Welcome!
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ALS is More than a Pain in the Neck: Identifying and Managing Pain in ALS

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Attendees are advised that portions of this webinar will be recorded for later viewing in our archives. If you would like to review the recording, please refer to our website, for information (www.alsa.org).

Hosted by:
The ALS Association
National Office-Care Services
ALS is more than a pain in the neck...

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Disclosures

- Ileana Howard, MD
- Virginia Kudritzki, DPT
- Anielia Thomas, OTR/L

  - Have no financial interests to disclose
Overlooked
Poorly managed
Under studied
Neglected
Under estimated
Low reported
Misunderstood

PAIN
Why Talk About Pain in ALS?

- ALS was once thought to be a “painless disease”
- Pain affects about 70% (15-85%) of pALS
- Can be present at all stages of disease
- Negatively impacts quality of life
Impact of Pain in ALS

• Pain is the most important contributor to distress and suffering

• Correlated with a deterioration in patients QOL and increased prevalence of depression
Muscle twitching (fasciculations)

- Firing of the peripheral nerve due to damage or changes in the ion channels
- Usually painless
Muscle Cramps

- Sudden, involuntary muscle contraction
  - Motor nerves fire up to 150 times per second during a cramp!
- Last seconds to minutes, soreness can last up to three days after the cramp
- Stretching/lengthening muscle can abruptly end a cramp
Musculoskeletal Pain

The acromion is the top part of the shoulder blade.

The rotator cuff is a group of muscles and tendons that attach the arm bone to the shoulder blade and help the shoulder to move.

The humeral head is the top part of the arm bone. It's shaped like a ball and rests against the shoulder socket.

The cartilage is the smooth covering on the ends of the bones. It acts like a cushion, allowing the bones to move without pain.

The glenoid is the shallow socket that forms a cradle for the head of the arm bone.

The capsule is a sheet of fibers that surrounds the joint. It is tough enough to keep the joint stable, yet flexible enough to allow it to move freely.

The synovium lines the capsule and produces a fluid that lubricates the joint and keeps the ends of the bones from rubbing.
Spasticity

- “Velocity-dependent increase in tone”
- the faster you try to move a limb, the stiffer it becomes
- Can interfere with walking
- Can limit stretching program
- Can cause pain with involuntary limb movements, often at night
Neuropathic pain in ALS

- Less common than musculoskeletal pain
- Burning pain
- Pins & needles pain
- Often worse at night

Moisset, Xavier, 2016
Constipation

- Constipation common in ALS
- May be related to
  - Reduced mobility
  - Reduced water intake
  - Change in diet
- Bloating, abdominal pain, nausea, vomiting
Respiratory-related pain

- Sores from Bi-level mask
- Pain related to trach stoma
- Pain from suctioning
- Pain may increase with improved oxygen status!
Itching

- ~30% of persons with ALS describe itching
- May be side effect of pain medications (narcotics)
- May be related to other dermatologic processes
Pain is NOT inevitable in ALS
Occupational and Physical Therapy
Head and Neck Pain

- Cervical extensors fatigue
  - Providing cervical collars for fatigue management
  - Gentle cervical range of motion
  - Adequate head support in tilted position
  - Soft tissue massage

- Headache
  - Active trigger point referring pain into the head
  - Trauma from falls
Head and Neck External Supports

- Head master collar
- Baseball Hat
- Use gravity as your aide: use a recliner
Neck Stretches

**NECK - 6 Active Neck Rotation**
With head in comfortable position and chin gently tucked in, rotate head to the right. Hold __ seconds. Repeat to the right.

Repeat all __ times. Do 1-2 sessions per day.

**NECK - 4 Range of Motion (Flexed)**
Gently tuck in chin and bring toward chest. Hold __ seconds. This exercise can also be done on back for more resistance. Repeat __ times. Do 1-2 sessions per day.

Repeat __ times. Do 1-2 sessions per day.

**NECK - 2 Axial Extension**
Gently pull chin in while lengthening back of neck. Hold __ seconds.

Repeat __ times. Do 1-2 sessions per day.

**NECK - 8 Shoulder Circle Shrug**
Bring shoulders up and rotate around backward.

Repeat __ times. Do 1-2 sessions per day.

**NECK - 5 Lateral Flexion**
With head in comfortable position and chin slightly tucked, gently bring right ear toward right shoulder. Hold __ seconds. Repeat with left side.

Repeat all __ times. Do 1-2 sessions per day.

**NECK - 3 Shoulder Retraction**
Tuck in chin and gently pull shoulders back. Hold __ seconds.

Repeat __ times. Do 1-2 sessions per day.
Head and Neck Pain

Power/Manual wheelchair options

- Increase back support: High back chair or power wheelchairs that support the whole back through neck
- Increase head support on PWC: Savant head rest vs Adjust a plush

![Adjustable Head Positioning](image-url)
Trunk/Spine

Causes: Weakness, poor posture, muscle tone

Treatments:

- Proactive corrections of posture: reduce lean to favored side
- Stretching: thoracic stretch and side laying stretch
Trunk Stretches
Trunk and positioning continued

Modifications in a Power wheelchair

- Add lateral supports
- Increase upper extremity support
  - Try a lap tray
  - Larger arm pads
- Move joy stick to mid line to reduce side ways lean
EXTREMITY PAIN

Common areas:
- Shoulder (most common)
- Elbow
- Hand/fingers
- Calf
- Knee
Shoulder Pain

- Nociceptive pain arising from damage to non-neuronal tissue
- Cascade of pathophysiological events at the junction between the nerve and muscle fiber ultimately resulting in strain the tendons, joints, and ligaments and micro trauma to muscles.
- Poor posture, poor body mechanics, and prolonged mobility from weakness can initiate the pain or exaggerate existing pain.
Should Pain Treatment

- Patient/caregiver education
- Active range of motion
- Passive range of motion
- Physical agents (i.e. taping, cold/heat, TENS)
- Positioning, optimizing posture
- Braces/Slings
Extremity Pain

- Elbow - pressure injury from wheelchair armrest
- Wrist and fingers - weakness and formation of contractures
Lower extremity pain (AT)

- Theater sign: Pain of the inner knee area, often a result of decreased movement
  - Treatment: AROM or PROM, use elevating leg rests changing position of legs

- Calf cramping
  - Treatment: Massage, stretching (20 second hold)
The 5 Ps for Managing Pain in ALS:

Physical Medicine and Rehabilitation
Why Rehabilitate ALS?

Frank Krusen, MD
1898-1973
Visual Analog Scale

- Most simple pain assessment tool
- Universally used and understood
- Can report:
  - Pain right now
  - Average pain last week
  - Best/worst pain scores
ALS-Specific Quality of Life (ALSSQOL-20)

- Free access
- Downloadable from Penn State University
- Assessment of:
  - Negative emotion
  - Physical functioning
  - Bulbar function
  - Interaction with People and the Environment
  - Religiosity
  - Intimacy
The 5 Ps for Managing Pain in ALS:

PHYSICAL MODALITIES
Non-Medication Pain Treatments
Non-pharmacologic pain management

- Examples of modalities:
  - TENS
  - Vibration
  - Heat/ice
  - Taping

- Benefits:
  - Portable
  - Minimal side effects
Pharmaceuticals

The 5 Ps for Managing Pain in ALS:
Medication Management for Pain in ALS

Answering these questions may help guide your providers to the best treatment option:

- Is pain restricted to one symptom, or are there *multiple* pain symptoms?
- Are there other symptoms, such as:
  - Poor sleep
  - Excess saliva
  - Depression
  - Fatigue
# Types of Pain Medications for ALS

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<thead>
<tr>
<th>Type</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Topicals</strong></td>
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<tr>
<td><strong>Analgesics</strong></td>
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<td><strong>Anti-inflammatory (NSAIDS)</strong></td>
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<tr>
<td><strong>Nerve Pain Medications</strong></td>
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<td><strong>Anti-spasticity Medications</strong></td>
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<td><strong>Narcotic Pain Medications</strong></td>
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<td><strong>Other Medications</strong></td>
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<td><strong>Injections</strong></td>
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Injections for Shoulder Pain
Risks and Benefits
Be Proactive!

better to HAVE and NOT NEED, than NEED and NOT HAVE!
Feeling Overwhelmed?

ALS team → pALS → caregiver → Palliative care, hospice → Community, family, spiritual support

ALSA & ALS community
Conclusions

- Pain is a common and TREATABLE symptom in ALS
- There are many interventions for pain control:
  - Prevention
  - Positioning
  - Physical Medicine & Rehabilitation (PM&R) interventions
  - Physical Agent Modalities
  - Pharmaceuticals
- Best results occur when patients and families team up with their care providers and community resources
  - Tell others when you are experiencing pain
  - Follow up if your treatments aren’t working
Works Referenced

Thank you!