



**Greater Philadelphia
Chapter**

Pain and ALS

Fatigue, Mobility Issues, Respiratory Difficulties, and Speech/Communication and Swallowing Problems are often the ALS symptoms that we read or hear about—pain doesn't seem to be as emphasized in the literature. And yet for some PALS (Person with ALS), pain is unfortunately very much a part of their lives.

Cramps are one of the early symptoms and can occur in over 80% of the ALS population. While it is normal for healthy adults to have occasional cramps in their calves, called 'Charley-horses', PALS have reported cramps in the muscles of their limbs, abdomen, back, neck, jaw and even tongue. A cramp is often described as a sudden, involuntary sustained muscle contraction that can interrupt activity and sleep. Cramps are generally limited to a certain muscle group, e.g., hands or feet. A cramp is more likely to occur with over-exercising a muscle group, if the muscle is cold, or if circulation is decreased. The treatment for cramps includes stretching and massaging the affected area, drinking tonic water, and the prescribed medications Neurontin[®], Dilantin[®] and Tegretol[®].

Spasticity is also a problem for some PALS. A spastic muscle feels like a sustained pulling or tightening of a muscle, and can be quite severe. Like cramps, all of the voluntary muscles can be affected by spasms. Spasticity tends to affect larger areas of the body, e.g., arms, legs, trunk. Heat and cold may help to decrease the spasm, along with range of motion and stretching exercises. A physical or occupational therapist can teach the PALS and/or caregiver how to do the exercises and treatments. Medications such as Baclofen[®], Zanaflex[®], Clonazepam[®] and Botox injections may also be beneficial in alleviating the pain involved with spasms.

Numbness or a burning sensation of the legs, feet and hands are occasionally reported by the ALS population. Elevating the limb may help, along with the prescribed medication, Neurontin[®].

Immobility can cause pain along pressure or bony areas, e.g., the sacral area, heels, elbows and hips. It's important that the PALS who is bed or chair-ridden, to either change positions themselves ideally every two hours) or have someone change their position for them. Use of gel pads and mattresses, sheepskins and/or "egg-crates" are often helpful in relieving pressure. Gel pads and mattresses are usually covered items under most insurance plans. Sheepskins and egg-crates can be purchased at Medical Supply stores.

Joint contractures occur when joints have little or no mobility, secondary to muscle death surrounding the joint. Simply stated, a joint contracture is a permanently immobile joint. Any voluntary or involuntary movement of the joint can cause severe pain. Of particular concern with the ALS population are the shoulder joints. Once these joints are contracted, it is often difficult to transfer a PALS pain-free. Contractures are preventable with daily range of motion exercises and/or splinting the affected joint(s). You are not alone if you are a person with ALS who experiences pain. Fortunately, most symptoms are treatable. Let your physician, and other members of the ALS team know if you experience any discomfort that is not being adequately treated.