Managing Saliva and Phlegm in ALS

The build-up of saliva is a common problem among people with ALS who have tongue and throat muscles that are weak and not able to automatically swallow the saliva that builds up in the mouth. A tenacious kind of mucus can also build up in the mouth, compounding the problem. This build-up of saliva can cause choking and disrupt sleep. Relief may come from home remedies, over-the-counter products, prescription drugs and, in extreme cases, even surgical procedures.

Saliva is needed to moisten the mouth cavity and to help with swallowing and digesting food. It is poured in copiously (at about a fivefold increase) when we smell, taste, chew and swallow food. Saliva is normally secreted by three major pairs of salivary glands and numerous minor glands in the mouth cavity. Some secretions also come up through the respiratory tree, as part of the protective mechanisms that we all have. Saliva comes in two parts—thin, watery secretions and thick, mucus-containing secretions.

In ALS, there is no problem with saliva production. Saliva production is normal; it’s the handling of saliva that is not normal. In ALS, you can have weak muscles around the mouth, tongue, throat and so forth, which can compromise the handling of saliva in the mouth and the swallowing mechanism. Some people have a lot of drooling, also called sialorrhea. Others complain more of phlegm sitting in the throat. They can’t swallow it, and they can’t cough it up because of weak muscles. Sensation is normal in ALS, so patients know that secretions are sitting in the mouth and building up, and that they’re drooling.

Managing Saliva

The first step in treating sialorrhea is typically to prescribe medications to reduce the production of saliva. For example, many patients are on antidepressants and doctors will commonly try to give them antidepressants that have the side effect of dryness of the mouth. This side effect is notable with the tricyclic type of antidepressants such as amitriptyline (brand name Elavil), imipramine (brand name Tofranil) and clomipramine (brand name Anafranil). In some patients, doctors use a scopolamine patch (brand name Scopoderm), which is usually used for motion sickness. The patch is applied to the skin. Other medications that are often prescribed include atropine sulfate (brand name Sal-Tropine), clonidine (brand name Catapres) and propantheline (brand name Pro-Banthine).

All these agents block the action of acetylcholine, which comes from the nervous system and normally gives a “kick” to the salivary glands to produce saliva. Acetylcholine is a neurotransmitter, a chemical that carries signals between the nervous system and other organs. The glands are still intact, and not all the saliva is gone. Up to approximately half the saliva production is knocked down in patients who can tolerate these medications. These are mild drugs, and their side effects are mild.

If tricyclic antidepressants, scopolamine or these other medications are not effective, the next step is to go to more potent drugs like glycopyrrolate (brand name Robinul). These drugs block acetylcholine wherever it is in the system, and they can cause constipation, urinary hesitancy and impaired potency. Drugs such as Robinul can also worsen glaucoma in those that already have it, can increase urinary obstruction if people have an enlarged prostate gland and can worsen confusion in people with memory loss. Patients in a humid environment may also feel a little more discomfort because of decreased sweating. All these symptoms are from the blockade of acetylcholine. Some patients have more side
effects than others. Some people don’t tolerate these medicines because of side effects, and in some people they’re just not effective.

If medications like Robinul are not effective, the next step is the injection of botulinum toxin (brand name Botox or Myobloc), which comes from the bacterium Clostridium botulinum. It works in the same way as the medications, by blocking acetylcholine release from nerve endings, but only at or near where it’s injected. Typically the botulinum toxin is injected into each parotid gland. The parotids are the major glands for the thin, watery part of the saliva. The problem with botulinum toxin is that if it’s injected at the wrong site or if it travels, it can block muscles in the area and increase dysphagia (difficulty swallowing) and dysarthria (difficulty speaking). It takes a week to 10 days for the maximum effect to be seen. In about two weeks, you know whether or not it has worked. If it hasn’t, after about three weeks, a little more of the botulinum toxin can be injected on both sides. Depending on the response, the botulinum toxin can be injected a second or third time. Typically saliva production is knocked down by about 50 or 60 percent in about half the patients. With a second or third injection, it’s usually effective in about 75 percent of patients.

In a few patients, radiation of the salivary glands has been used as a last option. The idea is to damage the gland and to induce scarring which takes several weeks or months. The idea is not to knock down saliva totally but to decrease it to relieve drooling. The problem with radiation is that it’s irreversible. There are also reports in the medical literature of surgeries that can be done on the salivary glands, but this is not generally done in ALS.

**Dealing with Thick Phlegm**

At some point many ALS patients may experience problems with the thick mucus or phlegm that accumulates in the back of the throat. This is often exacerbated during or after meals or liquid intake. Coughing it up can be a tiring and arduous process, and take it’s toll on the patient and the caregiver. It also has a tendency to block airways or make food stick in the throat, so coughing it up is essential.

There really isn’t a good treatment for the mucus secretions, because those don’t have a major nerve supply that can be blocked. Adequate fluid intake is the first essential step in prevention. Sips of cold carbonated drinks, hot tea with lemon, Rose’s Lime Juice, and apple, pineapple or papaya juice, all available at most supermarkets, may help. These may be kept in the fridge and used on a swab for the mouth if the patient is unable to swallow. Meat tenderizer mixed with a little water can also be used to coat the tongue or can be placed under the tongue. Some patients have found that 12-hour allergy medications such as Zyrtec, Claritin or Allegra significantly reduce the amount of mucus produced.
For PALS who face unresolved problems with phlegm, contacting your physician and requesting an order for a suction pump and a visiting nurse to educate and demonstrate safe and effective airway secretion clearance is a good idea. Often times, doctors or clinics only think of suction machines for use with trach patients, so it’s important for you to tell your doctor this is something you need. Also, request two types of suction catheters if you have feelings of phlegm stuck in the throat. While physicians may order only Yankauer suction tubes (often referred as Tonsil Tips), those tubes cannot reach secretions or phlegm effectively down in the throat. Therefore, a French suction catheter (such as a size 14) is always good to have on hand. This is a long narrow, soft and flexible plastic tube. Because training on suction techniques is a skilled nursing procedure, expenses for home visits by a registered nurse are covered by Medicare, Medicaid and most health insurance companies. However, be sure to request that ONLY a registered nurse with respiratory care experience be sent out to demonstrate how to use it safely and effectively to suction the mouth and the throat.

The Cough Assist machine (also know as a Coffalator or In-Exsufflator) may be effective for selected individuals, although not everyone may have insurance coverage for it or adapt to its use (particularly those with advanced bulbar impairment). However, PALS who do use the device will usually also need a suction pump with appropriate suction catheters to clear phlegm and secretions from the throat and mouth. A portable suction pump provides a means for quick secretion clearance, and thus, helps to serve as a safety precaution. However, all suction machines need to be checked regularly to be sure they are working properly and have adequate “suck power.” Be sure to always keep portable units charged and ready to use. Some portable units have a tendency to lose their power after a period of time. Therefore, ask your respiratory equipment supplier about your unit and how to check and see if the pressure settings are adequate.

It’s best to order and start using a suction machine (and Cough Assist) early on, while the ALS patient still has the ability to cough. This way he/she can help force the phlegm to the top of their esophagus and where the “yankheur” tool can easily reach to suction it away. It is helpful to suction the roof of the mouth, back of the throat (watch out for the uvula, you don’t want to suck that up) to reduce the stream of mucous. Make sure to ask that your physician prescribes a portable suction machine rather than a table top unit. A portable suction machine is lightweight and maneuverable. The portable machines generally have a battery backup, as well as a removeable AC cord and many come with a carrying case and a DC converter, which allows you to plug it into a cigarette lighter. A portable unit allows the caregiver to bring the relief to the patient rather than vice versa. It also allows you the luxury of bringing it with you when going out. Suction machines are considered durable equipment, so your Medicare or insurance should provide for its purchase.

Below are a variety of portable suction machines and their manufacturer or dealer.
Care-E-Vac by: Squire-Cogswell/Aeros

VacuMax by: Medical Industries America/Quantum Air