



## **Oral Care for the Patient with ALS: A Guide for the Caregiver**

### **Introduction**

Most people perform activities throughout the day without thinking, but for the person with ALS many simple activities can become tiresome, time-consuming chores. Yet, while it may take a little longer to complete these tasks, independence and autonomy are vital to a patient's well-being and quality of life. Your role as caregiver may include providing assistance and care for loved ones to make these tasks less fatiguing. The time may come when your loved one can no longer perform these tasks and will rely on the help of others to meet these needs. It is important in providing care to maintain open communication in order to make your loved one as comfortable as possible. Considering all the responsibilities a caregiver may have, it can be easy to overlook non-urgent things that need attention. For example, oral care may often be neglected because patients can have difficulty expressing their desire for more attention in this area. As a caregiver, you can be in-tune with the need and desire for oral care through effective communication.

Oral care may not spring to mind as an important task, and when the caregiver is absorbed in larger tasks such as transfers, hourly movements of the patient during the night, and feeding and bathing, it is understandable that some duties may be neglected. This article offers information on the importance of oral health and maintenance so that in the midst of daily routines, mouth care will be remembered.

### **Objective**

The goal of this instructional guide is to educate patients and caregivers on important information that encompasses oral care and its impact on people with ALS. This guide provides information on dental disease, oral dangers related to ALS, adaptive devices to make oral care easier, and step-by-step instruction on proper oral care.

### **Dental visits**

Oral care is very important for everyone, but for the patient with ALS normal dental factors have to be considered along with the obstacles that the disease introduces. Oral care may become very difficult to perform by the patient and even, eventually, by a caregiver. If ALS affects the arms and hands, reaching up to the mouth can be fatiguing, strenuous, or impossible for the patient. Swallowing may become difficult; therefore, extra water and toothpaste in the mouth could become dangerous. It can be difficult and challenging for a caregiver to perform proper mouth care. Using the dental team as a regular partner in oral health will benefit the client with ALS. Regular exams should ensure that any problems the patient or caregiver may have would not result in further disease or poor dental health.





Daily living and responsibilities that come with ALS can be very demanding and tiring. Transportation may become difficult or impossible, so taking a trip to the dental office may not be an option. However, if possible, plan a visit once or twice per year. **It is also important to realize that, despite the fact that some patients may be wheelchair bound, they can be seen in the dental office.** To make sure the dental office can accommodate clients in a wheelchair, the caregiver should call the office to inquire about the office site, asking questions about wheelchair accessibility. Parking areas should be in close proximity to the building, chairlifts should be installed in stairwells, halls and doorways should be wide enough to easily fit a wheelchair, and the staff should be prepared to treat the patient in the wheelchair. Some office staff may be willing to transfer the patient to the dental chair, but only if the patient and caregiver feel comfortable consenting to this offer. If the client has a “rocker” wheelchair with a headrest, the dental staff may be able to work while the patient remains sitting in the wheelchair.

Caregivers and patients should not hesitate to inform the dental staff of any special needs the patient may have and also to remind staff members that the patient may tire easily during any procedure. Time should be taken to gather information concerning how to overcome any obstacles the patient or caregiver may be having at home. Asking such questions of the dental team will help to solve problems and find more options for making oral homecare easier.

### **Home care**

Instruction for oral care begins with basic habits of brushing, flossing and using mouth rinses. For the patient with ALS and for the caregivers, these tasks may become difficult or even impossible in the progressive stages of the disease. Fortunately, many helpful devices have been designed to allow the patient or caregivers to continue performing these daily routines. The following section includes instruction in these basic homecare routines; the instruction is followed by descriptions of modifications and adaptive equipment that allow patients with ALS to perform tasks independently as long as physically possible. Instructions for caregivers are also given to ensure the best oral care for the patient as long as possible.

### **Brushing**

Tooth brushing is the most basic form of oral care, but sometimes proper and frequent brushing is neglected. After meals and before bedtime are the most recommended times to brush teeth because brushing removes the food particles and bacterial plaque that play such a large part in causing gingivitis. Focus should be placed on the gum line while brushing. This area is important because it is the portal through which bacteria begin their damage.

**Tips for the caregiver:** Brushing another person’s teeth can be difficult and challenging, but when the patient with ALS is unable to do these tasks independently, your help is needed. When





a patient is in a wheelchair, it may be easiest to stand directly in front of or on the side of the chair, facing the patient. If a headrest is not attached to the chair the chair may be backed against a wall in order to keep the head from falling forward or backward. Using one hand to stabilize the chin and pull the lips open, move the brush around the teeth with your other hand. Perfection is not expected: Do as much as possible. The object of brushing is to remove as much debris and bacteria as possible.

Electric toothbrushes provide a great alternative to manual brushing. They produce much of the action needed to sweep away bacteria. However, there may be some challenges in using electric brushes, such as larger handles that can become slippery and difficulties adapting the bristles to all areas of the mouth while holding the slightly heavier device.

Patients with ALS may develop swallowing difficulties and therefore cannot tolerate conventional brushing. A portable suction device has been developed that attaches to a specially designed toothbrush allowing water and toothpaste to be evacuated from the mouth as the teeth are being brushed (see Assistive Devices section).

### **Flossing and interdental cleaning**

**Tips for the caregiver:** Flossing may be a greater challenge than brushing, but if it is at all possible to apply the floss to the patient's mouth, any attempt is worthwhile. To floss another person's teeth, position yourself carefully. Two positions can be used. First, stand along the side and slightly to the rear of a wheelchair or any other chair the patient is sitting in. Wrapping your arms around the patient's head and leaning over to look into the mouth will allow access into the mouth very much as if the patient's own hands were doing the flossing. The second position is similar to that of a dentist to a patient in a dental chair. With the patient lying on a bed, you can sit or stand along the side of the bed slightly behind and to the side of the patient's head. This allows more visibility into the mouth with less strain to the neck.

If flossing with the hands becomes too difficult, using a floss holder can make flossing easier. This inexpensive plastic device secures the floss so that the patient or caregiver does not have to wrap the floss around the fingers or put hands and fingers inside the mouth. Eliminating the bulk of hands in the mouth allows more visibility of the teeth.

### **Mouth Rinses**

Mouth rinses can also help to achieve healthy gums and teeth. When used in conjunction with proper brushing and flossing, various rinses also provide additional prevention and therapy for disease. Antiseptic mouth rinses are beneficial for killing bacteria that can cause gingivitis and for reducing or eliminating inflammation and bleeding. However, beware of high levels of alcohol in these types



of rinses (some rinses are available that are 100% alcohol free). Fluoride rinses are available that help prevent decay and that also reduce or eliminate sensitivity. Prescription strength rinses are available through the recommendation of a dentist or dental hygienist. These rinses contain Chlorhexadine, an element that reduces or halts the progress of periodontal disease.

For the client with ALS, rinsing may become impossible because of swallowing difficulties. Until this problem arises, rinsing should be an aid in oral health.

### **Dentures and removable partial dentures**

Oral health is important not only with natural teeth present, but also with removable prostheses. Denture care is very simple and should be as important as caring for natural teeth. Removable appliances often introduce bacteria into the mouth, making the task for cleaning prostheses very important. **Tips for the caregiver:** In later stages of ALS the patient may lose muscle control of the cheeks and tongue. These muscles, when strong, work to propel food and liquid from the front of the mouth to the back and eventually to the throat for swallowing. When these muscles become too weak to function properly, food can become trapped in the **vestibule** (the area between the cheek and teeth). Food that stays in this area for long periods of time can cause offensive odors as well as breakdown and speed the process of decay to the neighboring teeth.

If the patient wears full or partial dentures, they should be removed in order to clean the vestibule properly. To clean the vestibule, pull open the cheek to increase visibility. Using a moist cloth, finger, cotton swab, or a large sponge-tipped swab (Toothett), sweep from the back of the vestibule forward to remove large particles of debris.

### **Other factors**

Patients with ALS may experience an increase or a decrease in saliva that results from taking various medications or from breathing through the mouth. An increase in saliva is not of particular worry in the area of dental disease because saliva acts as a natural cleanser for the teeth, “washing” away debris. A decrease in saliva, however, can be a problem by eliminating the cleansing benefits and drying the teeth. A dry mouth encourages plaque bacteria to stick to tooth surfaces, making brushing less effective in reducing bleeding and inflammation. Saliva substitutes are available to replenish this loss and may make the patient more comfortable.

As the swallowing muscles weaken with the progression of ALS, a softer diet may be prescribed. This softer diet imposes increased levels of plaque and debris from lack of chewing. Teeth are naturally cleansed while chewing from the friction of solid foods being moved around the teeth. When this friction is no longer a factor because of the lack of chewing, plaque can begin to deposit and develop into calculus or cause increased inflammation of the gums. A softer diet may



require an increased frequency of brushing to rid the mouth of debris that can break down and cause decay or gum irritation.

The progression of ALS often affects the respiratory muscles to the point that patients request the need for assisted ventilation. Ventilators often have mouthpieces that cup around the mouth. Studies have shown that the presence of periodontal disease or plaque bacteria can infect the lungs by way of ventilator mouthpieces, potentially causing pneumonia. Oral health can have a great impact in preventing such diseases.

### **Assistive devices**

When ALS is diagnosed, patients begin to receive care from teams of various health-care professionals such as nurses; doctors; physical, occupational and speech therapists; dietitians; and psychologists. Each discipline offers different yet important components in the care of the patient with ALS. Occupational therapists are particularly good resources for evaluating patient capabilities, and in accessing equipment designed to assist patients while performing everyday tasks.

Occupational therapists are trained to recognize patient strengths and limitations and to teach patients how to adapt to changes. Adapting to changes may require the use of specially designed equipment to allow independent self care as long as possible. Adaptive equipment includes items such as motorized wheelchairs, elastic shoelaces, one-way straws and large handled utensils. Adaptive equipment is also available to aid in mouth care. As ALS progresses, a patient may lose the ability to lift the arms up to the mouth, brush the teeth without becoming fatigued, or grip small objects to clean between teeth. Adaptive devices have been designed to improve mouth care by making these obstacles easier to overcome.

**Toothbrushes:** Toothbrushes come in many different shapes and sizes, but not all brushes available to the general public are suitable for clients with disabilities. Most brushes found in stores have small, skinny handles that are difficult to grip. The patient with ALS may have difficulty closing the hand around the small handle, and may also have difficulty uncurling the fingers from the handle once the handle has been gripped. Patients may also have difficulty in lifting the arms to reach the mouth if the toothbrush has a short handle. The following list includes equipment designed to allow patients or caregivers to continue performing homecare with ease.

- Velcro or metal hand and wrist cuffs— Can be fitted around the hand or wrist. Toothbrush attaches to cuff and can be moved with arm action. Some cuffs have a self-rotating brush attached to make maneuvering the toothbrush easier.



- Electric toothbrushes— Eliminate need for extensive arm action. Many models are designed with large handles to make gripping easier. Disadvantages may be that the device is too heavy to lift; handles can become slippery and difficult to grip. But these brushes may make plaque removal easier, and their use is not discouraged. The patient with ALS may initially find an electric toothbrush easy to use, but as the patient becomes more dependent, a caregiver may have to help the patient in using the electric brush.
- Handle build-ups— A very inexpensive aid that makes gripping handles easier. No purchase is necessary. 1. A racquetball or tennis ball can fit over the end of a brush handle after one cross cut has been made into the ball. 2. Styrofoam tubing (available through catalogs from healthcare providers) can fit over skinny handles of regular toothbrushes.
- Extended handles— Provided through catalogs; ask an occupational therapist for availability. Long metal or plastic rods that hold the toothbrush at mouth level while the arm, remains at waist or chest level, provides the movement.
- Suction toothbrush units— Also available through healthcare provider catalogs. A hollow handled toothbrush is attached to a hose leading to a suction reservoir. Best for the patient that has lost the ability to swallow; these units decrease the chance of choking by evacuating toothpaste and saliva.
- Toothpaste dispenser— Eliminates the need to squeeze paste from a tube. For patients with decreased hand function, a tube or pump of toothpaste is inserted into the holder and paste is placed on the toothbrush by depressing a large handle on the dispenser (available through catalogs).

**Flossing aids and interdental cleaning aids:** As mentioned earlier, flossing cleans between the teeth where the toothbrush cannot. Unfortunately, dental floss can be very difficult to handle and manipulate. Some devices, readily available in stores, have been designed to make flossing less cumbersome.

- Floss holders— Basic designs available at stores. The “Y” shaped plastic holder includes a handle, a knob to secure floss, and two grooved extensions to guide floss into a short horizontal position. The handle is held while the horizontal section of floss is slid between the teeth. Generic models require the purchase of a separate container for the floss of choice; other models are longer and have a spool of floss contained within the handle.





- Proxabrush— For use once self-care is too difficult. This toothbrush-like handle holds a small cylindrical- or cone-shaped brush and is best for cleaning open spaces between teeth, around isolated teeth and under fixed appliances such as bridges (available in stores).

### **Denture care**

Denture care includes care of removable appliances, but also care of any remaining natural teeth, and oral tissues that the appliances contact and cover. Care of natural teeth should be done using the previously mentioned aids or conventional and adaptive devices. Denture care may not be as much of a challenge because they are removable and can be cleaned at arm level. Brushing action is still important for removing soft debris from dentures and partial dentures, but when arm or hand movement becomes limited, ingenuity for denture care is needed. When the caregiver is responsible, conventional denture brushes can be used. As long as a patient is able to perform the task of denture care, various options are available for brush application.

- Suction cup brushes— Conventional denture brushes can be secured in plastic holders suctioned to preferred surfaces. Brushes designed for nail cleaning have more surface area to clean with, and their base can be suctioned to a preferred surface. When use of one hand is limited, the stronger hand holds the denture and moves it over the brush surface to clean debris.
- Oral stimulation— As mentioned previously, an extra-soft brush or wet cloth can be applied to oral tissues deprived of proper oxygen when dentures or partial dentures are in place. Stimulation provides increased blood flow and removes trapped debris from the mouth.
- Sponge- or foam-tipped swabs (Toothetts)— Resembling cotton swabs, these swabs have tips that contain small cylinder-shaped foam or sponge material. Apply to oral tissues for stimulation, gross plaque removal, and to remove large or small pieces of debris from the vestibule of the mouth to reduce odor as well as decrease the chance of decay on any remaining teeth.

### **Patient wishes**

Most importantly, the caregiver needs to be mindful of patient wishes. Communication is vital in making the patient as comfortable as possible. Living with ALS involves trusting others to provide the care the patient has always supplied for his or her own body in the past; so caregivers must learn to talk to the patient so that the caregiver does not overlook something the patient may wish to have done. In other words, unless homecare is a significant part of the caregiver's daily routine, the patient may receive less oral health care than he or she wishes.



Caregivers are so important in the life and well being of their loved ones and patients, that they must not become discouraged when faced with so many responsibilities. As a caregiver, remember to take time to understand your patient and his or her needs, and be mindful to keep the patient's wishes among all the demands that are vital to health and comfort. Use the knowledge and information that healthcare providers can offer. Ask questions, look for options, and rely on these professionals (medical and dental) to be a partner with you and the patient in maintaining the healthiest body, mind and mouth possible.

## **PRODUCT INDEX**

**Available in stores or by doctor's prescriptions**

### **ELECTRIC TOOTHBRUSHES**

- Braun Oral-B Plaque Remover Ultra
- Braun Oral-B Plaque Remover Ultra 3D
- Sonicare

### **MOUTH RINSES**

- Listerine-antiseptic, high alcohol content
- Tartar Control Listerine-helps decrease tartar (calculus) buildup
- Reach ACT-alcohol free, over the counter fluoride rinse
- Oral-B anticavity rinse-alcohol free, over the counter fluoride rinse
- Colgate Fluorigard-over the counter fluoride rinse
- Colgate Phos-Flur-Prescription strength fluoride rinse
- Peridex-Prescription strength Chlorhexadine rinse
- Perioguard-Prescription strength Chlorhexadine rinse



## **FLOSS AND INTERDENTAL DEVICES**

- Oral-B-Superfloss, alternating sections, for wide spaces and under bridges
- Glide-Threader floss, alternating sections, for wide spaces and under bridges
- **Floss holders**
  - Butler GUM
  - Glide
- Butler GUM-proxabrush, refills sold separately
- Oral-B-Interdental kit, refills sold separately
- **Rubber Tip Stimulator**-Butler GUM, refills sold separately

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The ALS Association thanks Ms. Lutz for her contribution to this FYI.

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