



# 10 Facts about Pain and ALS

## Fact Sheet

While the emotional pain of ALS is often spoken about, causing depression and sadness in those living with ALS, the physical pain associated with ALS is less frequent, and often ignored. The following are some facts about physical pain associated with ALS and how those living with the disease deal with the physical repercussions of ALS.

**#1** While some patients do report feeling physical pain, joint discomfort or cramping with ALS, pain is not a common feature of ALS.<sup>1</sup>

- Joint pain is not a common symptom of ALS, but it does occur in some people who have ALS.<sup>2</sup>
- Joint pain and stiffness can occur because of lack of movement and use of one's limbs. For many, joint pain can be alleviated by moving around and not sitting in the same position for a long length of time. Those who are immobile should have a caretaker assist with movement exercises.
- Joint Pain can also be improved by careful positioning to avoid strain or stress; a physiotherapist or occupational therapist can assist in providing recommendations.
- If symptoms persist, persons with ALS should contact their physician.

**#2** Muscle cramping, spasticity (including jaw spasms), and fasciculation (involuntary twitching or muscle contractions) can sometimes cause pain for the person with ALS.

- Cramping and light pain can be alleviated by keeping the muscle warm and

having a caregiver stretch out the areas causing discomfort.

- There are medications specifically used to treat spasticity (severe muscle stiffness) and these should be discussed with your doctor.
- A regular stretching/range of motion program has also been shown to reduce spasticity and spasms. A physiotherapist can help teach you and your caregivers these exercises.
- Pressure relieving equipment may also be available through the *Equipment Loan Program* at the local provincial ALS Society.
- Joint pain, spasms, and muscle cramping should be brought to the attention of one's physician or physiotherapist.

**#3** Physical activity / therapy can be used to help with pain management.

- Some studies show that physical therapy, including stretching exercises and functional mobility training, seem to make a difference in pain management and alleviating pain symptoms for those living with ALS.<sup>3</sup>
- Research is still being conducted on the benefits and/or consequences of physical activity for people with ALS as

experts in the field give conflicting reports. Please consult with a physician before beginning any type of physical therapy regime.

- Physical exercises should not cause additional pain.
- Regular systematic exercises can be beneficial in improving flexibility in muscles affected and not affected by ALS, as well as maintaining flexibility in the neck joints, trunk, and limbs.
- Occupational therapists can assist with providing and suggesting physical activities/therapies for the individual with ALS.

**#4** Pain is a cause of suffering and correlates with emotional and social difficulties in people with ALS.<sup>4</sup>

- A 1999 study by the Mental Health Division at the Oregon Health Sciences University, found that pain is one of the main factors that people with ALS equate with suffering.<sup>5</sup>
- People with ALS who experienced moderate to severe physical pain rated their overall suffering higher than those who had little to no physical pain.

<sup>1</sup> Hecht, M., Hillemaier, T., Grasel, E., Tigges, S., Winterholler, M., Heuss, D., Hiltz, M.J., Neundorfer, B., "Subjective experience and coping with ALS", From *Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders*, 3(4):225-31, December 2002.

<sup>2</sup> Weiss, MD., Ravits, JM., Schuman, N., Carter GT., "A4V superoxide dismutase mutation in apparently sporadic ALS resembling neuralgic amyotrophy". From *Amyotrophic Lateral Sclerosis*, 7(1): 61-3, March 2006.

<sup>3</sup> Sancho, PO., Boisson, D., "Physical therapy in ALS" (French). From *Revue Neurologique*, 162 spec. No.2: 4S253-4S255, June 2006.

<sup>4</sup> Hirano, YM., Yamazaki, Y., Shimizu, J., Togari, T., Bryce, TJ., "Ventilator dependence and expressions of need: A study of patients with amyotrophic lateral sclerosis in Japan". From *Social Science & Medicine*, 62 (1403-13), 2006.

**#5 Physicians often fail to recognize, record and treat pain and/or depression in a person with ALS.**<sup>6</sup>

- Severe pain followed by further loss of function should be brought to the attention of one's physician to rule out additional problems or complications unassociated with ALS.<sup>6</sup>

**#6 Medication can be used for pain management.**

- Pain relief medications are recommended for people with ALS who are in moderate to severe pain. These can include some forms of opiates, non-steroidal anti-inflammatory agents such as aspirin, or acetaminophen.<sup>6</sup>
- There are also medications that can be used to treat painful cramps, and medications specifically used to treat spasticity (severe muscle stiffness).
- People with ALS should discuss medication options with their physician.

**#7 Pain is most prevalent in the back, shoulder and neck. Pain has also been reported in the buttock and hips, feet, arms and hands.**<sup>7</sup>

- Pain in the lower back, neck, and shoulders can be alleviated by changing one's posture. Special cushions, chair backs, lumbar (lower back) and cervical (neck) rolls can be used to help maintain correct sitting posture. Sitting in a reclined

position or using a neck collar can help maintain proper positioning.

- Pain or cramping in the arms and legs can be alleviated by raising them on a footstool or placing them on pillows. Shoulder slings can also be used for additional support.
- #8 Natural or alternative therapies are sometimes employed to help alleviate pain without prescription medication.**
- Some people with ALS report that cannabis use helps to alleviate physical pain and other unfavourable symptoms associated with the disease. Results of a 2004 study conducted by the Department of Rehabilitation Medicine at the University of Washington School of Medicine found that people with ALS who used cannabis found it helped to reduce their appetite loss, depression, spasticity, drooling and pain.<sup>8</sup>
  - Other alternative therapies may include massage, acupuncture, aromatherapy, hypnosis, or meditation.
  - Please Consult ALS fact sheet on Natural Health Products and ALS fact sheet on Complementary Therapies, for more information.

**#9 Pain can sometimes occur as a result of passive injury to joints where the controlling muscles are already weak.**

- This can include injuries or joint dam-

age as a result of assisted transfers, or improper use of mobility equipment.

- Braces (called orthoses) can be prescribed to support weak muscles and joints and, in certain circumstances, to reduce discomfort.
- Caregivers should ensure they have proper knowledge of how to use mobility equipment and should request a demonstration on how to use new or unfamiliar equipment where possible.

**#10 Pain and joint discomfort are more prevalent and severe in the later stages of ALS. Shortness of breath and choking episodes also become more frequent as the disease progresses.**

- Approximately half of medical studies related to physical pain in people with ALS focus on the near end-of-life stage.
- Pain relief is often a major goal for ALS patients in the last month of life.
- Seventy-four per cent of patients in the later stages of ALS report taking medication to help ease the physical pain associated with ALS.<sup>9</sup>
- Emotional pain becomes a major issue in the last months of life and can be heightened by increased physical pain.
- Anti-depressant medication may be recommended.

<sup>5</sup> Ganzini, L., Johnston, WS., Hoffman, WF., "Correlates of suffering in amyotrophic lateral sclerosis". From *Neurology*, 52(7): 1434-40, April 22, 1999.

<sup>6</sup> De Carvalho, M., Nogueira, A., Pinto, A., Miguens, J., Sales Luis ML., "Reflex sympathetic dystrophy associated with amyotrophic lateral sclerosis". From *Journal of the Neurological Sciences*, 169(1-2): 80-3, October 31, 1999.

<sup>7</sup> Jensen, MP., Abresch, RT., Carter GT., McDonald, CM., "Chronic pain in persons with neuromuscular disease". From *Archives of Physical Medicine & Rehabilitation*, 86(6): 1155-63, June, 2005.

<sup>8</sup> Ammann, D., Weydt, P., Johnson, KL., Jensen, MP., Carter, GT., "Survey of cannabis use in patients with amyotrophic lateral sclerosis". From *American Journal of Hospice & Palliative Care*, 21(2): 95-104, March/April, 2004.

<sup>9</sup> Mandler, RN., Anderson FA Jr., Miller RG., Clawson, L., Cudkowicz, M., DelBene M., ALS C.A.R.E. study group, "The ALS Patient Care Database: insights into end-of-life care in ALS". From *Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders*, 2(4): 203-8, December 2001.