

Managing Symptoms of ALS



LIVING WITH ALS
RESOURCE GUIDE



Managing Symptoms of ALS

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Table of Contents

Introduction	4
Oral Symptoms	4
Bowels And Bladder	12
Breathing	16
Sleep	18
Nutrition	18
Skin Problems	24
Muscle Changes	25
Mood And Emotions	32
Thinking And Behavior Changes	37
Summary Statement	40
Bibliography	41

A NOTE TO THE READER: The ALS Association has developed the *Living with ALS* resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.



Introduction

ALS will cause many different changes to your functioning. Not everyone will experience all of them and not all changes occur at the same time. As the disease progresses and different functions are affected, knowing what to expect and how to manage them is helpful.

In this resource guide the following symptom management topics will be covered:

- Oral and nasal symptoms
- Bowel and bladder symptoms
- Air hunger and breathing difficulties
- Insomnia and frequent awakening
- Nutritional issues
- Skin problems
- Muscle changes
- Pain and fatigue
- Mood and emotions
- Thinking and behavior changes

Oral Symptoms

Sialorrhea (Drooling)

Sialorrhea, commonly known as drooling, is a frequent challenge with ALS. The medical term **sialorrhea** can be broken down into “**sial**,” meaning saliva and “**rrhea**,” meaning to flow. Normally we produce approximately 1.5 liters of saliva per day (Dand and Sakel 2010). Saliva does have an important purpose: it serves as a lubricant to keep the mouth clean and helps with swallowing solids.

The excess buildup of saliva in a person with ALS patients can be due to an increase in the amount of saliva produced, but more often it is related to difficulty swallowing. Although appearing trivial in comparison to other ALS challenges, drooling can be a significant source of psychological distress.

Swallowing requires coordination among the brain, nerves, muscles, teeth and salivary glands. When you have ALS, difficulty with this coordination may cause sialorrhea (Lakraj, Moghimi and Jabbari, 2013). When weakness in the tongue and roof of the mouth (palate) develops, it is difficult to move saliva to the back of the mouth to swallow it. The saliva pools in the front of the mouth and leaks out.

TREATMENT OPTIONS

The goal of treatment is to reduce, but not eliminate, saliva. Below are possible management strategies of sialorrhea (drooling).

- The **“chin tuck”** is a simple strategy for both saliva management and eating. This is done with proper positioning (Dand and Sakel 2010). Ideally, you **sit in an upright position** making sure your head is stabilized. Then, **slightly tuck your chin downward during swallowing to prevent choking.** If you are slouched or in a reclined position while attempting to swallow, this could lead to food or saliva going into the airway causing choking.
- **Prescription medications** are a second option. These prescribed drugs **aim to decrease the production of saliva.** Common medications include glycopyrrolate (pill), scopolamine (patch applied to skin), amitriptyline (pill) or atropine drops. These medications can be used alone or combined to have a better effect.

Many healthcare providers prescribe **glycopyrrolate**, as it seems to have fewer side effects and is generally tolerated well.

Scopolamine comes in a patch and is often prescribed when a person with ALS can no longer swallow. The **scopolamine patch**

lasts longer than the glycopyrrolate because you use one patch every three days.

Amitriptyline is an older medication also used to treat depression, but it is handy for a person with ALS because of its side effect of causing a dry mouth. **This medication can also make you sleepy.** So, if given at night, it helps with sleeping and dries up the saliva.

Atropine drops are administered three or four times a day under the tongue. This medication has the advantage of a short duration of action. It dries up the mouth without making the mouth feel too dry. The choice is made depending on how much drooling occurs and when.

- **If you experience sialorrhea that does not respond to medications, the next possible step would be to use injections such as Botulinum toxin (Botox).** These injections are given into the glands. They decrease the amount of saliva produced and can provide benefits for up to three months. The injections must be provided by a specialist and can be painful in their application.
- **Radiation** can be applied to the salivary glands for more severe cases. This will stop the gland from functioning. Care must be taken with this procedure as this may cause the once thin secretions to turn into a very thick “wallpaper paste” consistency.
- **Surgery (ablation)** to completely destroy the salivary glands has been done in Europe. This would be the last and worst-case option as it could potentially leave you with very thick secretions or an uncomfortably dry mouth.

Dry Mouth / Thick Secretions

Normal breathing usually occurs through the nasal passages, which act to humidify the air before it reaches the lungs. The mouth in otherwise healthy persons is generally not used for breathing. In ALS, the muscles that normally keep the jaw and lips closed become weakened to the point that the mouth can't close, and the

mouth becomes the primary airway. This is called mouth breathing. **Mouth breathing causes the mouth to become dry, which results in thickening the saliva.**

Thickened secretions are more difficult to move and swallow. In a person with impaired swallowing or weakness of the tongue and palate, the thickened saliva makes the problem worse.

TREATMENT OPTIONS

Liquids help in thinning saliva and easing the movement of saliva toward the back of the mouth. **However, liquids are particularly difficult to swallow**, especially when swallowing abilities are poor. If a person is afraid of choking on liquids, it might make sense to drink less, but it will cause chronic dehydration. Chronic dehydration happens slowly over time and is often not recognized. The more dehydrated one becomes, the thicker the secretions.

The treatment involves a combination of fluid management and sometimes the use of medications or assistive equipment. The first step is to avoid dehydration. According to Yorkston, Miller and Strand (2004) the standard “liquid diet” or “blenderized meal” does not provide enough water in the system to prevent dehydration. People with ALS may have difficulties drinking thin liquids, such as water, but may be able to drink something a bit thicker, such as juice. Gelatin and ice pops are other possible fluid options.

Thickened secretions can also be managed through medications, which are listed based on the severity of the problem and what is causing it.

Over-the-counter medications can be purchased without a prescription. These may include:

- **Guaifenesin** (an expectorant cough medicine) can cause an increase in the amount of saliva produced, which is effective

in thinning the saliva (Yorkston, Miller and Strand, 2004).

- **Papase** is an enzyme that can be obtained in supermarkets or drugstores. It is one of the ingredients in meat tenderizer and is also found in papaya (juice). It has been reported to be beneficial in thinning secretions. Papase, when applied to the mouth, causes the thickened secretions to dissolve, allowing easier swallowing (Yorkston, Miller and Strand, 2004).

Prescription medications include:

- A **mucolytic** can be used to thin secretions. These are often used when the thick secretions are very far back in the throat, and you can't seem to bring the "stuff" forward to spit out or clear it with swallowing.
- **Acetylcysteine** is one of these mucolytic medications, given three times per day. **The patient inhales the medication using a machine called a nebulizer.** This medication is usually used for thicker secretions and when there is still sufficient coughing ability (Galves-Jimenez, 2014).
- **Potassium iodide (SSKI)** can also be used. SSKI acts as an irritant to the inside of the mouth, causing an increase in saliva which will thin secretions. This SSKI treatment, however, may take up to two weeks to show effect (Yorkston, Miller and Strand, 2004).

Even with these medications, at times it is still difficult for the patient to clear the secretions. Should this occur, mechanical devices can be incorporated. One such device is a home suction device. The home suction device can be used alone or in conjunction with a "cough assist" device, which assists the patient with a deep inspiration and then rapidly assists expiration, simulating a forceful cough. (Epstein, 2021)

Excessive Yawning

Excessive yawning is experienced by a significant number of people with ALS. The cause is not well understood, and unfortunately, there are few effective treatments. A common antidepressant, Lexapro

(escitalopram), lists yawning as a side effect. If you are taking this drug for depression and yawning has become a problem, you and our doctor may want to discuss changing the medication.

TREATMENT OPTIONS

Relief has been reported by sucking on hard candy or chewing gum. **Use caution if choking is a concern.**

Jaw Quivering or Clenching

When you have ALS, you may develop **muscle spasms** in any muscle. There are several muscles that control proper opening and closing of the jaw. **If the muscle spasm occurs in the muscles of the jaw, it can cause difficulty in opening or closing the mouth.** Jaw clenching can occur when the “jaw closers” or “jaw openers” develop a continuous and strong spasm. When this condition is severe, it can lead to jaw clenching with biting of the sides of the tongue and cheeks (Elman and McCluskey, 2014). If this condition is sustained for a long period of time, it can produce a contracture (permanent and substantial shortening of the jaw muscles) (Clark, 2003).

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TREATMENT OPTIONS

Botulinum toxin (**Botox**) can be used in cases of severe sustained jaw closing spasm (Clark, 2003).

Laryngospasm

Laryngospasm is a short-lived closure (most often lasting less than 30 seconds) of the larynx (throat), and it can be a terrifying experience. It is **caused by a rapid and forceful closure (spasm) of a muscle in the throat (laryngeal sphincter)**. It most often occurs in response to acid reflux or choking on food particles or liquids, including thickened saliva (Elman and McCluskey, 2014). During these episodes, people feel as though they cannot breathe. In severe cases, it can result in complete blockage of the upper airway (Kühnlein et al., 2008).

TREATMENT OPTIONS

Immediate treatment during a laryngospasm episode includes **rapid repositioning of the head and neck to an upright position with the jaw forward**. This technique has been found to shorten these episodes (Kühnlein et al., 2008). Long-term therapy would include lifestyle modifications, including smaller but more frequent meals. Medications such as short acting benzodiazepines are used to help muscles relax. Medications to control acid reflux are also used to decrease the frequency of attacks (Sperfeld et al., 2005).

Thrush

Thrush is a common fungal infection often referred to as a “yeast infection.” The “candida” fungus is naturally found in the gastrointestinal and genitourinary tracts of all humans. However, they can invade and take up “residence” in a place that they are not normally found, causing an overgrowth.

Thrush can occur with the use of some medications, such as antibiotics or inhaled corticosteroids for asthma or a runny nose. When you suffer from dry mouth you are at a higher risk for developing thrush (Kauffman, 2013). Many people with thrush complain of a **“cottony” feeling in the mouth, decreased sense of taste and, in some cases, pain when eating or swallowing. If you have thrush, you may notice white plaque or patches** in the mouth and on the tongue, roof of the mouth (palate) and sometimes down in the throat.

TREATMENT OPTIONS

The management of thrush involves an overall assessment of risk factors. Impaired salivary function can lead to an overgrowth of candida. Drugs such as inhaled steroids have been shown to increase the risk of thrush by possibly suppressing immunity. Treatment involves discontinuation of the inhaled steroid, if possible (Singh et al., 2014). If discontinuation of medication is not possible, frequent mouth rinsing is effective. **Thrush is simply and effectively treated with topical application of antifungal ointments** (Singh et al., 2014).

Nasal Congestion and Post-Nasal Drip

Any irritation or inflammation of the nose or the mucous membrane inside of the nose is referred to as **“rhinitis.”** Common symptoms include congestion, runny nose, sneezing, itching, obstruction and post-nasal drip. There are two major forms of rhinitis, **allergic and non-allergic.** Allergic rhinitis occurs when an allergen triggers nasal symptoms. Non-allergic rhinitis occurs when there is no allergen, but irritation and inflammation of the nose occurs, caused by changes in the weather, strong odors or cigarette smoke (Tran, Vickery and Blaiss, 2011).

TREATMENT OPTIONS

There are several treatments for rhinitis. The first is **avoidance of environmental triggers.** This can include strong odors from paints,

perfumes, strong soaps and air pollutants, such as smoke (including that from tobacco), that are known to be respiratory irritants (Tran, Vickery and Blaiss, 2011).

Decongestants can help when used with intranasal corticosteroids, topical antihistamines or both. Ipratropium bromide is a nasal spray recommended for a runny nose. Using this spray with a corticosteroid may be even more effective. People with mild symptoms often find relief with the use of a nasal saline spray. This can be effective to soothe the nose if it feels dry and help to relieve nasal congestion.

Antihistamines can also be used for their drying properties. A common over-the-counter medication is Benadryl (diphenhydramine). It is important to read the label and use caution as these medications can be sedating.

Talk to your healthcare provider about what treatment is right for you.

Bowels And Bladder

Urinary Urgency/Frequency

Most ALS information rarely focuses on issues of the bowel and bladder, leading people to believe the disease does not affect them. However, **urinary urgency (the “got to go” sensation) and constipation may occur frequently**, especially for people who experience more symptoms of muscle spasticity (called upper motor neuron symptoms). These symptoms, combined with increased difficulties with mobility, can lead to discomfort and embarrassment.

Urinary urgency leads to “urge incontinence.” This is caused by overactivity of the muscle in the wall of the bladder. Leakage of urine (incontinence) can occur before one has a chance to reach the toilet. **Some people try to cut back on fluid intake to reduce leakage**

episodes. This can often make symptoms worse and cause them to become dehydrated. The body will try to conserve water, and the urine will become concentrated which will also irritate the bladder lining (Griebling, 2009). This can also lead to constipation, which will be addressed later, and cause thickened secretions.

TREATMENT OPTIONS

The treatment of choice depends on the symptoms and severity. Individuals must play an active role in choosing a therapy that best fits one's lifestyle. **Treatments are either non-surgical or surgical as described below** (Griebling, 2009):

Non-surgical treatments include diet, scheduled toileting, pelvic floor exercises, protective undergarments and medications.

- **Diet:** Certain food and beverages make urinary symptoms worse because they act as a diuretic or as an irritant to the lining of the bladder. Caffeine, for example, is a diuretic. It is found in coffee, tea, chocolate and some soda. Diuretics make you have to urinate. Either eliminating caffeine or switching to a non-caffeinated product may improve the symptom. Alcohol and carbonated beverages irritate the bladder. Foods that are higher in acid or that contain large amounts of potassium can cause bladder irritation and urinary urgency and frequency.
- **Scheduled toileting:** This is effective in treating symptoms of urgency or urge incontinence when the bladder is full. Most people do not attempt to go to the bathroom unless they feel that the bladder is full. This, added to mobility difficulties, may result in not reaching the bathroom in time. Going to the toilet on a regular schedule to keep the bladder from becoming too full may be helpful.
- **Pelvic floor exercise:** These are commonly referred to as "Kegel" exercise. This is an exercise to strengthen the muscles associated with bladder support and sphincter control.

- **Absorbent pads and products:** There are a wide variety of these products available to help with incontinence. These are not a “cure” but are helpful with managing symptoms when they want to engage in physical or social activities.
- **Medication management:** There are several medications that work to suppress urgency and ensure effective urinary drainage. Oxybutynin is a medication that may help. It is taken by mouth up to three times a day. There is also an extended-release version of this medication. Oxybutynin is also available in a patch that is absorbed through the skin (a transdermal patch) applied two times per week. Tolterodine is another medication that is available in a long-acting form (Olek, 2005). Talk to your doctor about what might be best for you.

Surgical options: Suprapubic catheter placement. Unlike the more common catheters that are inserted through the urethra (tube that allows urine to flow from the bladder to the outside), this is inserted through a hole or portal located just above the pubic bone. It drains the urine into a bag that can be attached to the leg (Boerner, 2010). The portal is created using a minor surgical procedure that is commonly done as an outpatient procedure. The catheter is usually replaced monthly. This type of catheter has been reported to be more comfortable than the standard type of catheter and is not associated with recurrent infections and damage to the urethra due to insertion and removal procedures (Boerner, 2010).

Constipation/Diarrhea

Constipation: This can be very distressing. There are several factors that can contribute to constipation in ALS, such as lack of mobility.

When treating this symptom, we need to consider various causes, prevention and, as required, the use of medications, such as a stool softener and a stimulant medication (Andrews and Morgan, 2013).

Increased weakness involving the abdominal muscles makes it more difficult to push the stool from the body. Some people may become constipated due to medications or lack of fluid.

Diarrhea is a less frequent problem, however. Many individuals with ALS start on liquid formulas to maintain weight when eating becomes problematic due to swallowing difficulties and fatigue. Many of these formulas contain increased amounts of fiber producing a laxative effect.

TREATMENT OPTIONS

Increase fluid intake if dehydration is believed to be contributing.

Laxatives are often used for the treatment of constipation. Laxatives can be separated into four main headings: softeners, stimulants, bulking agents and osmotic agents.

Stool softener: Docusate sodium, dosage of up to 500 mg daily. This medication brings more fluid into the bowel. These can take several days to take effect.

Stimulant laxatives: Senna or Bisacodyl sodium picosulphate dantron. These medications have a stimulant effect. These can take effect in approximately 6–12 hours. Glycerol suppositories act as a mild irritant to the lining of the rectum. These can take effect in 15–60 minutes.

Osmotic laxatives: Magnesium salts and polyethylene glycol. These medications work to increase water absorption in the stool, making it softer, bulkier and easier to pass.

Non-medication management: A recipe provided by the American Dietetic Association for constipation management

- Three parts bran (wheat bran or 100 percent bran is best)
- Two parts applesauce
- One part prune juice

It is most effective if eaten three times per day. It can even be spread on toast.

If diarrhea occurs, treatment will involve assessment of the diet and possible adjustment to the dietary formula.

Breathing

Breathing Difficulties and “Air Hunger”

People with ALS easily recognize the weakness in the muscles in their arms and legs. Sometimes, there is weakness in the muscles that control breathing (respiration) signaled by various symptoms. The muscle that controls breathing is called the **diaphragm**. When we breathe, we take in oxygen and get rid of carbon dioxide. If the respiratory muscles are not working correctly, sometimes the body does not get enough oxygen, or there is a build-up of carbon dioxide in the body because they cannot get rid of it.

Weakness of the diaphragm often goes unnoticed when awake.

Sometimes, you may feel you cannot take a deep breath, but often, the symptoms are very subtle. You may feel drowsy when you wake up in the morning or feel tired all day. You may even notice a very mild headache. More worrisome is that this also happens at night during sleep. Diaphragmatic muscle weakness is particularly dangerous when the body is in deep sleep, called REM sleep. Normally, when a person is in REM sleep the diaphragm is the only respiratory muscle working. It is when the body is in this state of deep sleep that the diaphragm muscle must work well (Barthlen, 1997).

Weakness with taking air into the lungs (**inspiration**) can produce **shortness of breath and hypoventilation** (not enough ventilation). Sometimes people have difficulties with getting air out of the lungs (**expiration**). When there is weakness with getting air out of the lungs, there is often a **weak cough or difficulties with clearing of secretions** (Tripodoro and Vito, 2008).

According to the American Thoracic Society, **dyspnea is the term used to describe the sensation of breathing discomfort.** This discomfort varies in intensity. Most people with ALS develop dyspnea, agitation, anxiety and deep labored breathing (air hunger) in the final stages of ALS (Tripodoro and Vito, 2008).

With ALS, you may complain of the sensation of deep, difficult “labored” breathing. This symptom is called **“air hunger.”** Family members may report intermittent snoring. You may feel you cannot breathe when you lie flat (**orthopnea**). Some of the more subtle symptoms are a feeling of restlessness or the inability to fall asleep. The body’s response to decreased levels of oxygen (**hypoxemia**) is that it attempts to get more air into the body. If the body is not effectively able to get rid of the carbon dioxide, the level of this gas in the blood rises (called **hypercapnia**). As the level of carbon dioxide rises, you may initially feel anxious. Over time, as this level remains high it works as an anesthetic, and you can become sleepier.

TREATMENT OPTIONS

The most effective treatment for this is use of a device to support breathing at night (nocturnal) while sleeping. Nocturnal noninvasive ventilation (NIV) allows the respiratory muscles to rest and to recover at night. This is “noninvasive” and involves the use of a mask. The mask can be taken on or off as desired. It is not to be confused with a “ventilator.”

One type of NIV, bilevel positive airway pressure (BiPAP), is helpful to maintain an open airway. This type of support is called “bilevel” as it has two pressure levels—one to breathe in (inhale), the other to breathe out (exhale). BiPAP gives a higher pressure to “blow” air into the lungs

Not all people with ALS will experience every possible symptom. The good news is there are ways to prevent and treat many of the symptoms associated with ALS.

and a lower pressure to get the air out. The use of BiPAP support has allowed for better and longer survival in people with ALS (Barthlen, 1997).

Sleep

Insomnia and Frequent Awakening

Difficulties with falling asleep and frequent awakenings are often secondary to the overall body changes associated with ALS. These can include anxiety and/or depression, the inability to change positions independently or difficulties with breathing (such as dyspnea or orthopnea).

TREATMENT OPTIONS

The first step is to identify the underlying cause. Often, underlying difficulties with respiration, as previously discussed, do cause difficulties with achieving sleep. **Sedatives are used with caution, as we do not want to decrease respirations further.** Some tricyclic antidepressants are used because they have a dual purpose of treating an underlying depression and having a side effect of making patients sleepy (Amitriptyline, as mentioned earlier).

Nutrition

ALS can make it difficult to take in enough food and liquids. Weakness in your jaw and tongue can affect your ability to chew and swallow safely. When swallowing becomes difficult, the first step is changing your diet to foods and liquids that are easier to swallow. Mealtimes often take longer, which contributes to feeling full and eating less. Some people with ALS have a feeling of excessive fullness

when eating even small amounts (early satiety) or may feel full for many hours after eating. Others may have a lack of appetite and not feel the need to eat as much as they did before ALS. Also, muscle weakness in your arms and legs may make it hard to prepare meals or lift food to your mouth. All these changes can cause weight loss, malnutrition (not taking in enough fuel or nutrients to support body functions) and dehydration.

Early Satiety/Lack of Appetite

Early satiety (feeling full before eating adequate amounts) and feeling overly full for hours after eating are a common occurrence in ALS. The cause is not well understood. There may be changes to the nerves in the gastrointestinal tract in persons with ALS. Other symptoms caused by ALS, including constipation, lower levels of activity, depression and weakness, can also contribute to early satiety and lack of appetite. Identifying the root cause or causes of your difficulty is the key to finding the best management strategies. Sometimes, taking too many over-the-counter herbal supplements can increase feelings of fullness and lower your appetite. You can try eliminating herbal supplements to see if your food intake improves. If weakness and slowness of eating is problematic, make sure that you have enough help from your caregivers so that you can focus on chewing and swallowing rather than transporting food to your mouth.

Although mealtimes are important social events, you should not be expected to speak while chewing and swallowing. Have your caregiver explain to others that you need to spend your energy on eating rather than communication. Your tendency may be to isolate yourself at mealtimes; however, the social aspect of eating with others is important for both enjoying food and eating enough. We tend to eat more when we share our meals with others. Constipation and depression should also be addressed (see sections on bowels and bladder and mood/emotions). Acid reflux is common in people both with and without ALS and can worsen early satiety and lack

of appetite. Sometimes avoiding foods that trigger acid reflux is successful, but medications such as Zantac, Pepcid or Nexium can reduce acid and improve appetite.

If treating other causes does not improve appetite and food intake, several medications can be tried. Reglan (metoclopramide) speeds up the movement of food through the gastrointestinal tract and can reduce feelings of fullness or early satiety. For lack of appetite, medication options include mirtazapine and marinol. Mirtazapine has the added benefit of helping depression and insomnia. In more extreme cases that have not responded to other treatments, a hormonal medication (megace) is sometimes used.

Malnutrition/Dehydration

Malnutrition occurs when the food and nutrients you take in from eating are not sufficient for the activities your body performs.

Calories from foods and liquids are your body's fuel. Liquids also moisten your tissues and are vital for your body's ability to eliminate waste. Not taking in enough calories will cause your body to use

its own stores of fat and muscle to produce energy. While you may feel like losing fat stores will help you attain the body you've always dreamed of, loss of muscle can cause more weakness and speed up the progression of your disease. Without enough fuel, you will be more fatigued and may not be able to participate in activities you would otherwise enjoy. Protein, a specific source of calories, is also vital for skin and cell repair. Lack of protein makes it harder to heal from injuries and contributes to skin breakdown (e.g., bedsores).

It is good to know in advance all the ways ALS may affect you so you can recognize when you need to make changes to prevent or treat symptoms to maximize your comfort.

Chewing and Swallowing Muscle Weakness

When weakness in your chewing and swallowing muscles makes eating more difficult, it becomes hard to take in enough calories and nutrients. Make the following changes to boost your calorie count:

TREATMENT OPTIONS

- **Change the texture** of your foods to softer and moister foods that are easier to swallow.
- **Eat smaller amounts frequently** throughout the day.
- **Snack on high calorie foods** or nutritional supplements (shakes like Ensure, Boost and Carnation Instant Breakfast).
- **Have a speech-language pathologist evaluate your swallow** and tell you what foods will be easiest and safest for your weakness.
- **Increase your calorie intake by eating a high calorie diet.** Use heavy cream instead of low-fat milk, add butter and sauces liberally and avoid low calorie options. A dietitian can provide you with lists of high calorie food options that are safe for you and offer recipes for high calorie shakes, meals and supplements.

Trouble with swallowing can also make it hard to drink enough to support your body's needs, and your body can become dehydrated. Limiting the amount that you drink to prevent having to use the bathroom is another common cause of dehydration. **Liquids help with many important body functions, including producing saliva, eliminating wastes, preventing constipation, and carrying energy and oxygen throughout your body. If trouble swallowing is causing you to become dehydrated, there are several steps you can take to increase your fluid intake:**

TREATMENT OPTIONS

- **Drink thick liquids** like shakes instead of thin liquids like water.
- Specially designed powders can be used to **thicken beverages** to make them easier to swallow.
- You can also add liquids to foods by using **sauces, cream and gravy**.
- **Try sipping fluids throughout the day** rather than drinking large amounts at once.
- Your speech-language pathologist can give you strategies to help you swallow more effectively and efficiently, such as **tucking your chin, using a straw or taking small sips**.

Eventually, ALS weakens the chewing and swallowing muscles to the point where it is very tiring or even impossible to get enough nutrition and fluid orally (through the mouth). **Many people with ALS choose to have a feeding tube placed directly into their stomach to help supplement the food and liquid they are still able to eat and drink.** Sometimes drinking is more difficult than eating, so the tube is used for liquids, but food is still eaten. Sometimes swallowing pills is a challenge, so the feeding tube is used for medications, but the person with ALS can still eat and drink sufficiently. Whatever the case, the feeding tube is an option to get nutrition, fluid and medications that are difficult or impossible to swallow. Studies have shown that using a feeding tube can stabilize or even increase weight. **People with ALS often report that getting a feeding tube was a difficult decision, but they are almost always glad they had one put in.** Some frequent comments from patients are that they wished they had the feeding tube much earlier and that it greatly improved their quality of life.

Having a feeding tube does not mean you need to stop eating or drinking by mouth. Most people with ALS continue to eat and drink for pleasure if it is safe to do so. It also does not mean that your ALS will stop progressing. Although getting enough nutrition can prevent your body from using its muscle for energy, your motor nerves will

continue to be damaged, and weakness throughout your body will progress.

It is unclear whether feeding tubes significantly increase survival. Some studies indicate people with ALS who choose to use feeding tubes live longer than people with ALS who decline feeding tubes. However, other factors can influence the survival of these groups. It is likely that the better nutrition available to those with feeding tubes improves their survival somewhat, but **the most compelling reason for using feeding tubes in ALS is for improving your quality of life.**

Perhaps you have already decided that getting a feeding tube is right for you. You may wonder when the best time to have the procedure is.

A feeding tube should be considered if:

- You take a long time to eat,
- You are fatigued after mealtimes,
- You have been losing weight despite the use of a high calorie diet,
- You are spending a lot of your time or energy on taking in nutrition or liquids,
- You have difficulty with swallowing food, liquids or medications, or
- You know you want a feeding tube eventually.

Even if you don't have trouble with eating or drinking now, you can still have a feeding tube placed proactively. The benefit is that the procedure (minor surgery) is done while your breathing function is at its best. Studies indicate that there is a higher risk of complications, such as bleeding, infection and pneumonia, to a certain type of feeding tube procedure if your Forced Vital Capacity (FVC) is below 50%. Your ALS clinic should monitor your FVC and talk about the option of having a feeding tube placed early, before your FVC drops below 50%.

Regardless of whether you have a feeding tube placed, you can continue to eat foods that are safe for you to swallow.

Skin Problems

Did you know that your skin is an organ? It serves multiple functions for the rest of your body. It protects your muscles, bones and other organs. It shields against organisms like bacteria and viruses. It prevents water loss and temperature changes and gives you the sense of touch. **While ALS does not attack your skin, problems caused from ALS, like not being able to change positions, lack of protein intake and difficulty cleaning and drying your body, can cause damage to your skin.**

Fungal/Yeast Infection

Fungus/yeast is an organism that grows best in warm, dark, moist places. It usually infects areas where skin touches other skin (skin folds) like armpits, under breasts, the groin, inner thighs and between fingers and toes. Keeping these areas clean and dry can both prevent and treat yeast infections. A yeast infection usually looks red and raw and may be itchy or sore.

TREATMENT OPTIONS

- Keep skin clean and dry.
- Expose skin folds to air.
- Wear absorptive clothing (cotton and natural fibers).
- Over-the-counter antifungal creams can be used, but most infections will likely need a stronger prescription strength antifungal.

Bedsore

Bedsore are injuries to the skin caused from pressure or shearing (shifting between layers of the skin). Bedsore are more common in people with sensory loss, such as spinal cord injury patients, but can occur in anyone. They come in four stages, from mild redness and swelling (stage one) to loss of skin and muscle all the way to the bone (stage four).

TREATMENT OPTIONS

- Use pressure reducing cushions when sitting and mattresses when lying.
- Do not stay in the same position for long periods. Turn in bed and shift your weight when sitting in chairs.
- Keep skin clean and dry. Healthy skin is better able to withstand and repair damage from external forces.
- Avoid malnutrition and dehydration, which alter the skin's protective mechanisms and impair healing.
- Be sure to eat adequate protein, calories and vitamin C, which are essential for cell repair.

Muscle Changes

ALS is a disease of the motor neurons (the nerves that allow your brain to communicate with muscle fibers). **When the communication through motor neurons is damaged, the normal activity in muscle fibers is disrupted.** If upper motor neurons (nerves from your brain to your spinal cord) are damaged, muscles can weaken, become tight (spastic) and be prone to muscle cramps. If lower motor neurons (nerves running from your spinal cord to muscles) are damaged, muscles become weak and show signs like atrophy (wasting away) and fasciculations (twitches).

Fasciculations

Fasciculations, or muscle twitches, are brief contractions of the muscle fibers innervated by an individual lower motor neuron.

Everyone has fasciculations, but they are more common in people with diseases affecting the lower motor neurons. If you tighten or use the muscle that is twitching, the fasciculation will stop but can occur again when your muscle is back to rest. Many people do not notice their fasciculations until they have been pointed out. Fasciculations are not painful and generally do not need treatment.

Muscle Cramps

Muscle cramps or spasms involve a larger group of muscle fibers than a fasciculation, and rather than brief twitches, the muscle will contract or tighten for an extended duration. Muscle cramps can cause severe pain and discomfort. Many people report that cramping is worse if they have overused muscles. Specific movements that use specific muscles often trigger cramps. Avoiding such movements (when possible) is one technique to limit cramping. It can also be helpful to gradually stretch muscle groups before performing movements you find cause cramps or exercising the muscles involved. You can try taking an over-the-counter calcium and magnesium supplement, since the lack of calcium or magnesium can provoke muscle cramps.

TREATMENT OPTIONS

If cramping is frequent or bothersome, talk with your physician about medications to treat muscle cramps. Some options include anticonvulsant (anti-seizure) medication (levetiracetam, gabapentin and carbamazepine), muscle relaxers (baclofen and tizanidine) and benzodiazepines (clonazepam and diazepam).

You will need to weigh the risks and benefits of using medications, as many of these can cause sleepiness. You also may be using muscle

spasticity (tightness) to help compensate for muscle weakness, so taking medications that reduce your muscle tone (tightness) might affect your ability to perform activities like standing and walking.

Spasticity

Spasticity refers to stiffness, tightness, or increased tone of muscles.

It occurs when upper motor nerves are damaged. The exact cause of spasticity is not known, though there are several theories. Not everyone with ALS will have spasticity; those with upper motor nerve predominate ALS are much more likely to have spasticity that requires treatment than those with lower motor nerve predominant ALS.

Spasticity can make movements slow and more difficult and cause you to feel more fatigue. Because spasticity involves an inability for muscles to relax, it can sometimes be helpful, such as when a person with ALS has leg weakness but is still able to stand due to muscle tightness from spasticity. Being inactive for a long period of time can worsen spasticity. Many people with ALS find that spasticity is worse in the morning upon waking. Doing **gentle range of motion and stretching exercises** can loosen your muscles and make it easier to move.

TREATMENT OPTIONS

Your specific weakness, function (ability to do activities), and amount of spasticity should be considered before taking medication for spasticity. If you and your doctor decide an anti-spasticity medication is right for you, there are several that can be tried. Some medication options include baclofen, tizanidine, diazepam, clonazepam and dantrolene. **Baclofen and tizanidine, having fewer side effects and requiring less monitoring, are usually the first medications tried.** You should start with a low dose and increase it slowly over time. This allows you to watch for side effects like sleepiness, dry mouth and weakness. If one medication causes side

effects, don't be afraid to try a different medication, as side effects vary from person to person and from medication to medication.

When spasticity occurs in a specific area, localized treatment with Botox injections can be used to relax the muscles involved. This will increase weakness to the muscles and has the risk of spreading to nearby muscles. If muscle and joint movements are limited because of spasticity or weakness, tendons and ligaments will tighten and shorten causing contractures. Braces or splints may be needed to straighten body areas and prevent or minimize contractures.

Risk for Fatigue and Pain

Muscle changes like weakness, tightness and cramps make everyday activities more difficult. **You may have to work harder, and it may take you longer to do activities that you used to think were easy.** You might need to use two hands instead of one to raise a glass or lift your thighs higher to prevent tripping over your toes. All this extra work and muscle use can leave you feeling worn out. You may not move your body the same way you used to, and muscles and joints may

start to hurt. Adjusting to your body's new limitations can help you prevent more pain and enjoy life to the fullest.



Fatigue is common in ALS. Picture your body as a vehicle trying to drive up a hill. If you take away some of the vehicle's horsepower (muscle strength) and add a brisk wind (spasticity), it's going to be harder and take longer to reach the top. If that vehicle were alive, it would be tired at the end of the drive. Your body is a machine that is working harder and harder just to get through normal

activities. Treat your body like the machine it is by giving it rest, good fuel (food and liquids) and not asking it to do more than it should.

FATIGUE PREVENTION

In addition to getting good rest and nutrition, there are many things you can do to help prevent getting worn out and to live a full life despite feeling tired. **Energy conservation is a principle where you look at your activities and plan ways to use your energy for the most important tasks and in the most efficient way.** This lets you have energy for the things you most want to do and allows you to spend the least amount of energy on other tasks. Energy is like money: you have a limited amount and need to decide what to spend it on. Some energy conservation techniques that you can try are:

- Use **adaptive equipment** (reachers, built up utensils, lightweight glasses) to reduce your work.
- **Allow family and friends to help** with activities that are getting difficult.
- **Consider using a volunteer or hiring help** for household duties.
- Plan your day to **have rest periods** between scheduled activities.
- **Reduce or eliminate activities that do not contribute to your goals** or enjoyment of life.

Using energy conservation techniques will let you reserve energy to do activities that are most important to you.

Fatigue can also be a side effect to medications that are used in ALS. It is a rare side effect to Rilutek (riluzole). If you began to experience fatigue around the time that you started taking riluzole, try taking a “drug holiday” by stopping riluzole use for two weeks. If your fatigue improves, you will need to decide if taking riluzole is worth the fatigue it causes you. First, talk with your healthcare provider about this option.

While the loss of motor neurons and muscle is not painful, problems that can develop from weakness and muscle tightness can certainly cause pain. Joints that are not properly stretched will tighten and ache. Old injuries causing back pain, neck pain or joint pain may

worsen due to loss of muscle support. New areas of injury can occur if you push your body to do activities that require more strength than your body has left.

TREATMENT OPTIONS

Like many things in life, the saying “an ounce of prevention is worth a pound of cure” applies here. **Be kind to your body; don’t work it beyond what you should.** Use good body mechanics to prevent injuries and worsening old injuries. When you are no longer able to move joints (shoulders, elbows, wrists, fingers, knees and ankles) through their full range of motion, have a caregiver perform gentle stretching exercises on your body regularly.

If prevention is not enough and you find yourself experiencing pain, **use these tips at home to make yourself more comfortable:**

- **If a new injury occurs, make sure you have it evaluated** for problems that require medical attention.
- New injuries like sprains or strains should be treated with **RICE:** Rest, Ice, Compression and Elevation. Avoid using the affected area, apply an ice pack, wrap the area with an elastic or compression bandage and elevate it to reduce swelling.
- Older injuries or pain lasting more than one week can be treated with ice or heat packs (whichever works for your pain). **Massage and gentle stretches** help loosen tight muscles and reduce pain.
- **Over the counter medications** like Tylenol or NSAIDs (Non-Steroidal Anti-Inflammatory Drugs) can be used to reduce pain and inflammation:
 - **Ibuprofen** – A typical over-the-counter dose is 400 mg every four to six hours, but doses up to 800 mg every eight hours can be used. Avoid using ibuprofen for longer than two weeks as it can cause irritation to your stomach lining. It is best to take ibuprofen with food.
 - **Aleve** (naproxen sodium) – A typical over-the-counter dose is 220 mg every 12 hours, but doses up to 440 mg every 12 hours

can be used. Avoid using naproxen for longer than two weeks as it can cause irritation to your stomach lining. It is best to take naproxen with food.

- **Tylenol** (acetaminophen) – A typical over-the-counter dose is 700 mg every four to six hours, but doses up to 1000 mg every six hours can be used. Do not take more than 4000 mg every 24 hours as liver damage and death can occur. Acetaminophen does not reduce inflammation but does help with pain.

Make sure to read the warnings on any over-the-counter medication you try. NSAIDs should not be used by people with bleeding or clotting disorders or if you are taking certain medications such as warfarin. Acetaminophen should not be used if you have liver damage. If you need to use medication for pain longer than two weeks, talk with your physician or healthcare provider.

In some cases, Tylenol or NSAIDs are not enough to control pain. For mild to moderate pain, the next step is often to use Ultram (tramadol). Tramadol is a weak opioid that has fewer side effects than stronger opioid medications. If tramadol is not effective, ask your medical team about using opioid/narcotic medications. Although opioids have side effects including sleepiness and constipation, they are the most effective medications for moderate to severe pain. **You do not have to live in pain.**

There is also a specific type of pain called **neuropathic pain** that can be treated with medications other than NSAIDs and opioids. This type of pain is usually caused by injury or damage to the sensory nerves. Although ALS does not typically cause damage to sensory nerves, people with ALS may have damage to sensory nerves from other causes. People with neuropathic pain describe it as feeling pins-and-needles, burning or electrical pain. It can be treated with anticonvulsants (gabapentin and pregabalin), antidepressants (tricyclic antidepressants and selective norepinephrine and serotonin reuptake inhibitors) and topical agents (capsaicin cream and lidocaine).

Mood And Emotions

When you were given the diagnosis of ALS, you may have felt numb or unemotional. Or you may have felt angry, fearful or sad. We all experience a wide variety of emotions, and your emotions will likely be very affected by your diagnosis and the changes in your body. Your emotional reaction to the diagnosis may vary from one day to the next. These fluctuations in mood are normal and expected. It is normal to feel distress and grief—not just about having a fatal illness, but about all the little losses along the way. Grief is the emotional response to loss, and can trigger emotions like denial, anger and sadness.

Depression

Although sadness is a normal emotion often felt when grieving losses, **having a low mood that interferes with your ability to live and enjoy life is considered depression.** Depression is present in otherwise healthy individuals but is more frequent in people facing a severe and debilitating illness. Many people never seek treatment for depressive symptoms, but most people can get better with treatment. **Some common signs that you may be depressed include:**

- Low mood or sadness on most days of the week,
- Feelings of guilt, hopelessness, or emptiness,
- Loss of interest or pleasure in activities, including sex,
- Difficulty sleeping or sleeping too much,
- Overeating or undereating,
- Excessive crying,
- Fatigue or tiredness,
- Moving more slowly or quickly than usual,
- Thoughts of worthlessness,
- Difficulty thinking or concentrating,
- Irritability, restlessness or aggression, or
- Thoughts of hurting yourself or killing yourself.

While some of the symptoms of depression are present in people with ALS due to the disease itself (such as slow movements due to spasticity or undereating due to swallowing difficulty), the presence of many depressive symptoms may indicate depression. If the symptoms make it difficult for you to live your normal life or enjoy life, you should consider having treatment for depression.

TREATMENT OPTIONS

Depression that is mild can often be treated with **psychotherapy or counseling**. There are two main types of psychotherapy: cognitive behavioral therapy and interpersonal therapy.

In **cognitive behavioral therapy**, a therapist helps you identify negative thinking, develop strategies to view challenging situations more clearly and respond to challenges more effectively. In **interpersonal therapy**, a therapist helps you link your mood and disturbing life events to regain control of your mood and functioning. Therapy works best when you find a counselor that you feel comfortable with. If your first experience with therapy was discouraging, try seeing a different therapist and talking through your goals and experiences at the first visit.

There are also many medications that are successful in treating depression. The first line of medication treatment is usually a class of drugs called **SSRIs (selective serotonin reuptake inhibitors)**. These include such medications as Zoloft (sertraline), Paxil (paroxetine), Celexa (citalopram) and Prozac (fluoxetine). The most common side effects include sleepiness, nausea and headaches, which usually resolve after one to two weeks. To limit these side effects, you can start with a half dose for the first week and increase to the full dose starting the second week.

Like most medications, it is best to start with the lowest dose that helps depression first and increase slowly to the dose that is best for you. You may not see improvement for up to four weeks, and the full

effect of treatment may not occur until you have been on a specific dose for six to eight weeks. In rare cases, depression can initially get worse, so have your family watch for signs of worsening depression or thoughts of suicide when starting on medication for depression.

If the SSRI medications do not work for you, or if you have side effects to multiple SSRI medications, other medication options should be considered. A newer class of medication called SNRIs (serotonin and norepinephrine reuptake inhibitors) are not only helpful for depression, but are also being used for chronic pain and neuropathic pain. Duloxetine and venlafaxine are SNRIs. Other medications for depression that are not part of a specific

class, but have their own novel mechanisms of action, can help with other symptoms such as decreased appetite (Wellbutrin and mirtazapine), insomnia (mirtazapine) and decreased sex drive (Wellbutrin). If one medication does not fully control your depression, a second medication can be added to augment the first. The medications usually used to augment are called atypical antipsychotics (Abilify, Seroquel, Risperdal, Zyprexa and Latuda).

For people with severe depression who want or try to harm themselves, medication and therapy may not be enough and ECT (electroconvulsive therapy) may be considered.

Whether you feel more comfortable trying psychotherapy or medication to treat your depression, the important thing is asking for help. Living with untreated depression will make it harder to enjoy the time you have with family and friends and will affect your ability to achieve your goals and dreams.

ALS has an impact on many different body functions, emotions, thinking, behavior and the ability to function in everyday ways.

Anxiety

Anxiety is a feeling of worry, nervousness, or fear. It can be a common response to new or stressful situations. Sometimes, anxiety can become overwhelming and interfere with normal activities or happiness. Some signs of anxiety include:

- Feeling nervous, anxious or on edge,
- Not being able to stop or control worrying,
- Worrying too much about different things,
- Being so restless that it is hard to sit still,
- Becoming easily annoyed or irritable,
- Feeling afraid as if something awful might happen,
- Increased fatigue and muscular tension,
- Difficulty sleeping or relaxing,
- Headaches and pain in the neck, shoulders and back, and
- Increased blood pressure or fast heart rate.

While some of the symptoms of anxiety are present in people with ALS due to the disease itself (such as increased fatigue and muscle tension), the presence of several anxiety symptoms may indicate generalized anxiety. If the symptoms make it difficult for you to live your normal life or enjoy life, you should consider having treatment for anxiety.

TREATMENT OPTIONS

Treatment for anxiety includes **behavioral approaches and medication**. Counseling with a cognitive behavioral therapist can help you identify, understand and change your thinking and behavior patterns. You'll learn skills and strategies to view your situation more clearly and respond to it more effectively.

Relaxation techniques can help you train your body to respond more calmly. Types of relaxation techniques include meditation, adaptive yoga and acupuncture. **Mindfulness Based Stress Reduction (MBSR)** is a program that uses principles from yoga and medication to reduce

stress and anxiety. It is based on the ancient practice of mindfulness and teaches being present in the moment, deep relaxation and gentle movement. It can help you examine your reactions to life's stressors and recognize that you can choose how to respond. Most communities have classes available in yoga, meditation and MBSR. There are also books, DVDs and online resources.

In some cases, behavioral approaches may not be effective for controlling anxiety and medications should be used. **The first treatment of choice is to use antidepressant medications (SSRIs), which are also proven effective for anxiety.** Examples of SSRIs used to treat anxiety are Celexa (citalopram), Paxil (paroxetine) and Zoloft (sertraline). The most common side effects include sleepiness, nausea and headaches, which usually resolve after one to two weeks. To limit these side effects, you can start with a half dose for the first week and increase to the full dose starting the second week. Like most medications, it is best to start with the lowest dose that helps anxiety first and increase slowly to the dose that is best for you. You may not see improvement for up to four weeks, and the full effect of treatment may not occur until you have been on a specific dose for six to eight weeks.

For short-term treatment of anxiety, low dose benzodiazepines (lorazepam, clonazepam and diazepam) can be used. These are most often used during the initial treatment with SSRIs until the SSRI takes effect. They can also be used for long-term therapy if antidepressants are not effective or cause intolerable side effects. Side effects include sleepiness, cognitive impairment and weakness.

Just like depression, anxiety can impact your ability to enjoy life. Taking control of your anxiety can help you live life to the fullest.

Thinking And Behavior Changes

For a long time, it was thought that ALS did not involve changes to thinking or behavior. More recently, we have better understood that several types of cognitive changes can occur with ALS.

Approximately half of all people with ALS may have changes in their cognitive ability, though most often the changes are mild. Cognitive and behavioral changes with ALS fall into three main categories:

1. **ALS with cognitive impairment (ALSci).** ALSci refers to people with ALS who have changes in areas of attention, cognitive flexibility and word generation. Memory and visuospatial function are generally unchanged.
2. **ALS with behavioral impairment (ALSbi).** ALSbi is when ALS is accompanied by changes in social interactions and behavior.
3. **ALS with frontotemporal dementia (ALS-FTD).** ALS with frontotemporal dementia is the most severe form of thinking and behavior change associated with ALS. Only a small percentage of people with ALS meet criteria for FTD, and those that do often have signs of FTD present before the diagnosis of ALS. It is estimated that 15% of people with ALS also have frontotemporal dementia. It is more common in certain genetic forms of ALS but also occurs in sporadic ALS. Frontotemporal dementia includes altered social interaction, emotional blunting and loss of insight. A person with FTD may have impaired decision-making, language changes, inappropriate behavior, personality changes, emotional apathy, lack of empathy, dietary changes or obsessive behaviors.

Although opinion varies on the best tests to use to diagnose thinking and behavior changes in ALS, it is generally agreed that people with ALS and their caregivers should be asked about changes in thinking, personality and behavior. If changes are identified, decisions about future care should be discussed early in the disease while your thinking and decision-making abilities are at their best. While everyone with ALS should talk with their families and caregivers

about their wishes and put their wishes in writing by creating an Advanced Healthcare Directive, it becomes even more important if you have cognitive impairment.

Unfortunately, there is no available treatment for ALS with cognitive and behavioral changes. If there are changes in thinking, personality or behavior, **the best approach is to adjust the environment to promote safety and lessen the impact on both the person with ALS and others.** Establishing a routine and avoiding distressing situations can help to lessen the severity of behaviors. It may be embarrassing or upsetting to be around people who do not understand dementia. It is important for caregivers to have support and time away from the loved one with ALS to avoid caregiver burnout. Caring for a person with ALS and cognitive or behavior changes may require a larger team of caregivers, volunteers and community services.

Pseudobulbar Affect: Excessive Crying And/Or Laughing

Some people with ALS experience excessive crying and/or laughing, also known as **pseudobulbar affect, emotional lability or emotional incontinence.** It is caused by damage to specific tracts of nerves in the brain (the bilateral corticobulbar tract).

Pseudobulbar affect is uncontrollable, involuntary, sudden and often frequent crying or laughing that can be unrelated to your mood or excessive for the situation. It can be unprovoked, or it can occur when you would normally feel sad or happy, but not necessarily enough to make you cry or laugh. It can affect close to 50% of people with ALS and can range from mild symptoms that do not require treatment to severe symptoms impacting daily life. **It tends to be more common in the bulbar form of ALS.**

Sometimes laughing or crying occurs at inappropriate times, such as laughing during a funeral or crying when a joke is told. It can lead to frustration, humiliation, embarrassment, social phobia, withdrawal, isolation and caregiver distress. Because of its impact on relationships and quality of life, treating pseudobulbar affect is an important part of symptom management.

TREATMENT OPTIONS

Several treatment options are available to address excessive crying or laughing:

- **Nuedexta** (dextromethorphan-quinidine) is approved specifically for the treatment of pseudobulbar affect. It is generally well-tolerated with very few side effects.
- **SSRIs** (sertraline, fluvoxamine, fluoxetine) have been used for pseudobulbar affect for many years prior to the use of Nuedexta. Since they are also used for depression and anxiety, patients with these symptoms can take one medication to treat more than one symptom.
- **Tricyclic antidepressants** (amitriptyline, nortriptyline) have also been used for pseudobulbar affect since prior to the use of Nuedexta. In addition to treating pseudobulbar affect, they are also helpful for reducing saliva and treating insomnia. If you have more than one of these symptoms, you may want to use a tricyclic antidepressant for treatment.

If one medication does not help your crying or laughing, don't be afraid to ask your physician to try a different medication. **Gaining control over your pseudobulbar affect can have a huge impact on your quality of life.**

Summary Statement

ALS is a neurological disorder that results in damage to motor neurons and primarily muscle function. However, **ALS also has an impact on many different body functions, emotions, thinking, behavior and the ability to function in everyday ways.** For example, not being able to easily move can cause skin sores, and not being able to chew and swallow can lead to malnutrition and dehydration. Not all people with ALS will experience every possible symptom discussed. The good news is there are ways to prevent and treat many of the symptoms associated with ALS. It is good to know in advance all the ways ALS may affect you so you can recognize when you need to make changes to prevent or treat symptoms to maximize your comfort.

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About The ALS Association

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.