PRADER-WILLI SYNDROME ASSOCIATION

-Still hungry for a cure.—

Dental Tips and Tricks

Provided by Barbara Dorn, WI chapter

Start teaching tooth care at a young age. Cleaning teeth should be done twice daily, beginning as soon as the first teeth appear.

- Start cleaning teeth in infants and toddlers with a very soft toothbrush, a washcloth or finger toothbrush pads. Not only will this help establish good dental habits and prevent tooth decay – this may help with oral motor stimulation and strengthening.
- Wide brush handles often make brushing easier. There
 are many brands and styles. One trick is to insert a
 bicycle handle grip, rubber pencil grip or other special
 grip device (available from an Occupational Therapist)
 on to the toothbrush handle.
- Ask your dental hygienist to help teach and motivate the person receiving dental care. (Many often do more to please others than they do to please parents.)
- Use a SOFT brush to prevent or minimize trauma to gums.
- Typically the parent should assist in brushing teeth up until early middle school. Encourage and teach the child to do it ... but the parent should finish it up with a "once (or twice) over" to make sure all areas have been reached.
- Make tooth-brushing fun. Don't be afraid to vary things to keep it fun as well as novel. There are many fun toothbrushes. Ones with:
 - Movie and cartoon characters. Let the child choose!
 - Music (so the child/person learns to stop brushing when the music stops).
 - Batteries "Electric" toothbrushes.
- Use good tasting toothpaste w/ fluoride. Always provide supervision with toothpaste use to prevent the child from overeating it. Toothpaste in small amounts will not hurt you.
- 1-2 times a week, use tablets or a stain to check for plaque build up. Your dental care provider may be able to assist you with obtaining tablets or a small amount of food coloring on a Q-tip works well too.
- Make the tooth care a game. Establish a routine. "Count 20 brushes on the top right; 20 on the top left; 20 on the bottom right; 20 on the bottom left; and don't forget the areas behind the upper and lower front teeth and tongue". Post the sequence on a small index card and post it to the mirror or other nearby spot so everyone who may be assisting uses the same approach.
 - Make a chart ... use incentives for good habits and cooperation. (Possibly reward with a new toothbrush, sugar-free gum...)

- Use a tooth-brushing timer so that adequate time is spent doing the brushing. (See Product Sharing)
- Teach and encourage flossing. There are flossing instruments available at most pharmacies and other stores to help make this easier.
- Limit sugar and/or use sugar-free products. (Sugar + Bacteria = Acid Production Acid + teeth = Cavities)
- Visit a dental professional every 6 months for cleaning and monitoring.

PRODUCT SHARING

- "TOOTH TIMER" is a fun device that helps patients brush their teeth for 2 minutes, the proper time for brushing. NO batteries needed. COST: \$9.99 + \$4.95 for standard shipping. Available at Open Wide catalog at 1-800-232-4244 or on line at www.OpenPlease.com Just write "timer" in the search box (item # CM940)
- 2. BIOTENE (toothpaste, mouthwash & gum) are products that help decrease bacteria and found to be very effective in decreasing the white ring and/or crusting often seen around the mouths of persons with PWS. It is expensive and not available at all stores. (Walgreen's carries it) ... and it is worth it.

Finding a Dentist for the Person with PWS

- Select a dentist who is not only a good professional but one that also makes your child and the experience a positive one.
- Don't be afraid to shop around. Talk to other parents in your community. Get a referral. Choose a dental team that works well with children/adults who have cognitive limitations. Finding dental professionals that take Medical Assistance is very challenging. Since the reimbursement rate is very low, dental practices often choose not to take this type of insurance. If your child/ young adult has been receiving dental care from a dentist for many years and then begins to be covered under MA, talk to him/her to see if they would be willing to continue to care for your child. A dental practice can dictate how many patients they serve with MA and if you have a long-term relationship with this professional, he/ she may consider doing this. Some dental care providers have opted to donate their services in lieu of filing with MA.

In planning for your child's future, you may want to budget funds so that your son/daughter can receive adequate dental care. Even with dental insurance, there are many services that are either only partially covered or not covered at all.

Dental Tips and Tricks

Dental Problems and PWS

By Dr. Tom Hughes, DDS, Treasurer PWSA of WI, Inc and Parent of Sara w/ PWS

Most dental problems with PWS are related to decrease salivary flow and mouth breathing. These two concerns combined promote tooth decay, periodontal disease and crowded arches. What can be done? First, make sure the child or adult has either a fluoridated water supply or fluoride tablets (1 mg /day to help fight tooth decay.) Have them brush with a fluoride toothpaste after each meal and then before bedtime. Parents will need to check their teeth after brushing, especially at night so that they don't leave food along their gum lines. This leads to decay and periodontal disease. Persons with PWS also have a tendency towards dry mouth because of their mouth breathing which leads to thicker saliva, which promotes both decay and periodontal disease. Normal saliva is thin and washes the teeth clean, while thick saliva sticks to the teeth and harbors bacteria that cause tooth decay and periodontal disease. Finally, as a result of mouth breathing during their early years, individuals with PWS have a greater chance of developing narrow arches which causes crowded teeth. Getting orthodontic care early (age 6-9) to help develop the arches to a more normal shape can make it easier to keep the teeth clean, which helps prevent tooth decay and periodontal disease. It can also help reduce their tendency to mouth breathe, which would decrease tooth decay and periodontal disease. Professional dental cleanings every 3 to 6 months is also a big help in keeping the teeth and gums clean and healthy.

Ask the Dentist

The following are common questions regarding dental issues for persons with PWS. Dr. Hughes has provided us with some answers.

QUESTION 1: Sealants are often used in protecting a child's teeth from the formation of cavities. Is this something an adult with PWS could have done? Yes, an adult can have this done but this only protects the biting surfaces from decay. Along the gum lines is where most decay due to dry mouth and thick saliva occurs. In these cases, only proper brushing with fluoride toothpaste and topical fluoride rinses or varnish is effective.

QUESTION 2: Is there anything a dentist can do to help this be covered by the person's insurance? The Wisconsin Medical Assistance program covers sealants on permanent posterior teeth (which are the only ones that need sealants) the problem with the program is that it is under funded and difficult to work with. That is why many dentists don't accept it in their practices. (Please contact your state assembly and senate person and ask them to fund this program better.) Other insurances may cover this if a preauthorization is completed however, each insurance may be different.

QUESTION 3: Is there anything to help address the thick sticky saliva that is often seen in persons with PWS? Would

scheduling "water snacks" at certain intervals help? The reason for thick saliva is mouth breathing for the most part and less fluid intake secondly. "Water snacks" (a glass of water 4-6 oz.) might help but too much water is bad also. (Water intoxication can occur if a person drinks a very large amount of fluids in a short period of time. The large amount of fluid washes away the sodium in their system and can result in a serious health emergency.) However, if this was done twice a day mid morning and mid afternoon it could help. (Many parents also report the use of Biotene toothpaste has been helpful.)

QUESTION 4: Is it true that chewing gum after meals helps to prevent tooth decay? If so, is there any special gum that helps more than others? Chewing gum could help clean the teeth, but here again you have to be careful. Use sugar free gum and only let them chew 1 (one) piece. This can last from breakfast to lunch or lunch to dinner or dinner to bedtime. But as we know, many people with PWS will try to eat many pieces either at a time or one after another as the flavor goes away. If they eat many pieces of gum containing sugar, it can have the opposite effect and cause cavities and weight gain.

QUESTION 5: Is it true that there are certain foods (like apples or carrots) that can actually assist in removing the build up of plaque? Foods with hard textures do help clean the teeth of plaque. But again you have to use them in moderation because they still have calories and eating all day long produces plaque buildup.

QUESTION 6: Are there foods that should be avoided that may be contributing to the development of cavities? *Any food that is soft, sticky and sugary (raisins, "gummy anything", candy ...) should be avoided.*

QUESTION 7: It is often common to see white crusting on the sides of the mouth in persons w/PWS - what causes this and can anything be done to prevent this? This is dried saliva from mouth breathing. If your child has crowded teeth and narrow arches (need a dentist to assess this), having orthodontic treatment to widen the arches might help with their ability to breathe through their nose instead of their mouth. Also have their tonsils and adenoids checked because if they are enlarged this causes mouth breathing also.

QUESTION 8: Are there any special considerations that parents and dentists need to be mindful of when considering orthodontia for a person w/PWS? The biggest problem is keeping the teeth cleaned. Parents will have to help their children keep their teeth cleaned during orthodontic therapy.

Did You Know??? Water with fluoride is available in plastic disposable bottles. If your water source does not contain fluoride, feel free to use it not only to drink but also with your recipes, juices, and/or Kool-Aid.

In addition to cavities, gum disease and periodontal disease, poor oral care can lead to other health problems. Bacteria can break away from the teeth and gums and travel to other parts of the body causing infections.