

Practical Oral Care for People With Down Syndrome

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Providing oral care to people with Down syndrome requires adaptation of the skills you use every day. In fact, most people with mild or moderate Down syndrome can be successfully treated in the general practice setting. This booklet will help you make a difference in the lives of people who need professional oral care.

Down syndrome, a common genetic disorder, ranges in severity and is usually associated with medical and physical problems. For example, people with this developmental disability may have cardiac disorders, infectious diseases, hypotonia, and hearing loss. Additionally, most people with this disorder have mild or moderate intellectual disability, while a small percentage are severely affected. Developmental delays, such as in speech and language, are common.

Early professional treatment and daily oral care at home can allow people with Down syndrome to enjoy the benefits of a healthy mouth.

Health Challenges in Down Syndrome and Strategies for Care

People with Down syndrome may present with mental and physical challenges that have implications for oral care. Before the appointment, obtain and review the patient's medical history. Consultation with physicians, family, and caregivers is essential to assembling an accurate medical history. Also, determine who can legally provide informed consent for treatment.

INTELLECTUAL DISABILITY. Although the mental capability of people with Down syndrome varies widely, many have mild or moderate intellectual disability that limits their ability to learn, communicate, and adapt to their environment. Language development is often delayed or impaired in people with Down syndrome; they understand more than they can verbalize. Also, ordinary activities of daily living and understanding the behavior of others as well as their own can present challenges.

- ▶ Listen actively, since speaking may be difficult for people with Down syndrome. Show your patient whether you understand.
- ▶ Talk with the parent or caregiver to determine your patient's intellectual and functional abilities, then explain each procedure at a level the patient can understand. Allow extra time to explain oral health issues or instructions and demonstrate the instruments you will use.
- ▶ Use simple, concrete instructions, and repeat them often to compensate for any short-term memory problems.

BEHAVIOR MANAGEMENT is not usually a problem in people with Down syndrome because they tend to be warm and well behaved. Some can be stubborn or uncooperative, but most just need

a little extra time and attention to feel comfortable. Gaining the patient's trust is the key to successful treatment.

- ▶ Talk to the caregiver or physician about techniques they have found to be effective in managing the patient's behavior. Share your ideas with them, and find out what motivates the patient. It may be that a new toothbrush at the end of each appointment is all it takes to ensure cooperation.
- ▶ Schedule patients with Down syndrome early in the day if possible. Early appointments can help ensure that everyone is alert and attentive and that waiting time is reduced.
- ▶ Set the stage for a successful visit by involving the entire dental team—from the receptionist's friendly greeting to the caring attitude of the dental assistant in the operatory.
- ▶ Provide oral care in an environment with few distractions. Try to reduce unnecessary sights, sounds, or other stimuli that might make it difficult for your patient to cooperate. Many people with Down syndrome, however, enjoy music and may be comforted by hearing it in the dental office during treatment.
- ▶ Plan a step-by-step evaluation, starting with seating the patient in the dental chair. If this is successful, perform an oral examination using only your fingers. If this, too, goes well, begin using dental instruments. Prophylaxis is the next step, followed by dental radiographs. Several visits may be needed to accomplish these tasks.
- ▶ Try to be consistent in all aspects of providing oral health care. Use the same staff, dental operatory, appointment times, and other details to help sustain familiarity. The more consistency you provide for your patients, the more likely that they will be cooperative.

Address your patient directly and with respect.

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- ▶ Comfort people who resist oral care and reward cooperative behavior with compliments throughout the appointment.
- ▶ Use immobilization techniques only when absolutely necessary to protect the patient and staff during dental treatment—not as a convenience. There are no universal guidelines on immobilization that apply to all treatment settings. Before employing any kind of immobilization, it may help to consult available guidelines on federally funded care, your State department of mental health/disabilities, and your State Dental Practice Act. Guidelines on behavior management published by the American Academy of Pediatric Dentistry (www.aapd.org) may also be useful. Obtain consent from your patient's legal guardian and choose the least restrictive technique that will allow you to provide care safely. Immobilization should not cause physical injury or undue discomfort.

MEDICAL CONDITIONS. Though their average life expectancy has risen to the mid-50s, people with Down syndrome are still at risk for problems in nearly every system in the body. Some problems are manifested in the mouth. For example, oral findings such as persistent gingival lesions, prolonged wound healing, or spontaneous gingival hemorrhaging may suggest an underlying medical condition and warrant consultation with the patient's physician.

CARDIAC DISORDERS are common in Down syndrome. In fact, mitral valve prolapse occurs in more than half of all adults with this developmental disability. Many others are at risk of developing valve dysfunction that leads to congestive heart failure, even if they have no known cardiac disease. Consult the patient's physician if you have questions about the medical history and the need for antibiotic prophylaxis (www.americanheart.org).

COMPROMISED IMMUNE SYSTEMS

lead to more frequent oral and systemic infections and a high incidence of periodontal disease in people with Down syndrome. Aphthous ulcers, oral *Candida* infections, and acute necrotizing ulcerative gingivitis are common. Chronic respiratory infections contribute to mouth breathing, xerostomia, and fissured lips and tongue.

- ▶ Treat acute necrotizing ulcerative gingivitis and other infections aggressively.
- ▶ Talk to patients and their caregivers about preventing oral infections with regular dental appointments and daily oral care.
- ▶ Stress the importance of using fluoride to prevent dental caries associated with xerostomia.
- ▶ Use lip balm during treatment to ease the strain on your patient's lips.

HYPOTONIA affects the muscles in various areas of the body, including the mouth and large skeletal muscles. When it involves the mouth, it leads to an imbalance of forces on the teeth and contributes to an open bite. If the muscles controlling facial expression and mastication are affected, problems with chewing, swallowing, drooling, and speaking can result. A related problem is atlantoaxial instability, a spinal defect that increases the mobility of the cervical vertebrae and often leads to an unsteady gait and neck pain.

- ▶ Maintain a clear path for movement throughout the treatment setting.
- ▶ Determine the best position for your patient in the dental chair and the safest way to move his or her body, especially the head and neck. Talk with the physician or caregiver about ways to protect the spinal cord. Use pillows to stabilize your patient and make him or her more comfortable.

More than half of all adults with Down syndrome experience mitral valve prolapse.

SEIZURES sometimes occur in this population, especially among infants, but can usually be controlled with anticonvulsant medications. The mouth is always at risk during a seizure: Patients may chip teeth or bite the tongue or cheeks. People with controlled seizure disorders can easily be treated in the general dental office.

- ▶ Consult your patient's physician. Record information in the chart about the frequency of seizures and the medications used to control them. Determine before the appointment whether medications have been taken as directed. Know and avoid any factors that trigger your patient's seizures.
- ▶ Be prepared to manage a seizure. If one occurs during oral care, remove any instruments from the mouth and clear the area around the dental chair. Attaching dental floss to rubber dam clamps and mouth props when treatment begins can help you remove them quickly. Do not attempt to insert any objects between the teeth during a seizure.
- ▶ Stay with your patient, turn him or her to one side, and monitor the airway to reduce the risk of aspiration.

HEARING LOSS and DEAFNESS may further complicate poor communication skills, but these, too, can be accommodated with planning. Patients with a hearing problem may appear to be stubborn because of their seeming lack of response to a request.

- ▶ Patients may want to adjust their hearing aids or turn them off, since the sound of some instruments may cause auditory discomfort.
- ▶ If your patient reads lips, speak in a normal cadence and tone. If your patient uses a form of sign language, ask the interpreter to come to the appointment.

Speak with this person in advance to discuss dental terms and your patient's needs.

- ▶ Visual feedback is helpful. Maintain eye contact with your patient. Before talking, eliminate background noise (turn off the radio and the suction). Sometimes people with a hearing loss simply need you to speak clearly in a slightly louder voice than normal. Remember to remove your facemask first or wear a clear face shield.

VISUAL IMPAIRMENTS such as strabismus (crossed or misaligned eyes), glaucoma, and cataracts can affect people with Down syndrome.

- ▶ Determine the level of assistance your patient requires to move safely through the dental office.
- ▶ Use your patients' other senses to connect with them, establish trust, and make treatment a better experience. Tactile feedback, such as a warm handshake, can make your patients feel comfortable.
- ▶ Face your patients when you speak and keep them apprised of each upcoming step, especially when water will be used. Rely on clear, descriptive language to explain procedures and demonstrate how equipment might feel and sound. Provide written instructions in large print (16 point or larger).

Record in the patient's chart strategies that were successful in providing care. Note your patient's preferences and other unique details that will facilitate treatment, such as music, comfort items, and flavor choices.

Oral Health Problems in Down Syndrome and Strategies for Care

People with Down syndrome have no unique oral health problems. However, some of the problems they have tend to be frequent and severe. Early professional treatment and daily care at home can mitigate their severity and allow people with Down syndrome to enjoy the benefits of a healthy mouth.

PERIODONTAL DISEASE is the most significant oral health problem in people with Down syndrome. Children experience rapid, destructive periodontal disease. Consequently, large numbers of them lose their permanent anterior teeth in their early teens. Contributing factors include poor oral hygiene, malocclusion, bruxism, conical-shaped tooth roots, and abnormal host response because of a compromised immune system.

- ▶ Some patients benefit from the daily use of an antimicrobial agent such as chlorhexidine. Recommend an appropriate delivery method based on your patient's abilities. Rinsing, for example, may not work for a person who has swallowing difficulties or one who cannot expectorate. Chlorhexidine applied using a spray bottle or toothbrush is equally efficacious.
- ▶ If use of particular medications has led to gingival hyperplasia, emphasize the importance of daily oral hygiene and frequent professional cleanings.
- ▶ Encourage independence in daily oral hygiene. Ask patients to show you how they brush, and follow up with specific

recommendations on brushing methods or toothbrush adaptations. Involve patients in hands-on demonstrations of brushing and flossing.

- ▶ Some people with Down syndrome can brush and floss independently, but many need help. Talk to their caregivers about daily oral hygiene. Do not assume that all caregivers know the basics; demonstrate proper brushing and flossing techniques. A power toothbrush or a floss holder can simplify oral care. Also, use your experiences with each patient to demonstrate sitting or standing positions for the caregiver. Emphasize that a consistent approach to oral hygiene is important—caregivers should try to use the same location, timing, and positioning.

DENTAL CARIES. Children and young adults who have Down syndrome have fewer caries than people without this developmental disability. Several associated oral conditions may contribute to this fact: delayed eruption of primary and permanent teeth; missing permanent teeth; and small-sized teeth with wider spaces between them, which make it easier to remove plaque. Additionally, the diets of many children with Down syndrome are closely supervised to prevent obesity; this helps reduce consumption of cariogenic foods and beverages.

By contrast, some adults with Down syndrome are at an increased risk of caries due to xerostomia and cariogenic food choices. Also, hypotonia contributes to chewing problems and inefficient natural cleansing action, which allow food to remain on the teeth after eating.

**TIPS FOR CAREGIVERS ARE AVAILABLE IN THE BOOKLET
DENTAL CARE EVERY DAY: A CAREGIVER'S GUIDE, ALSO PART OF THIS SERIES.**

- ▶ Advise patients taking medicines that cause xerostomia to drink water often. Suggest taking sugar-free medicines if available and rinsing with water after dosing.
- ▶ Recommend preventive measures such as topical fluoride and sealants. Suggest fluoride toothpaste, gel, or rinse, depending on your patient's needs and abilities.
- ▶ Emphasize noncariogenic foods and beverages as snacks. Advise caregivers to avoid using sweets as incentives or rewards.

Several **OROFACIAL FEATURES** are characteristic of people with Down syndrome. The midfacial region may be underdeveloped, affecting the appearance of the lips, tongue, and palate.

- ▶ **The maxilla**, the bridge of the nose, and the bones of the midface region are smaller than in the general population, creating a prognathic occlusal relationship. Mouth breathing may occur because of smaller nasal passages, and the tongue may protrude because of a smaller midface region. People with Down syndrome often have a strong gag reflex due to placement of the tongue, as well as anxiety associated with any oral stimulation.



- ▶ **The palate**, although normal sized, may appear highly vaulted and narrow. This deceiving appearance is due to the

unusual thickness of the sides of the hard palate. This thickness restricts the amount of space the tongue can occupy in the mouth and affects the ability to speak and chew.

- ▶ **The lips** may grow large and thick. Fissured lips may result from chronic mouth breathing. Additionally, hypotonia may cause the mouth to droop and the lower lip to protrude. Increased drooling, compounded by a chronically open mouth, contributes to angular cheilitis.
- ▶ **The tongue** also develops cracks and fissures with age; this condition can contribute to halitosis.

MALOCCLUSION is found in most people with Down syndrome because of the delayed eruption of permanent teeth and the underdevelopment of the maxilla. A smaller maxilla contributes to an open bite, leading to poor positioning of teeth and increasing the likelihood of periodontal disease and dental caries.

- ▶ Orthodontia should be carefully considered in people with Down syndrome. Some may benefit, while others may not.
- ▶ In and of itself, Down syndrome is not a barrier to orthodontic care. The ability of the patient or caregiver to maintain good daily oral hygiene is critical to the feasibility and success of treatment.

TOOTH ANOMALIES are common in Down syndrome.

- ▶ **Congenitally missing teeth** occur more often in people with Down syndrome than in the general population. Third molars, laterals, and mandibular second bicuspids are the most common missing teeth.

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- ▶ **Delayed eruption of teeth**, often following an abnormal sequence, affects some children with Down syndrome. Primary teeth may not appear until age 2, with complete dentition delayed until age 4 or 5. Primary teeth are then retained in some children until they are 14 or 15.
- ▶ **Irregularities in tooth formation**, such as microdontia and malformed teeth, are also seen in people with Down syndrome. Crowns tend to be smaller, and roots are often small and conical, which can lead to tooth loss from periodontal disease. Severe illness or prolonged fevers can lead to hypoplasia and hypocalcification.
 - Examine a child by his or her first birthday and regularly thereafter to help identify unusual tooth formation and patterns of eruption.
 - Consider using a panoramic radiograph to determine whether teeth are congenitally missing. Patients often find this technique less threatening than individual films.
 - Maintain primary teeth as long as possible. Consider placing space maintainers where teeth are missing.

TRAUMA and INJURY to the mouth from falls or accidents occur in people with Down syndrome. Suggest a tooth-saving kit for group homes. Emphasize to caregivers that traumas require immediate professional attention and explain the procedures to follow if a permanent tooth is knocked out. Also, instruct caregivers to locate any missing pieces of a fractured tooth, and explain that radiographs of the patient's chest may be necessary to determine whether any fragments have been aspirated.

Physical abuse often presents as oral trauma. Abuse is reported more frequently in people with developmental disabilities than in the

general population. If you suspect that a child is being abused or neglected, State laws require that you call your Child Protective Services agency. Assistance is also available from the Childhelp® USA National Child Abuse Hotline at (800) 422-4453 or the Child Welfare Information Gateway (www.childwelfare.gov).

Making a difference in the oral health of a person with Down syndrome may go slowly at first, but determination can bring positive results—and invaluable rewards. By adopting the strategies discussed in this booklet, you can have a significant impact not only on your patients' oral health, but on their quality of life as well.

Additional Readings

Fenton SJ, Perlman S, Turner H (eds.). *Oral Health for People with Special Needs: Guidelines for Comprehensive Care*. River Edge, NJ: Exceptional Parent, Psy-Ed Corp., 2003.

Roizen NJ. Down Syndrome. In Batshaw ML, Pellegrino L, Roizen NJ (eds.). *Children With Disabilities* (6th ed.). Baltimore, MD: Paul H. Brookes Publishing Co., 2007.

Weddell JA, Sanders BJ, Jones JE. Dental problems of children with disabilities. In McDonald RE, Avery DR, Dean JA. *Dentistry for the Child and Adolescent* (8th ed.). St. Louis, MO: Mosby, 2004. pp. 524-556.

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Practical Oral Care for People With Developmental Disabilities

Making a Difference



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This booklet is one in a series on providing oral care for people with mild or moderate developmental disabilities. The issues and care strategies listed are intended to provide general guidance on how to manage various oral health challenges common in people with Down syndrome.

Other booklets in this series:

Continuing Education: Practical Oral Care for People With Developmental Disabilities

Practical Oral Care for People With Autism

Practical Oral Care for People With Cerebral Palsy

Practical Oral Care for People With Intellectual Disability

Wheelchair Transfer: A Health Care Provider's Guide

Dental Care Every Day: A Caregiver's Guide

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