

Managing Your Symptoms

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As a nurse, there are many ways I've observed and learned to help patients manage their various symptoms. The top three tips I'd give to all patients are:

Emotional Lability/Changeability

Especially in Bulbar Onset patients, ALS affects the ability to control emotion. The patient can feel like crying and laughing in the same breath. This roller-coaster of emotions is not depression, but actually a true and annoying symptom of ALS. Laughing or crying can be managed best through a few medications your doctor can prescribe for you. The most common prescription is Elavil® (Amitriptyline). For any patients that may have issues with saliva control, Elavil® has an added benefit of drying out the mouth and limiting the amount of drool. Taken prior to bedtime it helps you sleep and keeps the pillow dry.

Spasms/Fasciculations

Although they are tiresome and exhausting, spasms do indicate there are still electrical impulses and activity in that area of your body—something you want to keep active as long as possible. The key is to balance the spasm with tone for mobility. This can be accomplished with stretching, also known as range of motion (ROM) exercises. The most important areas to stretch are your shoulders, fingers, wrists, elbows, ankles, knees, and hips. Never force a joint that appears stiff; take it to a point of stress, then relax it. These exercises will help you sleep better and make sitting in your recliner chair or wheelchair more comfortable. The best times to stretch are in the morning and right before bedtime. In addition, after a warm shower muscles are more pliable and easier to work. Your physician may also prescribe Baclofen to help.

Oral Care

To stay kissable at all stages of ALS, be sure to keep your tongue clean and wiped down with tongue scrapers. Gel toothpaste seems easier to manage than white toothpaste. Mouth products (gel, paste, or rinse) with excessive sugar or alcohol seem to produce more saliva. A useful product-line out there is OxyFresh (www.oxyfresh.com). It has an excellent toothpaste, mouth scraper, and mouthwash that are all quite effective. Its bath products work well, too.