemotherapy. Drugs used to treat cancer can make saliva thicker, causing the mouth to feel dry.
- Nerve damage. Injury to the head or neck can damage the nerves that tell salivary glands to make saliva.
- Also, milk products can make the saliva much thicker and more difficult to cough up secretions or suction.

Dry mouth is not normal. So if you think there is a problem of dry mouth with your child, see your Dentist or Physician - there are things you can do to get relief. Dry mouth is the condition of not having enough saliva, or spit, to keep the mouth wet. The technical term for dry mouth is Xerostomia.

b. Symptoms include:

- A sticky, dry feeling in your mouth like cotton
- Trouble chewing, swallowing, tasting, or speaking
- A burning feeling in the mouth
- Cracked lips
- A dry, tough tongue
- Mouth sores
- An infection in the mouth

c. Why is saliva so important? Saliva does more than keep the mouth wet.

- It helps digest food.
- It protects teeth from decay.
- It prevents infection by controlling bacteria and fungi in the mouth.
- It makes it possible for you to chew and swallow.

Without enough saliva you can develop both decay or other infections in the mouth. You also might not get the nutrients you need if you cannot chew and swallow certain foods.

Some people feel a dry mouth even if their salivary glands are working correctly. People with certain disorders, like Alzheimer's disease or those who have suffered a stroke, may not be able to feel wetness in their mouth and may think their mouth is dry even though it is not.

d. What can be done about dry mouth?

Dry mouth treatment will depend on what is causing the problem. If you think you have dry mouth, see your Dentist or Physician. He can try to determine what is causing your dry mouth.

- If your dry mouth is caused by medicine, your Physician might change your medicine or adjust the dosage.
- If your salivary glands are not working right but can still produce some saliva, your Physician or Dentist might give you a medicine that helps the gland work better.
- Your Physician or Dentist might suggest that you use artificial saliva to keep your mouth moist .

e. What can I do?

- Sip water or sugarless drinks often.
- Avoid drinks with caffeine, such as coffee, tea, and some sodas. Caffeine can dry out your mouth.
- Sip water or a sugarless drink during meals. This will make chewing and swallowing easier. It may also improve the taste of food.
- Chew sugarless gum or suck on sugarless hard candy to stimulate saliva flow; citrus, cinnamon or mint-flavored candies are good choices.
- Be aware that spicy or salty foods may cause pain in a dry mouth.
- Use a humidifier at night.

f. Tips for keeping your teeth healthy.

Remember, if you have a dry mouth, you need to be extra careful to keep your teeth healthy. Make sure you:

- Gently brush your teeth twice a day.
- Floss your teeth every day.
- Use toothpaste with fluoride in it. Most toothpastes sold at grocery and drug stores have fluoride in them.
- Avoid sticky, sugary foods. If you do eat them, brush immediately afterwards.
- Visit your Dentist for a check-up at least twice per year. Your Dentist might give you a special fluoride solution that you can rinse with to help keep your teeth healthy .

5. Bruxism (Grinding of the Teeth)

Bruxism (grinding of the teeth) can come from many things ranging from anxiety to malocclusion of the teeth. It is important to determine whether the grinding is secondary to something else.

If the cause of the bruxism is something bad for the child in other ways, such as chronic pain or anxiety, it is of course important to get to that problem first. (The pain in this case would be somewhere else in the body, not in the teeth.)

If the grinding is caused by malocclusion of the teeth, a professional will have to determine if straightening or some other treatment is needed. Not many disabled children get Orthodontics but that may be just traditional. There is usually no reason not to do it if your child is cooperative. Other treatments such as equilibration of the teeth or a bite guarding splint can be made if the bruxism is indeed causing problems or if it is a symptom of another problem such as TMJ (refer to glossary) dysfunction.

The good news is that in most children, plain grinding by itself does not cause any permanent harm, other than to change the looks of the teeth over time. It does not cause cavities or any other problems to crop up as long as the mouth is kept clean. It can sound bad, especially if a child does it all of the time or at night when they sleep, but it is just one of those things that the rest of the world has to get used to in the disabled population because the disabled population is not going to change to conform to the expectation of the rest of the world. A sweatshirt was noticed at a recent conference which stated "The problem is not the way I look, but the way **you** see me". Refer to the picture of bruxism on page 22.

6. Facial Pain

a. Nerves involved

This symptom may result from various neurologic, vascular, or infection disorders. It can also be referred to the face in disorders of the ear, nose, paranasal sinuses, teeth, neck, and jaw. Typically, paroxysmal and intense facial pain may occur along the pathway of a specific facial nerve or nerve branch, usually cranial nerve V (Trigeminal nerve) or Cranial nerve VII (Facial nerve). Differentiating facial pain from the more diffuse pain of a headache is sometimes difficult, since many children refer to all head and facial pain as a headache.

Begin by characterizing the child's facial pain. Is it throbbing, stabbing, or dull? When did it begin? How long has it lasted? What relieves it? Worsens it? Ask your child to point to the painful area. If the pain is recurrent, have your child describe a typical episode. Review the medical and dental history, noting especially previous head trauma, dental disease, and infection.

Evaluate oral hygiene by inspecting the teeth for dental caries, percussing any diseased teeth for pain, and asking your child about any sensitivity to hot, cold, or sweet liquids or foods. Have your child open and close his mouth as you palpate for tenderness, spasm or crepitus.

b. Things the Dentist will be testing for:

- Cranial nerve V - tell your child to clench his teeth, then the temporal and masseter muscles will evaluate muscle contraction.
- Test pain and touch sensation on your child's forehead, cheeks and jaw.
- Test the corneal reflex by lightly touching the cornea with a piece of cotton or kleenex
- Cranial nerve VII - inspect the face for symmetry.
- Have your child perform facial movements - raise the eyebrows, frown, show his teeth, and puff his cheeks - to demonstrate facial muscle strength.

c. Medical causes of facial pain

- Dental caries. Caries in the molars can produce ear and temporal lobe pain (sides of the head) from the lower jaw, and eye pain and center of the head pain from the upper jaw.
- Sinusitis - can produce pressure, fullness or burning pain behind the eyes and over the cheek, nose and upper teeth. Bending or stooping increases the pain. Other findings include nasal congestion and purulent discharge, red, swollen nasal mucosa, facial swelling, trismus, fever, and malaise.

d. X-rays and pain medications

Your child may have x-rays done of the sinus, skull and dental areas and possible a CAT scan. Give pain medication as ordered, and apply heat or administer a muscle relaxant to ease muscle spasms. Provide a humidifier, vaporizer, or decongestant to relieve nasal or sinus congestion. If appropriate, teach your child to avoid stressful situations, hot or cold foods, or sudden jarring movements which could trigger painful attacks.

For small children it may be difficult to assess facial pain if his language skills are not developed sufficiently for him to describe the pain. Be alert for subtle signs of pain, such as facial rubbing, irritability, or poor eating habits.

D. Preventive Dental Care

1. Referral to Dentist - recommend and refer for dental care by the age of 2 or within 6 months of eruption of first tooth (preferably to a Dentist with expertise and interest in treating children with disabilities); provide a Dentist with complete, up-to-date medical history, including doses and frequency of previous and current medications; discuss with your child and his parents what will happen at dental visits to decrease anxiety; refer for behavior modification therapy or sedation to reduce anxiety about going to the Dentist, as needed, and recommend dental checkups twice per year or more frequently if indicated.

2. At-home Care - recommend twice daily brushing with fluoride toothpaste and flossing if possible, which may require the assistance of a caregiver; ensure comfortable, appropriate positioning during teeth brushing; if your child will not cooperate with brushing, teach the caregiver to use desensitization by starting with some wet gauze or a washcloth on the mouth

and gradually moving to a soft, dry toothbrush, then a wet toothbrush, and finally a toothbrush with toothpaste; refer to occupational therapy for adaptations to dental hygiene equipment and assistive devices like mouth props and adapted toothbrush handles, as needed; recommend daily fluoride tablets or drops if water supply does not contain recommended amount of fluoride.

3. Healthy teeth require conscientious and effective cleaning. To achieve maximal benefit from tooth brushing, the latter should be performed immediately after eating. The purpose is to remove food particles that lodge in crevices, around and between the teeth, and to prevent tartar formation. Proper hand brushing of the teeth requires a firm bristled brush of a size that permits easy access to all surfaces. The upper teeth are brushed downward and the bottom teeth upward so that the gum is not pushed away from the tooth. Horizontal scrubbing is reserved for lateral molar surfaces. Ten strokes is recommended for each surface. The normal movements of muscles used in eating and the normal flow of saliva aid greatly in keeping the teeth clean. Even so, it is necessary to brush the teeth in the morning and evening and after each meal to keep the mouth healthy.

4. Natural cleaning process - Many ill children do not eat and salivate normally, which reduces the natural cleaning process. If your child is unable to clean his teeth adequately, he must be taught to do so, perhaps being aided by a caregiver, parent, or nurse. If your child can not brush his teeth by himself, an oral lavage (half water and half hydrogen peroxide can be sprayed into the mouth around the teeth using a squeeze bottle with a fine hole tip. Gly-oxide also can be used. When this solution comes into contact with tissue, oxygen is released and exerts a mechanical cleansing action. A sponge-rubber device is also available that allows the teeth to compress and release alternately the fluid-filled cells of a sponge. The foaming action and massage of gums helps prevent gingivitis.

5. Medications - use an alternative to Dilantin if possible; recommend rinsing the mouth with water or brushing after each dose of medication; recommend sugar-free medications when possible. When giving oral medications to an infant, administer it in liquid form if possible. For accuracy, measure and give the preparation by syringe; never use a vial or cup. Lift your child's head to prevent aspiration of the medication, and press down on his chin to prevent choking. You may also place the drug in a nipple and allow the infant to suck the contents. If your child is a toddler, explain how you are going to give him the medication. Do not mix medication, with food or call it "candy" even if it has a pleasant taste. Let your child drink liquid medication from a calibrated medication cup rather than from a spoon: it is easier and more accurate. If the preparation is available only in tablet form, crush it and mix it with a compatible syrup. (Check with your pharmacist to make sure tablets can be crushed without losing their effectiveness). If your child is older who can swallow a tablet or capsule by himself, have him place the medicine on the back of his tongue and swallow it with water or fruit juice. Remember, milk and milk products may interfere with drug absorption and can

thicken secretions. Unless indicated to do otherwise, see that your child receives all oral preparations on an empty stomach to maximize absorption.

6. Diet and Nutrition - refer to a nutritionist for healthy diet and sugar limitation; encourage chewing activity, even when soft foods are eaten; encourage to wean from bottles as soon as possible; recommend foods with texture if possible; advise your caregiver to help your child avoid pouching by inspecting his mouth after giving food or medications and giving liquid medications rather than pills. A dental soft diet is an adequate diet consisting of soft foods. It is given to children who can not chew foods well because of missing teeth or the inability to swallow meats etc., or who may have a painful mouth due to thrush, decayed teeth, etc. Foods may include milk, cheese, eggs, soup, soft fruits such as bananas, cooked or pureed vegetables, cubed, minced or ground meat or fish, and soft bread. Ensure that selections are varied to make the diet appetizing.

7. Other - consider an occlusal splint at nighttime or behavior modification to control bruxism; recommend therapy to achieve lip closure, as needed; recommend behavior modification or a mouth guard for self-injurious behavior.

E. How to Assess and Examine your Child's Teeth

1. Assessment

A toddler or preschool - age child may cooperate more easily if you examine his parent's mouth first. He will probably want his mouth examined too. Let your child handle the tongue depressor before you examine him to allay any fears he may have. You can also let your child place the tongue depressor on his tongue as you guide his hand. Inspecting an uncooperative child's mouth is not easy or pleasant. One technique for bypassing clenched teeth is to ease a tongue depressor along the lips, toward the back of the mouth, and then insert it between the posterior teeth in a downward motion, which triggers the gag reflex when you depress the posterior tongue. You then have a brief period to examine your child's mouth.

If you can identify dental or mouth problems in your child, he may be able to receive treatment before costlier (or permanent) problems occur. First, observe your child for malocclusions. Do not ask your child to show the Dentist his teeth, because reflex alignment may make his bite appear normal. Instead, ask him to bite down hard while his mouth is closed; then open his lips and observe the bite.

Inspect your child's teeth carefully for dental caries and tooth eruption. Dental caries in primary teeth pose a special problem because of possible infection, loss of teeth, and loss of space for permanent tooth eruption. Also check for lack of tooth eruption by age 1 and for missing teeth in older children.

2. Tips

To avoid making your child gag when examining his mouth, try these tips:

- Tell your child to stick his tongue out and pant like a puppy when you examine his mouth
- Avoid touching your child's posterior tongue when using a tongue depressor except when viewing the posterior pharynx (or examining an uncooperative child)
- Use the tongue depressor on each side of your child's tongue and examine one half of the throat at a time.

3. Dental Treatment

a. Desensitization - many children with developmental disabilities will not feel comfortable having their mouths examined or worked on, especially if this experience is new to them. If your child will not cooperate with a dental exam or procedure, encourage his or her caregiver and/or Dentist to use desensitization by starting very slowly and gradually increasing the level of intensity.

b. Restraints - a restraint should only be used when absolutely necessary and should not cause any injury or trauma. It is important to obtain consent for dental exams and procedures. As needed, recommend restraints in the following order: mild restraint, nitrous oxide, oral premedication, mouth props, intravenous sedation, and general anesthesia.

c. Surgical Procedures - ensure that your child with congenital heart disease receive antimicrobial prophylaxis before dental procedures; consider surgical correction of overgrown gums as a result of Dilantin; refer for surgical correction of bone grafting to enhance jaw size and dental arch stability if needed.

d. Other - refer to Periododontist as needed; refer to Orthodontist to improve tooth position and occlusion, as needed.

F. Education and your child's IEP (Individualized Educational Plan)

Oral Health Care of the Pre-School and School Age Child

1. Prevention and promotion of oral health working with schools

- Oral health education programs should be established in special schools and units.
- Oral hygiene should be included in the child's individual educational plan (IEP).
- Oral hygiene should be included in personal hygiene training.
- Healthy eating policies should be promoted in schools.
- A friendly and supportive clinical environment should be provided.
- Continuity of dental personnel and a team approach should be maintained.
- Children should be acclimated to the clinical environment gradually.
- Each step of any treatment should be explained clearly.
- Disability awareness training including learning disability to the dental team should be available.

- Equal access to dental treatment under sedation and general anesthesia should be available.
- Access to emergency treatment under general anesthesia for pain should be provided.
- Increased resources for treatment under sedation and general anesthesia should be made available.
- Home visits should be provided when required.
- Oral health education programs should be developed that address the needs of individuals and care-givers (personnel or professional).
- Oral health education should be provided for all and tailored to individual needs.
- All care-givers (family or professional) providing care or support for individuals unable to care adequately for themselves should be given advice in oral health education.
- Oral care to be provided at home for children with learning disabilities should be documented in individual oral care plans.
- Standards for oral care should be part of operational strategies in individual residential homes.
- The consumption of sugary foods and drinks should be limited to meal times.
- Snacks should be avoided between meals.
- Collaboration between Dentists and Dieticians will ensure that appropriate preventive advice is offered.
- Sugars should not be added to bottles of infant formula or follow-on formula.
- Sugary drinks should not be given in bottles of feeders, especially at bedtime.
- Infants should not be left to sleep with a bottle containing sugary or acidic drinks, which will lead to dental decay and erosion of the tooth enamel.
- Prolonged use of feeding bottles should be avoided.
- Fruit flavored sugar containing drinks should be limited to meal times.
- Parents should be advised that some baby juices are acidic.
- Ensure that, as far as possible, when medicines are given, they are sugar-free.
- Information on access to available services should be circulated to parents, carers, and health care professionals.
- Early referral to the Dentist should be encouraged from child development teams and consultant pediatricians.
- Health care professionals and care-givers should be advised of the alternative ways in which oral healthcare can be delivered as in home visits, mobile dental units, in special schools in addition to a dental practice.
- Professionals should collaborate to identify children with learning disabilities in mainstream and special education centers and refer to the appropriate oral healthcare services.

2. Regular attendance, fluoride use and fissure sealants

- An oral health care plan should be agreed with parent/care/child.
- Regular visits and reviews should be established and tailored to individual needs.
- Acclimation to dental treatment should be provided.

- Provision of regular monitoring is the key to the prevention of pain and infection.
- Fluoride toothpaste should be used.
- Children over the age of 6 years should be encouraged to use standard fluoride level toothpaste.
- Direct supervision by an adult is advisable.
- Parents should be fully involved in the decision to supplement fluoride levels.
- The risks and benefits should be carefully explained so that parents can make an informed choice.
- Professionally applied topical fluoride should be biannual Fissure Sealants.
- Children at risk of dental caries should have fissure sealants applied to permanent teeth soon after eruption.
- Parents should be advised of the need for regular monitoring and maintenance of fissure sealants.

3. Oral Health Education, orthodontics and oral care assessment and planning

- Instruction in oral hygiene and motivation are important.
- The dental team should appreciate the everyday problems encountered by parents who are attempting to implement a good oral health care routine.
- The causes of gingival bleeding should be explained.
- Oral hygiene programs should include supervised toothbrushing sessions.
- Oral health education should be given to parents and support services.
- Use of Chlorhexidine mouthwash or spray over short periods can be beneficial.
- Refer early with comprehensive information.
- Obtain an Orthodontic opinion before arranging treatment under a general anesthetic.
- Treatment plans should take into account your child's compliance.
- Avoid extracting permanent teeth until co-operation and oral hygiene are adequate.
- Everyone should have a regular oral assessment.
- The frequency of oral assessment should be related to the individual's needs.
- Care-givers should be encouraged to obtain an oral health assessment for their client.
- An annual assessment should be carried out for people who are edentate.
- Assessment should be more frequent for those with multiple disabilities.
- Oral care should be an integral part of social care planning and should be included in national, local and residence based learned disability strategies.
- Parents and professionals need to be aware of the possibility of dental pain.
- A dental opinion should be sought for unexplained changes in your child's behavior.

4. Oral Health Screening

- Oral health assessment should be included as part of the general health assessment.
- Screening programs should be developed and sustained in special schools and special needs units in mainstream education.
- Local programs and dental services should be developed that address the demographic and geographic needs of the local population.

- The increased use of mobile dental units in mainstream and special schools should be explored where appropriate.
- Parents and professionals need to be aware of the possibility of dental pain.
- A dental opinion should be sought for unexplained changes in your child's behavior.

5. Dietary Advice

- Dietary advice for all children with learning disabilities should be made within the context of healthy eating policies.
- Care-givers and health professionals should be provided with training to promote healthy eating and its effect on oral health.
- Policies should be developed to ensure referral to and advice from the dental team to instigate appropriate prevention techniques.

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 your 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.

6. Causes of dental issues

1. **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.

EQUIPMENT



USING THE WATER PIK

The water pik directs a pulsating jet of water around the teeth to massage gums and remove debris and food particles. It's especially useful for cleaning areas missed by brushing, such as around bridgework, crowns, and dental wires. Because the water pik enhances oral hygiene, it benefits patients undergoing head and neck irradiation, which can damage teeth and cause severe caries. The water pik also promotes oral hygiene in a patient with a fractured jaw or with mouth injuries that limit standard mouth care.

To use the water pik

- Assemble the following equipment: water pik machine, towel, emesis basin, pharyngeal suction setup, and if ordered, salt solution and mouthwash.
- Position the patient on his side to prevent aspiration of water. Then, place a towel under the chin and an emesis basin next to the cheek to absorb or catch drainage.
- Insert the water pik's plug into a nearby electrical outlet.
- Remove the cover of the water pik. Then, turn the cover upside down and fill it with lukewarm water or with a mouthwash or salt solution, as ordered. When using a salt solution, dissolve the salt beforehand in a separate container. Then, pour the solution into the cover.
- Secure the cover to the base of the water pik. Then, remove the water hose handle from the base, and snap the jet tip into place. If necessary, wet the grooved end of the tip to ease insertion.
- Adjust the pressure dial to the setting most comfortable for the patient. If his gums are tender and prone to bleeding, choose a low setting.
- Adjust the knurled knob on the handle to direct the water jet, place the jet tip in the patient's mouth, and turn on the water pik. Instruct the alert patient to keep his lips partially closed to avoid splashing water.
- Direct the water at a right angle to the gum line of each tooth (as shown below). Avoid directing water under the patient's tongue, because this may traumatize sensitive tissue.
- After irrigating each tooth, pause briefly and instruct the patient to expectorate water or solution into the emesis basin; if he can't, suction it from the sides of the mouth.
- After irrigating all teeth, turn off the water pik, and remove the jet tip from the patient's mouth.
- Empty the remaining water or solution from the cover, remove the jet tip from the handle, and return the handle to the base. Clean the jet tip with soap and water, and rinse the cover. Dry the jet tip and cover, and return them to their storage positions.



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 (refer to picture on page 35) or battery operated toothbrush may also be helpful, but not necessarily better than a regular toothbrush. All of these above mentioned possibilities of halitosis over time could affect the teeth like increasing gingivitis or periodontal disease.

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 your 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.

Possible causes for dental problems associated with Halitosis:

a. 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.

b. Bronchiectasis - (a condition where dilatation and destruction of the bronchial walls, resulting usually from infection) 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.

c. 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.

d. 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. Gingivitis is a big problem especially if taking Dilantin (a side effect of this drug).

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

f. 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.

g. Periodontal disease - halitosis is accompanied by an unpleasant taste. The gums bleed spontaneously or with slight trauma and are marked by pus filled pockets around the teeth, also will see facial pain, headache, and loose teeth covered by calculus and plaque.

h. 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).

i. 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.

j. 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.

k. 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.

l. Zenker's Diverticulum - is a condition of the esophagus causing bad breath and a bad taste in the mouth associated with regurgitation.

m. 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.

H. 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 your child's anxiety and/or control disruptive behaviors in the course of dental treatment. Laws regulating sedative administrative by dentists vary widely from state to state. Before your child is scheduled for a sedative procedure in a dental office, make sure that the Dentist has the appropriate certification required by your state for the type of sedation to be administered. It is very important that you completely familiarize your Dentist 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 unconsciousness sedation, all the way to general anesthesia. The degree of sedation is dependent upon the drugs utilized as well as the dosage and route of drug administration.

1. Types of Sedation

a. Inhalation - the combination of nitrous oxide and oxygen (commonly known as laughing gas) is the most commonly employed sedative agent in dentistry. It is not a particularly potent sedative but it is highly effective in inducing relaxation in patients with anxiety. One of the biggest advantages is its relative safety compared to most other sedative agents. Its rapid onset of action and short recovery time also contribute to its value as a conscious sedation agent. In fact, complete recovery usually occurs within 3-5 minutes of pure oxygen inhalation. The only disadvantage is that your child must be somewhat cooperative and be able to wear a mask and breathe in through his nose to be effective. It may be ineffective with children who are extremely disruptive behavior or those with significant cognitive deficits. It is also possible that nitrous oxide can cause nausea and vomiting; therefore it is advised that children do not eat before their appointment.

Most children with Batten Disease can tolerate using nitrous oxide and is approved by Dr. Boustany, one of our Batten Disease Doctors.

b. Oral - the oral sedative most frequently used by Pediatric Dentists is Midazolam (Versed); others use Chloral Hydrate (sleeping pill), Diazepam (Valium), and Hydroxyzine (Vistaril). All of these drugs are considered conscious sedative agents and in most cases your child will remain awake during the dental procedure. The major advantage is the ease of administration. The only cooperation required of your child is the willingness to swallow medication. Disadvantages include a fairly slow onset of action (at least 30 minutes) and variable levels of effectiveness from one child to another; one if there is difficulty in swallowing issues; child anxiety level, metabolism and rate of absorption through the stomach can all have an impact on the duration of action and effectiveness of oral sedative.

1. **Versed** - used in children to help alleviate anxiety before a diagnostic or therapeutic procedure or before anesthesia induction. Also to reduce the ability to recall events that occurred during sedation. It is being tried to treat epileptic seizures and as an alternative to terminate status epilepticus. Side effects may include fluctuations in vital signs including decreased respiratory rate, hypotension, over sedation, headache, drowsiness, grogginess, confusion, amnesia, euphoria, nervousness, agitation, anxiety, argumentative, restlessness, delirium, dreaming, nightmares, insomnia, nausea and vomiting, excessive salivation, retching, double/blurred vision, hives, loss of balance, chills, weakness, faint, and yawning. Normal dosage is .01-.05 per mg/kg but must be individualized in each child by your Doctor.

2. **Chloral Hydrate** - is a sedative/hypnotic, may see side effects of drowsiness, hangover, nightmares, dizziness, ataxia, disorientation, lightheadedness, confusion, headache, hallucinations, to name some. The usual dose is 500-1500 mg for most of our children with Batten disease. After taking it for a few days, you need to monitor alertness.

3. **Valium** - can be used as an anticonvulsant or for anxiety, muscle spasms, endoscopic procedures, and status epilepticus, side effects are very similar as with Chloral Hydrate - drowsiness, lethargy, hangover, ataxia, fainting, depression, restlessness, amnesia, psychosis, slurred speech, tremor, sedation, apathy, or fatigue. A normal dose of Valium is 0.2 - 5 mg depending on age. It is used a lot with status epilepticus, but IV access is needed to be helpful. It is not compatible with most other medications and will turn milky color if mixed for IV use.

4. **Vistaril** - used for symptomatic relief of anxiety and tension associated with psychoneurosis. Sedative when used as pre-medication and following general anesthesia, and prior to dental procedures. Side effects include drowsiness, dryness of the mouth, involuntary motor activity (rarely tremors and convulsions), dizziness, skin reactions. Usual dosage is 50-100 mg per day in divided doses.

c. Intramuscular (IM) - IM injection of sedative medication is another technique used in some dental offices. Several advantages are more rapid onset of action and more reliable absorption and useful in your child who is resistant to swallowing medication. The disadvantages include the impossibility to predict on a consistent basis the most effective dose for each child, the inability to quickly reverse the action of the drug, but it can be useful for fairly brief procedures or as a premedication for disruptive children to allow subsequent placement of an IV line

d. Intravenous (IV) - used primarily by oral surgeons and general and pediatric dentists. The advantages are the rapid onset of action and the effectiveness, additional medication can be administered as needed, the level of sedation can be better controlled, and also permits the completion of lengthier procedures, and emergency drugs can be given through an IV line if necessary. The major disadvantage is that your child must be cooperative during the IV stick - this may be difficult with either young, fearful children or children with resistant behavior.

e. General anesthesia - if your child cannot be treated safely and effectively by using the above explained techniques, the alternative would be treatment using general anesthesia. Behavior management and the inability to perform dental procedures under any other circumstances are indications for general anesthesia which may be the only way to deliver safe, quality, and comprehensive dental care for the exceptional child with special needs.

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.

I. 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 on 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 mouth while cleaning, especially if swallowing problems exist. 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 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.

1. Gastroesophageal reflux - 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. If reflux enters the mouth and is not rinsed out, the acidic enzymes, etc, will affect the enamel after some time has passed. 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, and low dose alcohol. Factors that decrease LES (lower esophageal sphincter) pressure include: fat, whole milk, orange juice, tomatoes, antifatulent (Simethicone), chocolate, high-dose alcohol, cigarette smoking, or lying on right or left side.

2. Insertion of an NG (Nasogastric) Tube The nasogastric tube, inserted into the stomach through the nose, has diagnostic and therapeutic uses, but again, if by not eating the mouth does not get cleaned, it can affect the teeth. 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 tube feedings. It is also used commonly after major surgery to decompress the stomach and prevent vomiting by keeping the stomach empty.

3. Medications - if your child has difficulties swallowing and unable to swallow pills, sometimes pills are then chewed. It is very necessary then to make sure the pills are rinsed completely out

of the mouth so not to affect the teeth by the chemicals in the medications. You may want to talk to your pharmacist about this.

4. Schedules - Scheduling of medications and feedings can also be helpful in dealing with dental issues. 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 mealtime 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 similar. 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. How can all of these things affect your child's teeth? You will not see change over night, but over time, there will or can be changes.

5. 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 fed 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 may lead to orthodontic problems (a tendency to tongue thrust may cause an over bite where the front teeth poke out).
- Plaque 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 if gagging is a problem.
- Fluoride is not a problem any longer since most water is fluoridated, but it is available in drops or tablets if not already in your local water system.

6. 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) .

J. What can we do as parents for our children?

1. Find a good Dentist for your disabled child - your local branch of the American Dental Association is a good place to start. Ask for a Dentist particularly skilled/experienced in treating disabled children. This will probably be a general Dentist or Pediatric Dentist. You may also call

your Dental School if there is one in your city - for those who teach the students how to work on disabled children. Many graduate students would be okay for a second choice. Ask for the advice from some of the parents you meet who have a child who is disabled at the Dentist office you have selected on your first visit. Ask how long they have been going to that Dentist. Ask what techniques the Dentist uses and if they like the Dentist. They will feel honored that you asked them; we are all family.

2. Most disabled children need some type of special help to cooperate. For some, this is just knowing the Dentist and having some level of trust that they will not be hurt or that any pain will be slight and will just last a few moments. Depending on the individual child's needs, this is a list of one Dentist's decreasing order of strength when your child does not know him or unable to cooperate.

a. General anesthesia in a hospital or out-patient setting. In the United States now, this is very safe and the anesthesia is usually kept at low levels for general dentistry. Oral surgeons can safely do general anesthesia in their offices. Anesthesiologists are better than nurse anesthetists. All anesthesia personnel are aware that special needs children present more risks than non-disabled children and they take into consideration when they recommend anesthesia. If you are skeptical about this, discuss risks with them far in advance of the procedure. Call the hospital and make a special trip just to have your child prescreened by the anesthesiologist, if you are worried.

b. Intravenous sedation in the hospital or in a private office. Many states require a special permit to do this. Your Physician should give a History and Physical and an okay before a procedure is done in the Dentist's office, as an extra precaution.

c. Nitrous oxide (laughing gas) and oral sedation together. This is safe for many children as long as the oral medication is not given in too high a dose. In some rare instances, Dentists who do not have hospital privileges or a permit to do intravenous sedation may be tempted to give a dose of oral medication that is too high. Ask your Physician about the dose if you suspect this. Nitrous oxide is generally safe except in a few cases (those who do not or will not breathe well enough through their noses sometimes just temporarily due to nasal congestion), some types of asthma and in those who can not handle being "high"

d. Nitrous oxide or oral sedation by itself. See above.

e. Psychological Techniques: May work with slightly frightened children. These techniques include systemic desensitization, tell-show-do technique, modeling good behavior, distraction, and a host of other tricks.

f. **Electronic anesthesia** (TENS unit, CEDETA dental unit, etc.) is not a very strong technique, but may work in some cases as long as your child is not the one controlling the unit (usually the patient is in control of the unit).

g. **Local Anesthesia (Novacaine)** by itself: consider yourself lucky if this is all the Dentist needs to do. This is only possible in approximately 20% of special needs children.

h. **Please do not go to a Dentist that uses any of the following techniques.** Papoose board, hand-over-mouth technique also called HOME, scolding, or restraints. A papoose board is probably okay if your child needs it to control involuntary movements but it can also be cruel to use it against your child's will if he is scared or unable to calm down. There are better techniques. Restraints are okay if your child only needs to be reminded to keep his hands away from his mouth while the Dentist is working. How do you know if these techniques are being used? Go in and watch the procedure. If the Dentist is uncomfortable or thinks your presence is making it harder to control your child, stand outside the door, where your child can not see you. You can leave and wait in the reception area if you trust the Dentist.

i. **Along with the nutritional things** that follow, remember that oral care and your child's teeth are vitally important as well, and oral care and nutrition pretty much go together. If your child is totally tube fed, can you see the importance of excellent mouth care being done throughout each day to preserve your child's teeth? If your child still eats, 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.
- Consider talking to a nutritionist/or start multi vitamins to supplement your child's daily intake of essential vitamins.

j. **Why not just let the baby teeth rot away** and fix the permanent ones? On the surface this seems sensible to parents who spend most of their energy/money on major medical problems, but it is a bad idea. Why? Baby teeth can get just as infected and abscessed as permanent teeth. Children avoid telling their parents when they have toothaches. Your child with or without a disability who has a toothache, REALLY has a toothache.

k. **Mechanical (electric or sonic) toothbrushes** are all right only if your child will accept something like that in his mouth and they have learned to accept a regular brush first (Children with seizure disorders should consult their Physician before using any electric or sonic toothbrush as in some cases this may trigger seizures) The most favorite toothpaste for most kids is Oral-B bubble gum flavor.

l. **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 and also remember oral care during this time of inadequate 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.

m. Does your child have any swallowing difficulties? Children with Batten Disease will at some point during their 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.

n. 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. 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.

o. 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.

p. General - ask if there has been a recent fever, weight loss, anorexia, fatigue or weakness. Record weights periodically, weekly or monthly is preferred.

q. 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.

r. Tongue - swollen, purple and raw-looking with sores or abnormal protrusions on the tongue.

s. Teeth - missing, or emerging abnormally; visible cavities or dark spots; spongy, often bleeding gums that may interfere with chewing.

K. State Initiatives to Improve Access to Dental Care.

I have a copy for each state that I downloaded from the internet. You are welcome to look at their website or if I can be of help to you, please give me a call and I will send you a copy or read you what it says for your state. The website address is www.healthlaw.org/pubs/200110dental.html.

For Ohio it states that the Bureau of Oral Health Services in the Ohio Department of Health receives 83 percent of its funds from title V. The Bureau of Oral Health Services is organized into three sections, based on the following areas of focus:

- Administers OPTIONS (Ohio Partnership TO Improve Oral health through access to Needed Services) a program funded by title V funds, state general revenue funds and money from the Ohio Dental Association. The program links low income, working poor, low income seniors and persons who are medically, mentally or physically challenged with volunteer Dentists who have agreed to provide donated or discounted care in their offices.
- Provides grants to local agencies to provide dental sealants to children in schools that serve low income families and to provide comprehensive dental services to high risk children. They also assist communities with water fluoridation efforts.
- Assists communities with local needs assessment and provides oral health training to staff and local programs such as Head Start, Child Health Clinics, WIC Programs, and schools. They also conduct screening in schools of children in grades 1-3.

Most of the states are fairly similar in the documentation that was presented, but there are some differences.

DENTAL ISSUES AND MOUTH CARE

GLOSSARY

A

Abdominal distention - the abdomen (stomach) becomes larger due to many reasons. Several being overeating, bowel obstruction from constipation, bowel obstruction from rupture of a segment of bowel which would produce air in the stomach, or simply constipation where there is an abnormally large amount of stool in the bowel and the inability to have a bowel movement

Abscess - a localized collection of pus in any part of the body, symptoms usually are redness, swelling, warm to touch, and pain

Acids - acids in this terminology refer to the acids from our stomach that are in our mouth and saliva and proper dental care keeps them to a minimum. If there is not good dental care, the acids can dissolve tooth enamel over time

Adenoids - one of two masses (one on either side of the neck) of lymphatic tissue situated on the posterior wall (back) of the nasopharynx behind the posterior nares (nose). During childhood these masses often swell and block the passage of air from the nasal cavity into the pharynx, preventing the child from breathing through his nose

Advocate - as advocates for our children, we need to be assertive in all areas of health and wellness for our kids no matter to what extent we need to go (Physicians, Dentists, or lobbying to our State Senators and Legislators) to get the complete care for our children needs in all aspects

Alzheimer's disease - pre senile dementia, characterized by confusion, restlessness, speech disturbances, inability to carry out purposeful movements, and hallucinations

Anomalies - deviation from what is regarded as normal as in congenital anomaly where there may be absence of a limb or the presence of an extra finger

Anorexia- 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, 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

Anterior labial gingiva - the gums on the front side of the teeth, seen in hyperplasia where the gums become much larger and grow over the teeth and look like extra lips (labia)

Antibacterial plaque treatment - medication or possibly sealants used as a treatment as a preventive or slowing down of the decaying process

Antidepressants - treating patients with medications to prevent or slow down symptoms of depression and preventing the development or pathogenic action of microbes, helps decrease an infection and allows healing of a wound

Antimicrobial defense - which means that you are treating a problem almost in a prophylactic state in defense of having the problem worsen

Anxiety - a state or feeling of uneasiness, agitation, uncertainty, and fear resulting from the anticipation of some threat or danger. It can become a pathologic condition if it is not based in reality and if it is so severe that it results in the inability to function

Aspiration - to draw in or out as by suction, foreign bodies may be aspirated into the nose, throat or lungs on inspiration; seen in aspiration pneumonia when foods or fluids are inadvertently inhaled into the lungs usually due to poor swallowing ability

Auscultation - the process of listening with a stethoscope for sounds produced in some of the body cavities, especially the chest and abdomen, in order to detect or judge some abnormal condition

B

Bacteria - unicellular, plant-like microorganisms, lacking chlorophyll, so it cannot carry on photosynthesis; if they live on living organisms they are called parasites; if bacteria produce disease in their host they are called pathogenic bacteria, if causing disease, need to be treated quickly

Barnacle-like white or yellow deposit - a deposit (when plaque combines with minerals) which forms on the teeth seen with poor oral hygiene that forms over a period of time, can be removed by a Dentist or dental hygienist

Behavior modification - a kind of psychotherapy that attempts to modify observable, maladjusted patterns of behavior by the substitution of a new response or set of responses to a given stimulus. The treatment techniques involve the methods, concepts, and procedures derived from experimental psychology, and include assertiveness training, aversion therapy, and contingency management, also called biofeedback

Bicuspids - having or ending in two cusps or points, one of the two teeth between the molars and canines of the upper and lower jaw, also called premolar tooth

Bite guarding splint - a device that is used for bruxism that is usually placed on the child at night to help prevent grinding of the teeth, and to prevent possibly biting the tongue, etc.

Bowel sounds - little gurgles that are heard with a stethoscope placed over the abdomen which signify that food particles are continuing through the intestines

Bronchial walls - the lining or walls of the bronchus which lead to the lungs

Bruxism - grinding of the teeth. It can be caused by many things ranging from anxiety to malocclusion of the teeth. The compulsive, unconscious grinding of the teeth, especially during sleep or as a mechanism for the release of tension during periods of extreme stress in the waking hours

C

Calcium - one of the most important and abundant minerals in the body and occurs mainly in the bone. Calcium is required for the transmission of nerve impulses, muscle contraction, blood coagulation, cardiac functions, and other processes

Carbohydrates - a group of organic compounds, the most important being sugar, starch, cellulose, and gum. Carbohydrates constitute the main source of energy for all body functions and are necessary for the metabolism of other nutrients. They are synthesized by all green plants and in the body are either absorbed immediately or are stored in the form of glycogen. Cereals, vegetables, fruits, rice, potatoes, legumes, and flour products are the main sources of carbohydrates. Symptoms of deficiency include fatigue, depression, breakdown of essential body

protein, and electrolyte imbalance. Excessive consumption may result in tooth decay, obesity, hypertension, cardiovascular disease, anemia, and kidney dysfunction

Cardiovascular disease - a disease pertaining to the heart and the blood vessels of the heart. The cardiovascular system includes thousands of miles of vessels, capillaries and veins and 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 the intestines, the cardiovascular system functions in close association with the respiratory system, transporting oxygen inhaled into the lungs and conveying carbon dioxide to the lungs for expiration. So, if things do not run as planned, disease can become very pertinent to the physical condition of the patient

CAT scan - computerized tomography - an enhanced x-ray where the patient is placed in a tunnel like machine that makes pictures or slices of the area being x-rayed, the x-rays are taken with or without dye, if dye is used it is done so to help with clearer diagnosis, whereas a MRI uses magnets instead of dyes for a better

Cavity fillings - a filling used in the tooth after the decayed material has been removed to protect the remaining tooth and its nerves

Cementum - the bonelike connective tissue that covers the roots of the teeth and helps to support them

Cervical lymphadenopathy - a disease in the lymph nodes in the cervical area in the neck, an enlargement of the lymph nodes

Chemotherapy - a treatment of a disease by chemical reagents that have a specific toxic effect on a pathogen or that are used to treat tumors

Chest percussion - a treatment in respiratory issues that involve a technique in physical examination used to evaluate the size, borders, and consistency of some of the internal organs and to discover the presence and evaluate the amount of fluid in a cavity of the body; direct or immediate percussion refers to percussion performed by striking the fingers directly on the body surface, fingers indirect or mediate percussion involves striking the fingers of one hand on the fingers of the other hand as it is placed over the organ to help loosen fluid in expectation of increasing the ability to expectorate those secretions

Chromosomal abnormalities - an abnormality in the threadlike structures in the nucleus of a cell that functions in the transmission of genetic information, consisting of DNA. The genes, which contain the genetic material that controls the inheritance of traits are arranged along each DNA strand

Chlorhexidine - one of the main medications that are used in the treatment of scaling and root planning. It is in the form of a mouthwash. It contains an antimicrobial agent to help control the bacteria when treating gingivitis and other gum surgery

Clubbing of the fingers - an abnormal enlargement of the distal phalanges (fingers) usually associated with heart disease or advanced lung disease. It is a mechanism by which diminished oxygen tension in the blood causes the clubbing in all ten digits, but most often in the fingers. The nails thicken and become shiny, hard, and curved at the free end

Cognitive impairment - when one becomes unable to retain the intellectual process by which he has become aware of, perceives, or comprehends ideas. It involves all aspects of perception, thinking, reasoning, and remembering

Collaborate - when one discusses with another a particular disease, method of treatment etc. to obtain the best possible results for each individual

Collagen - a substance consisting of bundles of tiny reticular fibrils, which combine to form the white, glistening, inelastic fibers of the tendons, the ligaments, and the fascia (collagen is needed to keep wrinkles away from our faces)

Compatible - the quality or state of existing together in harmony, congruity. The orderly, efficient integration of the elements of one system with those of another

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

Connective tissue - one of the four main tissues of the body, concerned primarily with supporting bodily structures and binding parts together, they also are involved in other functions such as food storage, blood formation, and defense mechanisms of the body

Conscious sedation - used during procedures to where a patient is sedated enough to not be able to remember what happens during the procedure, but not anesthetized enough to create respiratory problems. Drugs used most often today are Versed and Valium

Copious - large amounts; said of copious amounts of secretions (mucous) of the lungs

Cornea - the convex, transparent, anterior part of the eye, comprising one sixth of the outermost tunic of the eye bulb. It is a fibrous structure with five layers. It is dense, uniform in thickness, nonvascular (no blood supply through it), and projects like a dome beyond the sclera, which forms the other five sixths of the eye's outermost tunic

Cranial nerve V - is the trigeminal nerve, located in the pons of the brain stem, functions as motor and sensory in chewing and sensations of the face, scalp, and teeth

Cranial nerve VII - is the facial nerve located in the pons of the brain stem, functions as motor and sensory in facial expressions, taste (anterior two thirds of the tongue), salivation, and tearing

Crepitus - felt on the skin usually around the neck and chest area when air escapes from the lungs and is felt under the skin as small crackles (like popping the packaging material that has the tiny bubbles in it)

Crevice - a small fissure or crack

Crowns - an artificial restoration that replaces the natural crown of a tooth

D

Decompensation - one of the main functions of the mouth is the "decompensation" of starches, which means that due to the lack of or excessive saliva or the amount of acids in the mouth, there is failure in the defense system mechanism for the decompensation of starches to be initiated as it normally does

Decongestant - a substance that eliminates or reduces congestion or swelling

Dehydration - the process of dehydrating, occurs when output of water exceeds water intake, may result from deprivation of water (not taking enough water in), excessive loss of water

(possibly taking water pills to reduce swelling of the extremities), reduction in total quantity of electrolytes (not taking enough minerals in like salt, potassium, calcium or magnesium) or injection of hypertonic solutions (like in IV fluids that have too much salt in them)

Delayed rupture of teeth - that a baby's teeth whether it be their first ones or it could be any of their baby teeth do not appear until much later than normal. Rupture in this case means breaking through the gum or skin

Dental sealants - defined as a thin, plastic coating painted on the chewing surfaces of the back teeth (molars). They harden quickly to form a shield over the tooth. They are clear or tinted

Dentin - the chief material of teeth, surrounding the pulp and situated inside of the enamel and cementum. It is harder and denser than bone, it consists of solid organic substratum infiltrated with lime salts

Desensitization - to remove or reduce the painful response of vital, exposed dentin to irritating substances and temperature changes

Dilantin - one of the older medications (still used quite frequently) for seizure control, but one of its major side effects is hyperplasia of the gums (swelling to where the gums overlap the teeth)

Disparities - children with special needs usually experience disparities in their access to quality dental care which means that we as parents have to jump over a lot of hurdles before we can get dental care for our children through Medicaid, or private insurances, (in other words - we have to go through a lot of hassles)

Dozycycline - an antibiotic gel used to control bacteria and reduce the size of periodontal pockets. The medication is put in the pockets after scaling and root planning. It is released slowly over a period of about seven days

Dysfunction - unable to function normally

E

Eating aversion - a form of behavior therapy to help those who cannot stop eating

Enamel - a hard white substance that covers the dentin of the crown of a tooth

Endoscopy - inspection of the cavities by use of the esophagus and the endoscope, a lighted instrument which goes in the mouth and can examine the throat, stomach, and beginnings of the small intestine

Epilepsy - a neurological disorder characterized by various combinations of the following: recurrent episodes of petit mal or convulsive seizures, sensory disturbances, abnormal or repetitive behavior, loss of consciousness. Common to all types of epilepsy is an uncontrolled electrical discharge from the nerve cells of the cerebral cortex. Many causes are unknown, but with Batten Disease it is almost a sure thing with our children. The frequency of seizures can vary widely, can occur during sleep or after physical stimulation, as by a flickering light or sudden loud sound. Emotional disturbances also may be a significant trigger factor. Some seizures are preceded by an "aura", but others have no warning signs. Most are brief, either localized or general, with or without clonic movement and are followed by drowsiness and confusion (post ictal state). Diagnosis is made by observation of the pattern of seizures and abnormalities in an EEG. The kind of seizure determines the selection of treatment

Equilibration - a state of balance or rest owing to the equal action of opposing forces

Erosion - when there is poor oral hygiene, there is an erosive process that results from the action of bacteria on fermentable carbohydrates in the mouth, which in turn produces acids, the decaying of the enamel and thus forming a cavity

Exertional dyspnea - shortness of breath with any type of physical exercise

Extract - the pulling or excising of a tooth

F

Fatigue - a state of exhaustion or a loss of strength or endurance, as may follow strenuous physical activity, loss of ability of tissues to respond to stimuli that normally evoke muscular contraction or other activity; muscle cells generally require a refractory or recovery period after activity, during which time cells restore their energy supplies and excrete metabolic waste products

Fecal - stool, body waste

Fermentable - in this instance the meaning of fermentable is bacteria in our mouths from the foods we eat or specifically the carbohydrates we ingest can lead to an erosive process of the enamel on our teeth

Fissure - a cleft or a groove, a lineal fault on a bony surface occurring during the development of a part as a fissure in the enamel of a tooth where dental decay can begin with a small hole

Flaw - used the same as a fissure

Flossing - flossing of the teeth is using the string like material and going between each tooth to rid the teeth of food particles after eating. Without flossing, gingivitis or periodontal disease can become evident due to inadequate dental care

Fluoride - a salt of hydrofluoric acid, introduced into the drinking water and applied directly to the teeth to prevent decay and harden the enamel

Food impaction - foods lodged between the teeth especially seen in those with poor swallowing ability and/or difficulties with chewing foods. Extra care is needed to rinse the mouth and also adequate brushing and flossing of the teeth is required to prevent dental decay, gingivitis or periodontal disease

Frontal lobe - the largest of the five lobes of the brain, significantly influences personality and is associated with the higher mental activities, as planning, judgment and conceptualizing, and also is associated with nonverbal specialized activities

Fungi - a simple parasitic plant, lacking chlorophyll; is unable to make its own food and is dependent on other life forms. Most fungal infections are superficial and mild, although persistent and difficult to eradicate. Saliva in our mouths helps to control the bacteria and fungi and prevention of infection

G

Gastroesophageal reflux - (GERD) - a backflow of contents of the stomach into the esophagus that is often the result of incompetence of the lower esophageal sphincter (LES). Gastric juices are acidic and therefore produce burning pain in the esophagus. Repeated episodes of reflux may cause esophagitis, peptic esophageal stricture or ulcer

Gluey, gelatin-like substances - refers to dental plaques and their consistency which adhere to the teeth. A film comprised of microorganisms that attaches to the teeth and often causes caries and infections of the gums. Mucin (chief ingredient in mucus, present in most glands that secrete mucus and the lubricating body surfaces from friction and erosion) secreted by the salivary glands is also a component of plaque; it varies in thickness and consistency depending on individual metabolism, dental hygiene, diet, and environmental factors

Gly-oxide - a synthetic solution similar to saliva and a lubricating agent

Grafting - usually in this case is around the gums but may include the bone as well to promote healing once surgery has removed the decayed or infectious parts

Grooves - there are normal grooves in our teeth, especially the molars where food can get stuck and toothbrush bristles can not get out, therefore leading to decay of the enamel with poor dental hygiene. One way to protect the teeth or prevent this from happening would be to put sealants over the teeth

H

Halitosis - bad breath or offensive breath

Heart medications - there are some heart medications that can also affect the gums and gingivitis can occur due to the inadequacy of saliva, usually not a problem with children with Batten Disease

Humidifier - an apparatus to increase the moisture content of the air in a room

Hypoactive - due to many reasons an individual is unable to maintain the activity level as once was, as in this case the bowel sounds can become distant or inactive due to many different reasons resulting in food particles not moving through the intestinal passageways at a normal rate (constipation may result)

Hyperplasia - an increase in size in a tissue or organ resulting from proliferation (reproducing rapidly) of cells or the development of additional tissue of which the organ is composed, excessive formation of tissue

Hyperactive - as in bowel sounds where food particles are moving rapidly through the intestinal passageways and diarrhea is one result of this process

I

Inhalation - to breathe in or to draw in with a breath of air

Insertion of a nasogastric tube - putting a tube through the nose (and occasionally the mouth) into the stomach for purposes of most of the time feeding an individual. It can also be used in such cases where an individual is constantly vomiting

Integral - meaning the entire or whole of something

Intermittent - ceasing at intervals

J

K

Ketoacidosis - acidosis accompanied by the accumulation of ketones in the body, resulting from faulty carbohydrate metabolism, usually seen as a complication of diabetes, not usually seen in children with Batten Disease

Kidney disorder - many things can happen to the kidneys due to Batten Disease. First would be the inability to control the bladder and incontinence, second being inadequate intake or output causing multiple issues with health, infections are a third reason due to either a catheter being placed or just the incontinence of urine

L

Lateral molar surfaces - the surfaces/sides of the molar teeth, three on each side upper and lower

Lung Abscess - a localized collection of pus (infection) in the lungs, symptoms include fever, increased secretions, fatigue, cough, pain from coughing, seen on a chest x-ray, CT or MRI

Lymph vessels - lymph is a thin opalescent fluid originating in many organs and tissues that is circulated through the lymphatic vessels and filtered by the lymph nodes. Lymph is similar to plasma in the blood

M

Malaise - discomfort, uneasiness, indisposition, often indicative of an infection

Malformed teeth - may be due to various reasons - tooth eruption may be delayed, accelerated or inconsistent in children with growth disturbances (eruption depends on genetics, growth of the jaw, muscular action and other factors); malocclusion is a poor fit between the upper and lower jaw, and crowding of teeth occur frequently in children with developmental disabilities; tooth anomalies are variations in size, number, and shape of the teeth; and developmental defects appear as pits, lines, or discoloration of teeth

Malocclusion - abnormal contact of the teeth of the upper jaw with the teeth of the lower jaw

Mechanical cleansing action - a synthetic preparation (Glyoxide) which due to the inability for your child to brush his own teeth, this agent (oxygen) is released and cleans the teeth

Microorganisms - any microscopic entity capable of carrying on living processes. It may be pathogenic (bacteria, fungi, virus)

Millimeters - a metric unit of length equal to one thousandth of a meter

Minocycline - a medication that helps control bacteria and reduce the size of the periodontal pockets. They are tiny particles (microspheres) put into the pockets after scaling and root planning

Motor dysfunction syndrome - any disease or syndrome which would cause a child to fall or have equilibrium problems that could damage the teeth by hitting his mouth on something

Mucopurulent - mucus or secretions from the lungs, possibly an abscess that contains pus

Mucus - phlegm, the viscous, slippery secretions of the mucus membranes and glands, containing mucin, white blood cells, and water

Multifactorial disorders - many different issues playing a part in the general health of the individual

N

Natural cleaning process - many children who have disabilities do not eat and salivate normally, which reduces the normal process that saliva and food do to help keep the mouth and teeth clean, example, drinking water to rinse the mouth of food and sugary drinks to decrease decay

Neuromotor disorders - any disease or disorder that affects the nervous system of the body

Nerve damage - any damage to the nerves due to injury, disability, etc. to where the ability to perform tasks may be affected

Nerves - one or more bundles of fibers outside the central nervous system that connect the brain and the spinal cord with other parts of the body. Nerves transmit afferent impulses from receptor organs toward the brain and the spinal cord and efferent impulses peripherally to the effector organs

Neurologic - deals with the nervous system and its disorders, including the mental status, the function of each of the cranial nerves (which supply all of the nerves to the entire), sensory and neuromuscular functions, the reflexes, and other brain functions

Neutralize - an interaction between two things to keep the acid-base balance even

O

Occlusal splint - pertaining to the closure of an opening, specifically, to the relation of the contacting surfaces of the maxillary and mandibular teeth and to position the teeth - also called bite block

Occupational therapy - a subdivision of physical medicine in which handicapped or convalescing patients are trained in vocational skills and activities of daily life through a program designed to satisfy the specific needs of the child while providing diversion and exercise

P

Paranasal sinus - the air cavities in various bones around the nose, situated near or alongside the nose, close to the maxillary sinus (upper teeth)

Parietal lobe - the part of the brain which is located from the crown to the lower part of the skull, there is a left and a right, it is part of the cerebrum of the brain and a portion of the parietal lobe controls motor impulses which are carried to the muscles and sensory impulses come from the various sensory nerves

Parkinson's disease - a slowly progressive, degenerative, neurologic disorder, characterized by resting tremor, rolling of the fingers, a mask-like facies, shuffling gait, and muscle weakness and rigidity. Signs and symptoms include drooling, increased appetite, intolerance to heat, oily skin, emotional instability and defective judgment, increased fatigue, excitement, and frustration. Intelligence is rarely impaired. Palliative and symptomatic treatment of the disease focuses in correcting the imbalance between depleted dopamine and abundant acetylcholines; since dopamine normally appears to inhibit excitatory activity in the brain area. Treatment includes administration of drugs such as levodopa and dopamine products. Patients with the disease are encouraged to continue to work and remain active as long as possible and to prevent the spine from bending forward by lying prone on a firm mattress and by walking with the hands folded

behind the back. Hand tremor is less apparent if the patient grasps the arms of the chair when seated

Paroxysmal - a marked usually episodic increase in symptoms, like the heart rate, pain, cough, etc.

Per umbilical - around the umbilicus (belly button)

Pharyngitis - inflammation of the pharyngitis, usually associated with inflammation of the nasal mucosa - malaise, fever, dysphagia, pain in throat, secretions; treat with gargles, throat lozenges, bedrest, adequate fluids, analgesics, appropriate antibiotics after culture done

Pharynx - a musculo membranous tube extending from the base of the skull above to the level of the 6th vertebrae below where it becomes continuous with the esophagus, communicates with the nose, eustachian tube, mouth, esophagus and larynx, serves as a passageway for air from the nasal cavity to the larynx and food from the mouth to the esophagus

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

Physical defense - the mucous membranes of the mouth serve as a defense against many infections, etc., when normal body health is adequate through normal secretion of saliva to rinsing of the mouth with the foods and fluids we eat and drink

Pica - a craving to eat substances that are not foods, such as dirt, clay, chalk, glue, starch, or hair. The appetite disorder may occur with some nutritional deficiency state and in some forms of mental illness

Pits - little tiny holes on the surface of the teeth where food particles can get stuck in, and with poor oral hygiene dental decay can occur

Plaque - a thin film on the teeth made of mucin and colloidal material found in saliva and often secondarily invaded by bacteria

Pouching - holding food in the cheeks as a chipmunk would do

Premolars - one of eight teeth, also called bicuspid, the upper ones are larger than the lower, appear during childhood and remain until old age, they are smaller and shorter than the canine teeth

Prophylaxis - prevention of or protection against disease, often involving the use of biological, chemical, or mechanical agent to destroy and prevent the entry of infectious organisms

Puberty - the period in life at which one of either sex becomes functionally capable of reproduction

Pulp - the soft vascular portion of the center of the tooth

Pulsating - the rhythmic beat, as of the heart and blood vessels, a throbbing

Purulent - containing pus as an infection or an abscess

Putrid - decayed, rotten, foul

Q

R

Radiation therapy - treatment with a radioactive substance, given sometimes along with drugs in chemotherapy to eradicate tumors or cancers

Radiographs - x-ray pictures, a record produced on a plate, film, or paper by the action of roentgen rays or radium

Rales - an abnormal sound of crackling heard in the chest with a stethoscope, usually heard on inspiration, produced by the air through the bronchi which contain secretions or exudate or which are constricted by spasms or a thickening of their walls

Regurgitation - the return of swallowed food into the mouth

Resistant - refers here to fluoride which helps the teeth from decay when it has been added to the water or supplements given to children

Retained primary roots - refers to baby teeth that when loosen and fall out, some of the root remain embedded in the cavity

S

Saliva - the clear, viscous fluid secreted by the salivary and mucous glands in the mouth. It contains water, mucin, organic salts, and a digestive enzyme. It moistens the cavity to initiate the digestion of starches and to aid in chewing and swallowing

Salivary glands - one of the three pairs of glands that pour their secretions into the mouth, thus aiding the digestive process (one produces mucus, one fluid, and the other mucus and fluid)

Salivary lubrication - there may be such a case where not enough saliva is produced to even lubricate the mouth which is one of the main functions of saliva. There are artificial solutions available for this purpose

Salivary secretions - many children with Batten Disease produce an excess amount of saliva and are constant drooling, therefore the need to place your child on either side to prevent aspiration is important

Sealants - thin clear or tinted liquid that is painted on the teeth, especially the molars to protect and prevent dental decay

Sensorimotor - means both motor and sensory functions

Single locus - a single location in this reference, a single tooth

Sinusitis - inflammation or infection of the sinus tract, especially a para-nasal sinus, may be caused by viruses, bacteria, or allergy

Stomatitis - inflammation of the mouth, may be caused by many factors or conditions; heat, pain, flow of saliva, restlessness, bad breath, exhaustion, bacteria, viruses, mechanical trauma, hot deficiencies, blood disorders, poisoning by drugs, especially heavy metals, certain skin disorders, systemic infections such as measles, scarlet fever

Suctioning - to draw out as suctioning the lungs of secretions with a pump when an individual is unable to cough the secretions out himself

Suture - is used to pull together the skin after surgery or a fall/injury to promote faster healing and prevent infection from an open wound

Susceptibility - the condition of being more than normally vulnerable to a disease or disorder

Swallowing study - done to see if a child is aspirating food or fluids into their lungs, barium is used to have the child swallow and followed by fluoroscopy as it travels to the stomach. Changes in consistencies of foods may be necessary

Symmetry - correspondence in shape, size and relative position of parts on opposite sides of the body

Systemic disease - a disease which involves the whole body not just a localized or specific area

T

Tartar - deposits on the teeth when good oral hygiene is not done

Temporal lobe - the lobes of the brain located on the sides of the skull just above the ears. It contains the auditory receptive areas of function

Thrush - a common, budding, yeastlike, microscopic fungal organism normally present in the mucus membranes of the mouth. It is treated with a "swish and swallow" antibiotic

Tissue regeneration - some organs within the body are able to regenerate (make new ones), just like our skin sloughs off the dead cells as in dry skin and new tissue/cells are formed

TMJ - temporomandibular joint disorder - one of the two joints connecting the mandible to the temporal bone. It is a combined hinge and gliding joint, formed by the anterior parts of the mandibular fossae of the temporal bones, sometimes spasms occur and cause a great deal of pain

Tongue depressor - used by a Doctor or Dentist to examine the back of the throat - tonsils, etc.

Toxicity - of or pertaining to a poison, of a disease or condition, severe and progressive

Trigeminal nerve - either of the largest pairs of cranial nerves essential for the act of chewing

Trismus - a prolonged tonic spasm of the muscles of the jaw, also called lockjaw

U

Upper gastrointestinal series - an x-ray taken to examine the esophagus, stomach and duodenal portions of the gastrointestinal (GI) tract, usually the test is given with a white chalky (sometimes flavored) substance to drink to show the outlying structures

V

Vaporizer - a device for converting liquids into a vapor spray to add more moisture to the humidity of a room

Vascular - of or pertaining to a blood vessel

Vascular disorder - inadequate peripheral blood flow caused by narrowing or occlusion of the blood vessels, by a buildup of plaque or blood clots vessels, diseased or weakened walls of the veins and arteries. Signs and symptoms include pale, cyanotic, or mottled skin the affected area, swelling of an extremity, absent or reduced sensation per touch, tingling, diminished sense of temperature, muscle pain, atrophy (shrinking) of the muscle in the affected extremity

W

X

Y

Z

Zenker's diverticulum - a circumscribed herniation of the mucus 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

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