Pain in ALS

By Ileana Howard, MD

Does ALS cause pain?

The answer is yes, although in most cases it does so indirectly. From what we know at this time, the disease process in ALS only affects the nerve cells controlling strength (motor neurons) in the brain, spinal cord, and peripheral nerves. Fortunately, these nerves don’t send pain signals back up to the brain. Unfortunately, there are several reasons that the weakness associated with ALS can cause pain:

- Weak muscles can cause extra strain on muscles and joints, which often causes pain. This is most common in the neck, shoulders, and back.
- Immobility or the inability to change positions or roll in bed can cause abnormal skin pressure and result in pain or wounds.
- Medical treatments, like feeding tube or tracheostomy tube placement, can cause discomfort. In most cases, this is temporary following a tube placement.
- Constipation is common in ALS and can be really uncomfortable.
- Muscle cramps, tightness, or spasms.

The good news is...

That most of this pain is treatable, and there are a wealth of options at hand to minimize pain and maximize quality of life and function for persons with ALS.

What are some of the strategies to treat or manage pain symptoms in ALS?

- Stretching or range of motion. Loose muscles are less likely to cramp or spasm. Stretching is important to maintain range of motion and prevent permanent tightening (contractures) of the muscles or joints (such as frozen shoulder).
- Non-medication treatments. Vibration, electrical stimulation, and heat can be used to help relax tight, spastic, or painful muscles. Taping or bracing can help stabilize weak muscles causing pain. These tools are often available over-the-counter or through a therapist or by
prescription. The effect usually lasts several minutes, but can be more effective if used with stretching.

- **Medications.** Over-the-counter pain medications are usually safe to take in ALS. When these don’t work, specific medications are available for cramps, spasms, and pain. Please work with your ALS doctor to discuss options.

- **Injections.** When pain is focused in a specific joint or part of the body (e.g. shoulder or spine) sometimes injections can be helpful. Rehabilitation medicine doctors (physiatrists) often perform these types of injections, although other providers may offer them as well.

- **Wheelchair positioning.** When muscles aren’t working to support the joints and body, seating and positioning in a wheelchair can often be customized to allow pressure relief and support to vulnerable areas.

- **A routine bowel regimen.** An ounce of prevention is really worth a pound of cure when it comes to the gut. Daily bowel programs, consisting of fiber or bulking medication along with bowel-stimulating medications if needed, can help ensure regularity despite immobility in ALS. Occasionally, tube feeding formulas need to be changed if they cause stomach upset, constipation or diarrhea. Keep in mind that some pain medications, especially narcotics, can cause worsening or even severe constipation unless they are accompanied by routine bowel medications.

- **Acupuncture.** This treatment has been around for thousands of years, and has been found to be helpful for muscle spasms in other neurologic diseases- therefore, it might be helpful to control some pain symptoms in ALS.

- **Palliative care/hospice.** Palliative care is a growing specialty of medicine focused on improving quality of life for persons with severe illness. Hospice providers can also help manage pain and other troublesome symptoms at home for persons with advanced stages of ALS who don’t wish to have life-prolonging measures like mechanical ventilation.

**Remember that your ALS care team is your partner in this journey, and is available and willing to help. Communicate often and honestly with your team, and inform them when treatments are not working!**

*The ALS Association thanks and acknowledges Ileana Howard, MD, for sharing her time and expertise on this factsheet.*

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**Bibliography**


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