

Dental Health in Children and Adults with Prader-Willi Syndrome

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Individuals of all ages who have Prader-Willi syndrome (PWS), will eventually experience challenges with dental health. Research has identified a number of issues commonly experienced by these individuals, including dental caries (cavities), gingivitis (inflammation of the gums tissue surrounding the teeth), reduced salivary flow, enamel erosion, and severe tooth wear. It is critically important to address dental health at an early age to avoid lifelong complications. Further, proper dental habits and care, especially in adults with PWS, can help maintain overall health and prevent infections and tooth loss. Read on for additional tips.

DENTAL CARIES/CAVITIES, AND GINGIVITIS

The most common cause of dental caries/cavities and gingivitis is poor oral care. Mouth breathing is also a contributing factor in individuals who have PWS. Parents and caregivers should begin teaching and modeling good oral hygiene early to develop lifelong good habits. As time goes on, continue to monitor, and reinforce these skills.

Cleaning teeth should be done on regular basis 2-4 times a day.

Encourage and teach the child to clean their teeth, but the parent should finish it up with a “once over” to make sure all areas are reached. This is especially important if a person has braces and at bedtime, to make sure they don’t leave food along the gum lines.

- From birth to 6 months, or when the first tooth erupts, wipe the gums with a clean moist gauze pad or washcloth.
- Advance to using a very soft toothbrush or finger brush pad. This will help to establish good dental habits and assist with oral motor stimulation and strengthening.
- Wide brush handles often help to make brushing easier. A bicycle handle grip, rubber pencil grip or other special grip device (available from an occupational therapist) might be helpful.
- Always use a soft brush to minimize trauma to the gums.
- Typically, the parent or caregiver should assist in brushing teeth even up until early middle school if needed.
- Solicit help from a dental hygienist to help teach and motivate the person receiving dental care. They may be more successful in obtaining cooperation and successful mastery of the skill.
- Make tooth brushing fun.
 - Use fun toothbrushes; let the child or adult choose.
 - Use music or “tooth timers” to help with timing of how long to brush. Some toothbrushes light up and change colors to indicate proper brushing time.
 - Use battery operated or electric toothbrushes.
 - Use incentive charts. Provide rewards – new toothbrush or sugar free gum

- Use good tasting toothpaste with fluoride. Always provide supervision with toothpaste to prevent the person from overeating it. Toothpaste in small amounts will not hurt you.
- White crusting around the mouth is often seen. Toothpaste and/or mouthwash designed for persons with dry mouth has been very effective. A toothpaste that contains baking soda or one that is used for persons with dry mouth. (Examples include: Biotene, ACT-Dry Mouth, Salivea, SprinJene or Tooth Note),
- Teach and encourage flossing. There are several flossing instruments available at most stores and pharmacies.
- Limit sugar and use sugar-free products. When sugar combines with bacteria in the mouth there is increase acid production which can cause cavities and damage tooth enamel.
- Chewing sugar-free gum after eating can help increase salivation which could help prevent tooth decay. Limit to one piece and this does not substitute for brushing and flossing.
- Avoid food that is soft, sugary, and sticky like raisins, fruit snacks, or anything “gummy” that can contribute to creating cavities.

Dental examinations and cleanings should be done at least every 6 months.

- Do not be afraid to shop around. Get referrals from other parents in your community.
- Choose a dental team who is educated and experienced with patients with special needs or cognitive impairments.
- Many people with PWS have a high palate and undersized lower jaw. A consultation with an orthodontist is advised between ages 6-9 to assess the palate and structure of the mouth.

REDUCED SALIVARY FLOW AND ENAMEL EROSION

Thick, sticky saliva is caused by reduced production of saliva and is commonly found in individuals who have PWS. Reduced salivary flow contributes to enamel problems, such as enamel erosion (the wearing down of the protective covering (enamel) of the teeth). When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort and pain. However, since persons with PWS have an altered pain response, they might not voice any complaints. Health conditions including gastric reflux, medications (aspirin, antihistamines, and some vitamins), as well as a diet high in sugars and acid contribute to enamel erosion. In addition to good dental hygiene and care, there are additional steps that can manage and prevent these issues.

- Consult your dentist on use of sealants in preventing enamel erosion and tooth decay, even in adults.
- Drink water in moderation. Dehydration is often a contributing factor.
- Avoid beverages high in acid, such as soft drinks, sport drinks, juice, tea, and coffee.
- Swish mouth out with water or brush teeth after drinking beverages high in acid.
- Use a straw to keep acids away from teeth.
- Use fluoride toothpaste and an alcohol-free fluoride mouthwash. Use as a rinse and do not swallow. If needed, apply with a Q-tip.
- Report symptoms of Gastroesophageal Reflux Disease (GERD) such as a sudden loss of tooth enamel, excessive belching and/or burping to your health care professional to

identify if gastric reflux is present. This disorder has been identified in persons with PWS and can result in enamel destruction.

SEVERE TOOTH WEAR/GRINDING/BRUXISM

Teeth grinding or recurrent rubbing of the surfaces of the teeth can result in damage and severe tooth wear and other complications. This is often seen in children and adults with PWS. It occurs most often while sleeping.

- If a bite abnormality is identified a referral to an orthodontist is highly recommended.
- Mouth bite guard is recommended. It is best if it is individually fitted by dentist. It might require an incentive program for compliance.
- Discourage chewing on pencils, pens, or anything that is not food. Minimize chewing gum if present. The jaw muscles may become conditioned to clenching and increase likelihood of grinding teeth.

AGING ISSUES AND DENTAL HEALTH

Because of lifelong dental challenges, aging adults with PWS are now facing many dental issues and financial challenges. Because we know more today about dental issues facing people with PWS, many more persons are getting preventive dental care and doing more to maintain oral health. Some adults have experienced the loss of tooth enamel, as well as severe teeth grinding, resulting in deterioration and loss of teeth as they age. Others have problems resulting in the need for root canals, tooth extractions and the need for dentures. These services can be extra challenging because most state Medicaid programs may not cover these services and they are very expensive. Medicaid services are determined by both federal and state regulation. Certain services are considered mandatory, and every state must provide them to qualify enrollees. Dental care for adults is not considered mandatory, so states provide dental services as an optional benefit. Some states only provide emergency dental care services, such as extractions when an infection is present. Others may cover partial or complete dentures if it is determined a medical necessity for a patient. While each state may define “medically necessary” differently, it may mean that a patient must show a significant loss of teeth or bite alignment. There may only be coverage of dentures made of certain materials. Your dental care professional can help you determine what options are available to you so you can get coverage with your Medicaid provider. (See section on Finding a Dental Professional later in this article for suggestions on locating dental services.)

There are different types of dentures dependent upon the extent that teeth need replacing.

- **Partial Denture** is usually removable, artificial teeth that replace multiple teeth in the upper or lower portion of the mouth. They can enhance chewing and help with speech. You need to have teeth remaining to attach the partial dentures to. Some are removable and typically attach with a clasp. They can be made of plastic, polymers, or metal.
- **Complete Denture** (also known as a full denture, false teeth, or plate) is a removable appliance used when all teeth within a jaw have been lost and need to be prosthetically replaced. A complete denture is constructed when there are no more teeth left in an arch.
- **Permanent Denture** (also referred to as a full denture supported by dental implants) are replacement teeth that are attached to dental implants to provide a solid foundation for permanent replacement of teeth. Dental implants (posts) are surgically implanted into

the jaw, and they are used to anchor the teeth in place. They are designed to not be removable or only removed by a dentist, when needed.

FINDING DENTAL PROFESSIONALS

- Many persons with PWS benefit greatly from having dental insurance coverage. Many families are able to provide dental insurance for the person with PWS.
- Finding dental professionals that accept Medicaid or other financial assistance can be very challenging, and reimbursement for dental services in these programs is often inadequate. Contact your state dental association for a list of providers.
- Some dental care providers have opted to donate their services in lieu of utilizing financial assistance. Contact your state dental association to see if they have a Donated Dental Services Program in your state.
- Community health clinics often have free or reduced-fee dental clinics. Special Olympics in some areas provide dental services. Watch for regional FREE dental clinics.
- Consider utilizing a dental school for care.
- For persons on Medicare and Medicaid, check to see if a Medicare Advantage program is available in your state or area. Many plans offer additional dental services.
- Many dental professionals will work with patients to set up a payment plan. Determine your budget and see if this is feasible and possible.

Good dental health is important for everyone. It helps with communication, eating and improves the quality of life for persons with PWS. Research has also documented the importance of good oral health in maintaining and improving your mental health, preventing cardiac complications, and helping with your overall health in general.

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