



## PAIN MANAGEMENT

Fact Sheet

Pain is one of the least acknowledged symptoms of people living with ALS. More than 60 per cent of people living with ALS will admit to experiencing significant pain, varying in terms of intensity and etiology.

- Neuropathic pain: arising as a direct consequence of a lesion or disease affecting the somatosensory system, resulting in tingling, burning, numbness or shooting pains.
- Nociceptive pain: deep-seated pain, localized to a point of injury, resulting in aching, throbbing or stiffness.

Types of pain for people living with ALS vary, and treatments need to be tailored to the underlying source of pain:

- A common source of pain originates from the loss of subcutaneous tissue (both fat and muscle), which is the deepest layer of skin that insulates the body and protects organs and bones. This can cause significant pain in the bone or due to pinched nerves from increased compression.
- Immobility commonly results in deep aching pains, typically in the lower extremities.
- Spasticity in people living with ALS can cause clenched-muscle and straight-muscle spasms, creating significant amounts of pain.
- Fasciculations, or muscle twitches, common in ALS, are usually painful as well as distressing to patients.
- Joint pain by stiffness and scarring is created by capsulitis, commonly referred to as frozen shoulder syndrome. This throbbing pain can affect sleep and limit mobility and activity in patients. It should be treated early and aggressively with range of motion exercises before enlisting in medications such as steroid or lidocaine injections.
- Other types of pain may be secondary to the illness or related to medications needed to battle ALS.

Pain management depends on identifying (as closely as possible) the source of pain so that treatments will be effective. Non-pharmacological treatments include properly fitted wheelchairs, reasonable exercise such as tai chi or cycling, acupuncture and use of massage. These treatments help patients maintain their quality of life, increasing balance and mobility.

There are a variety of different medications used to treat pain, including antidepressants, anticonvulsants and anti-epileptics, serotonin/noradrenaline reuptake inhibitors and opioids among others. It is important to understand both the positive and adverse effects of medications, as well as the other factors that may influence someone to refuse to take a certain drug.

### Antidepressants:

- Although originally developed for depression, they have been known to manage neuropathic pain for many years. Drugs such as Amitriptyline are used in low doses to combat hyper-salivation, a common side effect for people living with ALS, as well as to treat frozen shoulder pain.
- Antidepressants may have adverse side effects such as constipation and causing confusion or encephalopathy.

### Anticonvulsants and anti-epileptics:

- Drugs such as gabapentin (Neurontin) and Pregabalin (Lyrica) work to manage the pain from immobility and help patients' sleep improve.
- These drugs help with anxiety in some people, though adverse effects include sleepiness, weight gain and in rare cases papilledema and blurred vision, so it's best to start patients on a low dose.

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#### Serotonin/Noradrenaline reuptake inhibitors:

- These are a class of antidepressants, including the drugs Venlafaxine, also known as Effexor, and Duloxetine, also known as Cymbalta.
- Effexor is good at controlling the highs and lows that people living with ALS experience from changes in their neuron functions.
- Cymbalta is good at controlling depression and neuropathic pain.
- These drugs are processed in the liver, which is a careful consideration when prescribing. They can also affect intimacy and sexual function, which makes many patients refuse them.

#### Opioids:

- These are widely used in palliative care because they are useful for deep, bony pain which occurs when patients have unusual pressure points or frozen shoulder syndrome.
- They are great for controlling pain but have many adverse effects, including nausea, vomiting, dizziness and constipation.
- A Fentanyl transdermal patch, while strong, can be used by bulbar patients and can help them avoid constipation.
- A new Buprenorphine patch, called BuTrans, is a mild opioid and a once a week patch, which has less side effects and may be very effective for bone pain.
- Morphine is another form of opioid, which can be used to treat pain, as well as the feeling of not getting enough air. Methadone may be used if Morphine is ineffective.

#### Other medications:

- Tramadol works well for neuropathic and nociceptive pain, as well as mixed pain and can be taken by patients that are still mobile and only need it once in a while.
- A new lidocaine patch coming out soon will be useful in focal pain such as shoulder pain.

- Cannabinoids, or marijuana-based drugs, include Sativex, a drug which mimics the plant, encompassing THC and cannabidiol in an oral mucosal spray.

This drug is effective, but currently under conditional approval in Canada for the treatment of multiple sclerosis, not ALS. People living with ALS can use actual marijuana to treat a lack of appetite or nausea, as well as both neuropathic and nociceptive pain. There are many different methods of using this type of treatment which can be chosen based on the patient's needs.

- The largest side effect of cannabinoids is the cognitive effect, which can make it more difficult for regular day-to-day functioning.

Pain in ALS is frequent, but is one of the most under-recognized symptoms. Patients do not often volunteer information about their pain if they are not asked about it specifically, but it is necessary to treat their pain, as it interferes with the patients' health, affecting their sleep, appetite and overall quality of life.

*This fact sheet is reporting on current research and is meant for informational purposes only. ALS Canada does not assume responsibility for the information contained within, nor does it endorse any specific medication. Please seek the advice of a health-care professional for more information.*

*Information provided by: Angela Genge, MD, director, Clinical Research Unit at Montreal Neurological Institute and assistant professor, Department of Neurology, McGill University.*