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Planning to go to the dentist

A GUIDE FOR FAMILIES AND
CARERS OF PEOPLE WITH AUTISM

Available online at www.ddwa.org.au/resources



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This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative. For more ILC events and resources please visit:

<http://www.disability.wa.gov.au/wa-ndis/wa-ndis/information-linkages-and-capacity-building/resources/>

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Going to see the dentist can be a daunting experience for most of us and often more so for a person identified with Autism Spectrum Disorder (ASD). This is because of potential sensory overloads that may trigger stress and anxiety in a dental clinic setting. This booklet aims to provide some knowledge on how to prepare for the dental visits and some tips maintaining good oral hygiene habits at home.

The Most Common Dental Problems for People with Autism

People with ASD sometimes struggle with effective oral hygiene routines and restrictive dietary choices. This can lead to decay and gum disease. Although these conditions are easily treatable, people with ASD may find it challenging to tolerate the treatment procedure in a dental clinic setting.

LISTED BELOW ARE EXAMPLES OF COMMON DENTAL PROBLEMS THAT PEOPLE WITH AUTISM MAY BE MORE PRONE TO HAVE.

- Gingival overgrowth (often medication induced)
- Plaque build-up (soft deposits on teeth)
- Calculus/tartar build up (calcified plaque)
- Tooth decay
- Gum disease – mild inflammation is called gingivitis and severe inflammation is called periodontitis
- Constant grinding of teeth, known as Bruxism, causes abnormal wearing of teeth which can lead to fractures, sensitivity and loss of tooth vitality in the long run.
- Pica (eating non-food items) which can lead to tooth fractures and abnormal wearing of teeth

What You Can Do To Prepare

A person with ASD may have varying levels of pain tolerance and difficulty in communicating their oral pain. This sometimes leads to the dental issues only being noted at an advanced stage. Sedation may have to be considered when the treatment indicated is complex and the patient is unable to tolerate treatment in the dental clinic. If they are unable to self-consent, a guardian may be needed to consent for the dental treatment. People with ASD can have extreme sensory and oral motor integration issues and visiting the dentist can be a very daunting experience.

If it is their first visit to the dentist, it is good to have a family member accompany them for re-assurance. Having them watch another member of the family go first can help to alleviate the anxiety. Looking at social stories or videos in advance about what to expect, can often assist the process and lessen the anxiety.



A lot of people with ASD have a general fear of the dentist because it overloads their senses and is a lot for them to process in a short period.

Finding a dentist who knows and understands their fears and has experience in supporting people with autism, is the best way to help them slowly overcome their fear. Your family dentist may refer you to another dentist who has this experience if they cannot provide the dental care themselves.

Finding the Right Dentist

Talking to prospective dentists is the best thing you can do to make the visit easier for someone who has ASD. A well trained and confident dentist makes the process easier for everyone and is better able to anticipate and understand their needs. This is not always easy though as some dentists do not feel prepared to treat people with additional needs. Not all dentists will be a good fit for a person with ASD and if unable to provide the appropriate care, they should be able to recommend other dentists who can provide the necessary care. Any additional information, concerns or suggestions about the person with ASD that you or your family member are supporting, will help the dental team anticipate and plan a positive experience.

Thankfully, many dental programs have begun providing additional training materials about supporting people with disability. This includes expanded education for dentists and the dental team on treating patients with disability to change the perception on a wide range of needs including those of people with ASD. This should hopefully increase the number of dentists more confident in treating people with disability or additional need. Here are a few questions you can ask when deciding on a dentist that is best for your family.

1. Are you comfortable working with a patient with Autism Spectrum Disorder?

The dentist you choose should be comfortable working with a person with additional needs. Many family dentists can treat people with ASD or may be able to refer to another dentist or specialist who is familiar with treating patients with special needs. Special Needs Specialist dentists have 2-4 years of extra training and will be able to better accommodate the needs of a person with ASD.

2. What experience do you have working with people who have autism?

Listen for specific examples of when a dentist worked with patients with additional needs. Dentists with previous experience will be more comfortable in ensuring the visit runs smoothly and that your loved one is at ease.

3. Can any special accommodations be made?

It is a dentist's goal to make a patient as safe and comfortable as possible.

SOME ACCOMMODATIONS THAT YOU MAY WANT TO REQUEST INCLUDE:

- Provide a specific flavour/no flavour of toothpaste
- To recline the dental chair before you come in
- To reduce the noise distraction by turning off the ambient music
- To reduce the amount of bright lights in the room
- To have desensitising appointments especially in the early phases
- Noise cancelling headphones, sunglasses or weighted blankets



These may seem small but can make a difference in their overall dental experience.



Asking Your Friends and Family for Suggestions

Dentists who specialise in care for people with special needs are typically hard to find, but they are out there. Speaking with friends or family who also have a family member with a disability is a great way to source a skilled dentist. Following this recommendation, do some additional research yourself to see whether or not they are what you are looking for in a dentist.

Asking Your Doctor

Your local doctor may be able to recommend a suitable dentist, as many GPs work closely with dentists that treat patients with special needs.

Advocacy Organisations can be Helpful

If there are disability advocacy organizations within your area, they may be able to point you in the right direction of dentists that have experience and can provide proper care.

Some dentists do not treat people with disability because of the greater degree of difficulty, so asking an advocacy organisation can be a good way to be pointed in the right direction.

In WA you could call

- Developmental Disability WA on 9420 7203
- People with Disabilities WA Inc on 9420 7279
- Ethnic Disability Advocacy Centre on 9388 7455



Preparing for the Appointment

Take the initiative to prepare for the first dental visit. Familiarise by showing your family member the dental practice website or by talking about the dentist they will be seeing. You can also tell them about your positive experiences at the dentist.

Preparing for an appointment can give your family member an idea of what to expect and help to familiarise them with what dental appointments are like.

HERE ARE SOME WAYS TO PREPARE FOR YOUR FAMILY MEMBER'S APPOINTMENT:

1. Find ways to visualise what happens at the dentist – Social Stories or videos can give the person with ASD a way to make a connection between the visual and their actual dental appointment.
2. Make a pre visit appointment to the dental clinic. This is beneficial because it allows the person with ASD to familiarise themselves with the environment i.e. seeing the lights and hearing the sounds. You and your family member can meet the dental team and be reassured about how they are going to accommodate the patient's additional needs.
3. Model how to behave at the dentist - Let the person with ASD watch while the dentist cleans your teeth and encourage them to ask questions. Siblings can help too: they could allow their brother or sister with ASD to watch their treatment.
4. Bring something familiar - If you are taking a child to the dentist, consider bringing their favourite toy. If they are older, something else, such as their favourite book may be a comfort. Either way, bringing something they love and are familiar with is a great way to ease the tension and anxiety. You can also consider bringing their own familiar toothbrush and paste.
5. Noise cancelling headphones, weighted blankets, communication devices and eye masks can also be used to reduce the anxiety levels at the dental clinic
6. Bring stress balls, fidget cube or chew toys/necklaces to the appointment



How to Help at the Dentist

There are ways you can help your loved one feel safe and secure while at the dentist. For example, if you are a parent of a young child who has ASD, consider finding one dentist that is understanding and will work with you and your child to keep their oral health in top shape. This eliminates the anxiety that they would have by going to different places each time.

Let the dentist know that your loved one has ASD and all members of the dental team including reception staff before the appointment. Provide information on your family member's medical history and current medication chart. Make sure this is updated at future dental appointments if there are any changes. The treating dentist may also ask information about the medical and financial guardian of the person with ASD if they are not self-consenting.

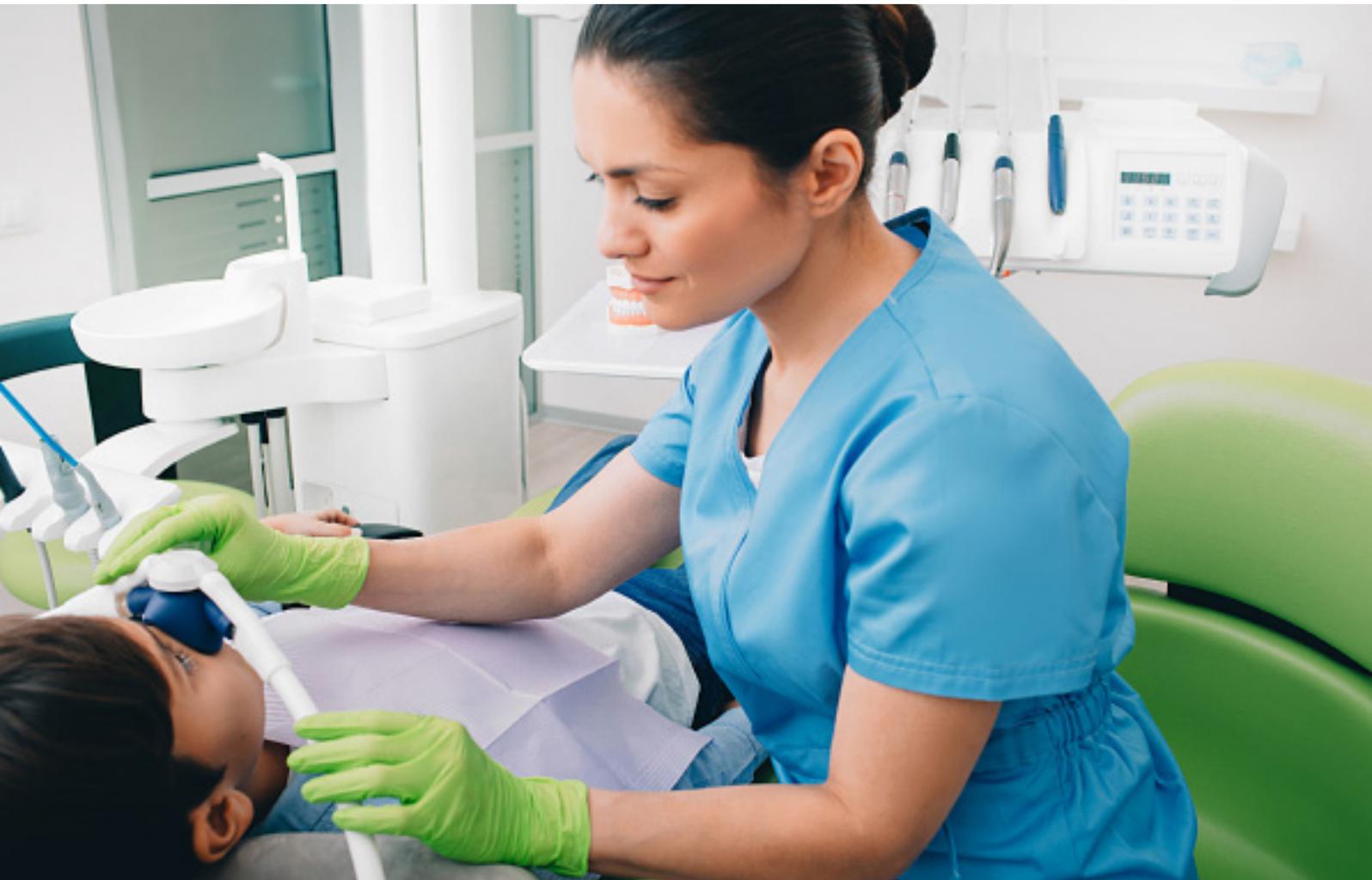
Consider spreading out the treatment plan especially in the early phases to build confidence. This is also known as desensitizing appointments. It may be better to book the appointment early in the day or towards the end of the working day when both the dentist and the person with Autism are more relaxed and there are less people in the waiting room. If the treatment needed is complex and/or invasive and the patient is unable to cope with chairside treatment, sedation may be considered.

Consider Dental Sedation

Due to sensory sensitivities, or fear of the unexpected, people with ASD often can not tolerate anyone touching their face or putting things in their mouth. Sometimes sedation may be required to ensure a person with ASD gets needed dental treatment completed.

Sometimes people have concerns about this for perceived safety reasons, but it's often the only way for people with ASD to receive the dental treatment they need when their anxiety levels are too high.

Sedation dentistry is actually very popular, even if the person does not have any form of disability. Sedation dentistry, also known as "sleep dentistry", is used to give people peace of mind and help them to relax during treatment.



Sedation can be used when a patient is feeling extreme anxiety towards the dental treatment. Here are 4 common types of sedation:

- Inhaled minimal sedation: Breathing in nitrous oxide combined with oxygen to help relax. Your dentist is in complete control of sedation that is given. This is quite popular and widely available.
- Oral sedation: Can range from minimal to moderate. This type of sedation is commonly associated with sedation dentistry. The pill will make the patient drowsy while a more moderate dose may make the patient fall asleep. You would need to discuss this with your GP and dentist.
- Intravenous (IV) moderate sedation: A sedation drug is given through a vein and works more quickly. Your dentist will be able to continually adjust the sedation levels.
- Deep sedation & general anaesthesia: Medication is given that will make the patient nearly or totally unconscious. While under general anaesthesia you cannot easily be awakened until the effects of the medication wear off or are reversed. Not all dental offices are equipped or provide this type of sedation in their rooms. This is usually conducted at a day hospital or general hospital.

Special Needs Specialist Dentists

Currently there is only one Special Needs Dentist in WA. This specialist is based in Fiona Stanley Hospital and mainly sees patients with complex medical conditions and inpatients only. So this is not an easily available option in WA. A Paedodontist (specialist dentist trained to see children) may be able to see ASD patients also.

In Western Australia, people who are eligible for support from the Dept. of Communities Disability Services and meet certain criteria can attend the Special Needs Dental Clinic in North Perth. Call the clinic on (08) 9201 9889 to enquire about eligibility and the process for a Parent/Guardian to request a referral form.

Health Insurance Dental Cover Options

If your family member is covered by your health insurance, call your insurer to enquire about any dentists they may be able to recommend based on your dental coverage. You may find that a special needs dentist or treatment under sedation is covered under your policy.

WHAT CAN BE DONE AT HOME FOR ORAL HEALTH?

Caring for your loved one's oral health is extremely important for their overall health. If they have poor oral hygiene it can lead to multiple issues such as decaying teeth, loss of bone structure in the jaw and other medical issues. Dental pain is often expressed in forms of escalating behavioural issues, self-harm, moodiness and/or refusal to eat or drink. Therefore, good oral care habits and regular dental check-ups are essential. The best oral hygiene practice includes a routine of brushing twice a day, flossing once a day and maintaining a healthy, varied diet with good water intake.

GIVE FLOSSING A TRY

Flossing may be difficult to do but it's worth giving it a try. Brushing alone usually cleans around 60% of the tooth surface, flossing is needed to clean the remaining 40%. Plastic floss picks (fossettes), interdental brushes or water flossers might be easier to use than traditional string floss. Start by getting your loved one familiar with dental floss and then show them how it works. You may not be able to achieve it initially, however, keep trying, so they know that it's very important for proper oral hygiene. You only need to floss once a day and don't be alarmed if you experience a bit of bleeding initially. Flossing should be done before brushing to allow toothpaste to reach the spaces between the teeth.

Keep the Routine Regular

Always ensure that you establish and maintain an oral health care routine, even if your family member does not yet fully participate in the process, it's very important that you stick to it. Your modelling is the best motivation for them.



Brushing Their Teeth Regularly

You should be supporting family members with ASD to brush their teeth at least twice a day for two minutes minimum each time. It is really important to brush teeth at night before bed as saliva production is reduced during sleep, so teeth are less protected. Always angle the brush 45 degrees to the line of the gums while brushing the soft tissues and the base of the teeth. For the surface of the teeth brush in a circular motion up and down, avoiding horizontal strokes that are too harsh.

If an electric toothbrush can be tolerated this may be a good option to consider. Better quality electric brushes have inbuilt timers and pressure sensors to ensure the correct duration and pressure is applied for optimum cleaning.

If a person is not accustomed to brushing their teeth regularly this is going to be tricky to establish routine.

Some practical strategies to try are:

- Bridging - Show toothbrush to ASD person. 'Mimic' brushing your own teeth. Place toothbrush in their hands and they may 'mirror' your actions
- Chaining - Carer starts the task and ASD person completes it
- Hand - over-hand: The carer's hand is placed over the ASD person's hand to guide them through the activity
- Distraction - A familiar item, i.e. doll or iPad, is placed in the ASD person's hands during oral care to act as a distraction
- Rescuing - If one carer is unsuccessful, another carer steps in to 'rescue' the situation and takes over the task - 'Good cop, bad cop' principle
- Task break down - simplifies the task by breaking it down into small, manageable steps for the ASD person.
- Most electric toothbrushes have a two-minute built in timer. You can also use a 2-minute brushing music video clip for this. Sometimes to achieve two minutes of toothbrushing it may take longer, if mini breaks need to be incorporated.
- Try different toothpastes. There are flavoured, unflavoured and even non foaming versions available in the shops and online.
- If you are assisting a person with ASD to brush their teeth, consider the ideal positioning for you and them. Most of the time the best position might be standing slightly off centre and behind them when they are in a seated position.



Conclusion

Helping your family member, whether they have ASD or other disability, with their oral health is a vital part of their personal care. Visiting the dentist and practicing proper oral hygiene daily is an important part of regular life, so ensure that you guide and show them what they need to do to promote good long-term wellbeing.

Resources

Australia

<https://ddwa.org.au/wp-content/uploads/2018/07/Your-Dental-Health-WA-version-web.pdf>

USA

<http://www.circleofmoms.com/autismaspergerspdd-awareness/taking-an-autistic-child-to-the-dentist-485809>

Great resource for mums who want advice/guidance from other mums.

<http://www.friendshipcircle.org/blog/2012/05/16/a-special-needs-guide-to-dental-hygiene-for-children/>

Even though it says it's for tips on kids with additional needs, it's good for both kids and adults depending on the circumstances.

<http://www.asha.org/About/news/Press-Releases/2015/Autism-Awareness-Month-Dental-Care-Tips/>

This guide is great for parents of children with ASD. It can also be helpful for adults with ASD, as well. It has very helpful tips on starting and maintaining a routine oral health regimen.

APPENDIX I

Questions to ask your dentist

You can prepare for your dental appointment by asking your dentist questions. Asking questions can help you feel more confident during your family member's appointment. Here are some questions to get you started when speaking with your dentist.

1. What experience do you and your staff have working with patients with Autism?

Ask your dentist if they've cared for patients with ASD or additional needs. Previous experience can assure you that your dentist knows what to expect and give your family member the care they need.

2. Do you have anything available during the appointment such as TV, music, or toys for my family member to focus on during their appointment?

If your family member is feeling anxious about their appointment, your dentist may have movies, music, toys, or other items to help them through their visit. You can also ask to bring your family member's favourite toy or blanket or whatever would make them feel most comfortable. If your family member is feeling nervous, talk with your dentist about possible ways to help ease those feelings.

3. If needed, what is your office's plan or procedure for sedation?

If your family member is feeling extreme anxiety around their dental appointment or procedure, dental sedation may be available. Ask your dentist the types of sedation they offer and which is the safest option for your family member. If your family member has any conditions or illnesses, or is taking any medication make sure that dental sedation will not complicate anything. Your family member's safety is the number one priority of your dentist and they will not want to endanger them in any way.

4. Do you have any videos, brochures or books to help prepare for the appointment?

Your dentist may have informational tools for you to help prepare for your family member's dental appointment. Videos, brochures, books and other tools can help visualise for your family member what their dental appointment will be like. Ask if your dentist has any advice or tips on preparing for the appointment.

5. Can I schedule a familiarisation appointment for my family member?

A familiarisation appointment is an appointment for you and your family member to visit the dentist office before any work or procedures are done. This is an opportunity for your family member to meet the dentist and staff members as well as become familiar with sounds, tools, and other elements of a dental appointment. Most dentists are willing to schedule these kinds of appointments so be sure to ask.

APPENDIX II

Checklist for visiting the dentist

Initial visit checklist

HAVE YOU...

- ✓ Called the dentist in advance advising your family member has ASD?
- ✓ Booked extra time for the session or an early in the day appointment?
- ✓ Arranged an orientation/meet and greet session first?
- ✓ Provided any relevant medical and dental history in advance?
- ✓ Ensure you have a comprehensive list of all medications and dosage
- ✓ Prepared any questions you might have?
- ✓ Talked to the dentist about your family member's communication skills/preferences?
- ✓ Let the dentist know of any special considerations relevant to the family member?
- ✓ Provided information on the sensory preferences of the family member?
- ✓ Read a book or talked to the family member about what to expect at the dentist so there are no surprises?

Regular checklist

HAVE YOU...

- ✓ Talked to your family member with ASD about what they liked at the last visit and what they want to be different? Communicate with your dentist.
- ✓ Written down and updated the progress of some dentistry related goals?
- ✓ Noted any concerns or changes in behaviour (positive and negative) since the last visit?
- ✓ Tracked the progress of any products or techniques recommended by your dentist?
- ✓ Ask the dentist if there is any additional information they need in order to provide better care to your family member with ASD.

Checklist adapted from Down Syndrome Australia – Dental Health Fact sheet



ADVOCACY



KNOWLEDGE



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