

Dental Care Tips for Children and Adults with Prader-Willi Syndrome

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Children and adults with Prader-Willi syndrome (PWS) of all ages face lifelong challenges in the area of dental health. People who have Prader-Willi syndrome have decreased, thick and sticky saliva that adheres to teeth and harbors bacteria that can cause decay and periodontal disease. Some also breathe through their mouth, which may result in the development of narrow arches and crowding of teeth. Many experience severe tooth grinding with increased tooth wear. There are many steps that can be taken to prevent or minimize problems as well as promote good dental health in everyone with PWS.

Begin Dental Care & Good Habits Early Before Teeth Appear:

- Wipe gums with a washcloth after feeding with gauze, a soft wet washcloth or finger toothbrush pads. This will help get rid of the sticky coating called plaque that can cause tooth decay.
- Getting your baby used to having his mouth cleaned as part of his daily routine should make it easier to transition into tooth brushing later on.
- For children who are fed via feeding tube, oral health is just as important to keep the mouth clean.
- Consultation with an Occupational or Speech therapist may be helpful in addressing any oral weaknesses and concerns.

When Teeth Appear:

- As teeth start to appear, brush teeth twice a day with water and a SOFT bristle toothbrush.
- Use fluoridated water. If your water supply is not fluoridated or if your family uses purified water, ask your dentist if fluoride supplements should be considered. (Fluoride tablets - 1mg per day.) Check labels on bottled water to see if they contain fluoride.
- Use fluoride toothpaste after each meal and at bedtime starting at age 3 years – use only a small, pea-size amount for younger children. Make sure they spit it out – minimize swallowing. Ingesting too much can cause stomach upset. Ask the dentist about use of fluoride rinses.
- Schedule first dental appointment within six months after the first tooth erupts, or by their first birthday, whichever comes first. Persons with PWS should see a dentist at least every 6 months – life long.

As Time Goes On:

- As permanent teeth grow in, the dentist can help prevent decay by applying sealant to the back teeth, where most chewing occurs. This protective coating keeps bacteria from

- settling in the hard to-reach crevices of the molars.
- Sealants can also be applied to chewing surfaces in adulthood. This does not prevent decay along the gum lines so proper brushing continues to be important.
 - Parents and caregivers need to teach, assist, supervise and inspect to make sure brushing is done and no food is left behind – especially along the gum line. Encourage to brush on the inside and outside of teeth, as well as the tongue to dislodge bacteria that can cause bad breath.
 - Teach, perform, and encourage flossing. There are many flossing devices available on the market.
 - Avoid foods that are soft, sticky, and sugary (raisins, gummy anything).
 - If the dentist notices high, narrow arches resulting in crowding of teeth, request referral to an orthodontist.
 - If you see or hear grinding of teeth, have it evaluated right away. A bite guard (worn at night) could be lifesaving for the future of his/her teeth.

Help for Some Challenges with Oral Health

Oral health care, like other personal care routines you may help with, takes patience and creativity. Establish a daily dental routine by using the same time, place, and position. Start with small steps, until the child gets used to you working in their mouth.

- If tooth brushing causes distress, experiment with positioning, times, places, distractions and rewards:
 - A small child may be cradled in the arms or brushing can be done standing behind the child with the head supported or from a seated or kneeling position.
 - Brushing teeth in the bath may be easier.
 - Use distractions such as music, singing or their favorite television show.
 - Provide rewards. Use stickers, tooth brushing charts which can be downloaded online and other incentives.
 - Let the person pick out their toothbrush; get him/her excited about brushing their teeth.
 - Let them choose a new toothbrush monthly to keep them interested. Include a new toothbrush on their monthly shopping list.
 - Make things fun to encourage cooperation.

Thick, sticky saliva is often seen and problematic for many with PWS. You may see crusting around the mouth.

- Use toothpaste or other dental products for dry mouth. (Biotene, ACT-Dry Mouth, Salivea, SprinJene or Tooth Note are some products that have been recommended)
- Make sure persons with PWS are receiving proper (not excessive) amounts of water daily. This provides moisture and helps to rinse teeth when there is a low production of saliva.
- Use a humidifier at night to help alleviate dry mouth symptoms.
- Use two people to brush teeth, one to brush while the other distracts or encourages

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