

**KNOWLEDGE IS POWER...**

# **ALS AND PAIN**

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If you Google 'pain associated with ALS', you will for the most part read that yes, pain is part of the ALS experience, but that pain is caused by the disease only indirectly. Muscle spasms, cramps, positioning, weak muscles and constipation can all be reasons for pain in ALS and all are treatable. But is there more to the pain experienced with ALS?

Recent scientific studies indicate that ALS may not be just a pure motor disorder. Evidence seems to support a new view of ALS – that it is a multisystem disease that in some cases may include changes in thinking, behaviour, mood, sleep and several other manifestations, including pain. Whether pain is directly or indirectly related to ALS, it is still pain, and has implications for management, to improve the life of the person with ALS.

It is important to talk to your caregiver about pain, and not to minimize it. Your quality of life can depend on it. No one can even attempt to 'fix' something if they do not know that it is 'broken'.

Primary pain in ALS can include neuropathic pain (pain caused by damage or injury to nerves that carry information from the body to the brain and spinal cord), thought to be rare, and pain from spasticity and cramping. It should be noted that neuropathic pain could just be independently occurring.

Secondary pain (pain as a consequence of the disease state) has many causes that can be related to muscle weakness, loss of mobility and even to the equipment you need to survive such as feeding tubes and home ventilation (consider an ill-fitting BiPAP mask as an example). Fortunately there are treatments for pain that are available to you. It is important to isolate, if possible, the source of the pain to try to customize the treatment.

- Climbing stairs
- Dyspnea (shortness of breath)
- Orthopnea (shortness of breath while lying down or recumbent)
- Respiratory insufficiency (inability to breath independently to sufficiently meet the needs of the body)

Treatments for pain associated with ALS include:

- Stretching or range of motion exercises. This can be active (performed by you) or passive, performed by a family member or other care giver, when you can no longer do it yourself. These forms of physical exercise help to maintain joint health (and prevent things like a frozen shoulder) and prevent your muscles from tightening up.
- Other non-medical therapies such as massage, application of heat or vibration can help relax tight, spastic or painful muscles. Braces and other similar equipment can help stabilize weak muscles and prevent pain. Your occupational and physical therapists have a wealth of information about what might work best for you.
- Discuss medication options with your doctor. Over the counter pain medications may be safe for you, but always discuss with your care provider first. There are prescription medications that used specifically to help with cramping, spasms and other pain, including neuropathic pain.
- Sometimes an injection can be helpful for joint pain. Once again, discuss this possibility with your doctor.
- Customized wheel chair seating and positioning can provide appropriate support and provide pressure relief.
- Read the Fact Sheet on Bowel and Bladder Control to find suggestions that will help you avoid the pain associated with gastrointestinal and bladder dysfunction. Remember the old adage 'an ounce of prevention is worth a pound of cure'.
- Some find acupuncture helpful for muscle spasms.

Remember to talk to your care team about any of these options and don't hide your pain – your care team is on your side and they want to help. You have enough to deal with. There is no need to add pain to the list.