Introduction

People with PWS often have a characteristic high arched palate, small lower jaw, and a different shape of lips or tongue, however this does not usually lead to oral problems. Some people experience thick saliva and a dry mouth which when combined with dietary complexities in PWS, may increase the risk of tooth decay.

Access to dental services and the dental treatment itself can be more difficult for many reasons, so the prevention of oral problems for people with PWS is very important.

Healthy Teeth

Tooth decay occurs over time when teeth are exposed to high sugar foods and drinks which causes holes to develop in the teeth (cavities). This causes a change in colour of the teeth, pain, infection and can lead to tooth loss.

The frequency of sugary foods and drinks seems to be more important than the actual amount of sugar. This is particularly important for people with excessive eating patterns.

For example: Tom and Nina each have a bag of 20 raisins. Tom eats all 20 raisins at once, but Nina eats 20 raisins throughout the day. Here, Tom has had 1 sugar attack, but Nina has 20 individual sugar attacks so she has a higher risk of tooth decay than Tom.

This also applies to drinks and sweets, so if we have a sugary drink or sweet together with a meal rather than sipping or snacking throughout the day, the risk of getting tooth decay is much lower.

Food and Drink Labelled as ‘Sugar Free’ and ‘No Added Sugar’

‘Sugar-free’ items are safe for the teeth and often have a tooth friendly symbol on them: ‘No added sugar’ items such as squash contain large amounts of natural sugars and are not considered safe for teeth between meals.

Fresh fruit juices, honey and dried fruits have many health benefits, but contain a large amount of natural sugar so it is important to have them with a meal to prevent tooth decay. Water and milk are safe to drink between meals.

Saliva

People with PWS may have thick saliva and/or a dry mouth. Saliva flow also naturally reduces during sleep. Night time brushing is most important because this is when the teeth are most at risk of decay. Milk, which is usually considered a safe drink, contains enough natural sugar to cause severe tooth decay if given at night time. This is common among children that have cow/breast milk in during the night, and is important to be aware of due to the feeding difficulties commonly experienced among babies with PWS.

People with a particularly dry mouth may benefit from saliva substitutes and a high fluoride toothpaste to prevent decay, which are prescribed by a dentist.
Healthy Gums

Plaque exists in everyone’s mouth, but if it is not brushed off, it looks like a thick yellow furry coating on the teeth. When plaque collects at the gum line, the germs (bacteria) cause the gums to become red, tender and sometimes they will bleed when brushed. This is called gingivitis and will usually settle within 2 weeks by improved brushing, even if the gums bleed when you do so. If hygiene is not improved, over time this can lead to more significant gum disease called periodontitis, where the teeth become loose and can fall out.

Tooth brushing

Low muscle tone and eye sight complications in PWS can make tooth brushing difficult. Each individual will have different needs depending on their age and preferences, but here are some tips:

1. Try to brush the teeth for 2 minutes twice per day. Brushing before bed time is most important as this is when the teeth are most at risk of decay. Focus along the gum line as well as the teeth.
2. Good hand skills are needed to clean all of their teeth properly. Encouraging independence is important, but carers must accept ultimate responsibility by brushing more thoroughly after the first attempt, especially in young people with delayed motor development.
3. Start brushing as soon as the first tooth appears. This allows a child to get used to the sensation of brushing and establish a routine.
4. Play a favourite song or sing to make tooth brushing fun and to ensure that you brush for the correct length of time. Counting numbers up or down while brushing may also improve co-operation.
5. Sometimes a second person may be needed to hold hands or feet to ensure safety.
6. Spit, don’t rinse! After brushing the teeth, don’t wash away the fluoride protection from the toothpaste by gargling with water or other mouthwash. Instead encourage them to spit out the bubbles to allow longer protection from the toothpaste. Instead use mouthwash at a different time to brushing.
7. Praise good co-operation with tooth-friendly rewards such as stickers.
8. Mouthwash, dental floss and interdental brushes are only useful to clean in between the teeth if there is sufficient co-operation, so prioritise good tooth brushing first.
9. A manual tooth brush may be better tolerated than an electric tooth brush as it does not vibrate.
10. Access to the teeth can be problematic. It may be easier to brush the teeth from behind while the individual is sitting or lying down.

The following techniques help to keep the mouth open on one side, so that we can clean the teeth on the other side:

- 2 toothbrushes: when the individual bites on the toothbrush handle, this allows good access with a toothbrush on the opposite side. Then swap over.
- Finger guard: when the individual bites on the guard, this allows good access with a toothbrush on the opposite side. Then swaps over. The finger guard should be solid, not soft, to minimise risk of injury to carers.
Toothpaste

There are lots of different toothpastes available, but the most important ingredient to prevent tooth decay is fluoride.

<table>
<thead>
<tr>
<th>Age</th>
<th>Recommended amount of fluoride in toothpaste</th>
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<tbody>
<tr>
<td>Up to 3 years</td>
<td>Smear of toothpaste containing 1000 ppm fluoride</td>
</tr>
<tr>
<td>3 years and over</td>
<td>Pea sized amount containing 1350 - 1500 ppm fluoride</td>
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The dentist may recommend a higher fluoride toothpaste which is only available on prescription if there is a significant risk of tooth decay.

If there are difficulties spitting and swallowing, there are a number of low foam toothpastes available. Generally these do not contain the ingredient sodium lauryl sulphate (SLS). Some people do not like the taste of toothpastes. Flavourless varieties are available with fluoride protection: check the label.

Medications

Medications are often prescribed in syrups because of difficulties swallowing tablets. Most are available as ‘sugar free’ varieties. Remind your doctor about this to help prevent tooth decay.

Some medications can have side-effects such as swollen gums, ulcers or a dry mouth. Often it causes more harm than good to change these medications and the oral side-effects have to be accepted. So good oral hygiene and diet control are important to prevent further problems in the mouth.

Erosion

Over time, acid can cause the teeth to dissolve. This may be due to acid in our foods and drinks, particularly excessive fruits, juices and fizzy drinks between meals. Alternatively, the acid may be from the stomach (gastro-oesophageal reflux). This can lead to the teeth changing shape and sometimes makes them uncomfortable to hot and cold.

A regular check-up with the dentist can help to detect erosion before the teeth have significant damage. They may be able to help by offering dietary advice, communicating with the GP to ensure that protective medication can be prescribed to prevent gastro-oesophageal reflux, and also inform about ways of preventing erosion / reducing sensitivity through appropriate choice of toothpastes alongside regular application of a protective coating known as fluoride varnish.

Dental Problems

Depending on the degree of learning disability and communication skills, it can sometimes be difficult to determine if a person has toothache, but you may notice signs such as:

- Change in behaviour or sleep pattern
- Increased drooling
- Placing fingers in mouth, hand on side of face or ears
- Redness and swelling in face
- Refusal to eat or drink
Access to Dental Services

It is a good idea for the whole family to see the same dentist, however the high street dentist may feel that they do not have the resources or experience to provide comprehensive care for people with PWS.

The Community Dental Services are comprised of dentists who have additional experience in treating children and adults with complex medical and behavioural needs, with the facilities to do so. Some people struggle to cope with routine dental treatment, but options can include acclimatisation and treatment under sedation to make the experience more comfortable.

Where further specialist treatment is needed, a referral can be made to a local Dental Hospital (Paediatric or Adult Special Care Dentistry Department), which is also able to offer additional options such as treatment under sedation or general anaesthesia and can liaise easily with other teams involved in other aspects of a person’s care.

To have treatment in the Community Dental Services and Hospital Dental Services a referral letter from the GP (family doctor) or a high street dentist is usually required.

Preparation for Dental Appointments

The visit to the dentist can be stressful for anyone, but especially if a person has learning disability. The following suggestions are dependent on the individual’s needs:

If it is the first appointment, prepare the Dental Team by giving as much information as possible about the individual. This allows them to make adaptations to their approach.

Inform the individual about dental appointment - this can be difficult if they have a poor concept of time but visual aids such as a calendar may be helpful.

Arrange the appointment at a time in the day that will cause least disruption, taking into consideration the journey to the dentist and possible waiting times.

Social stories, story books (such as ‘My First Visit to the Dentist’, QEB Publishing) and Easy Read materials (such as ‘A Picture of Health’ by NHS South West of England) can help a person to understand what happens at the dentist.

The noise of dental equipment can be upsetting. The dentist may be able to acclimatisate an individual over a number of visits through behaviour management techniques. Some people benefit from taking comforters as a distraction or listening to music through headphones.

Further Information

Local dental services

Further information about the Department of Health’s recommendations for preventing oral health problems

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