

# ALS and physiotherapy

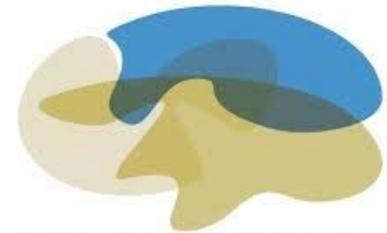
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McGill University  
Health Centre



neuro

# ALS Education day

Conflicts of interest:

I have received an honorarium from Mitsubishi Tanabe Pharma Canada for this talk today.



McGill University  
Health Centre



# Learning Objectives

- What gait aids are used with ALS patients and why?
- What exercise is beneficial?
- What exercises may be harmful?
- How do the exercises need to be modified as the disease progresses?
- What do we focus on at a follow up visit?

# Patient complaints

## TEST YOUR KNOWLEDGE

For non-bulbar symptoms, which two symptoms do patients find the most bothersome?

*-Fatigue*

*-Ability to move/strength*

(Raheja et al., 2017)

# Goals in physiotherapy

- Focus on what the patient needs most at any particular time
  - Identify problems and educate the patient
  - Control symptoms that arise from weakness
  - Maximize functional independence
  - Prevent falls

(Majmudar et al, 2014)

# Fatigue

- The term “fatigue” refers to both an inability to sustain motor function during exertion and a pervasive tiredness.
- Causes of fatigue are multiple, ranging from nocturnal hypoventilation with resulting excessive daytime sleepiness, uncontrolled pain and cramps that interfere with sleep and overuse.

(Paganoni et al., 2015)



# Physiotherapy role in fatigue management

- 1. Problem:** Inability to sustain motor function during exertion or dorsiflexor muscle fatigability with long distance walking

**Intervention:** patient may benefit from a flexible AFO during the day to avoid falls in the evening.

- 2. Problem:** Pervasive tiredness

**Intervention:** Breaking up the activities with rest periods or dividing big tasks to be done on different days

# “Can exercise make me stronger?”

Many people with ALS ask about the role of exercise

- integral component of  
their pre-morbid lifestyle >>



- exercise is often thought to be reparative, having positive effects on endurance and strength.

(Paganoni., 2015)

# Exercise

The evidence regarding the risks and benefits of aerobic / strengthening exercise in ALS is **limited**.

Clinical studies show that both endurance and resistance training have an advantageous impact on the quality of life of ALS patients without extending life expectancy

(Tsitkanou et al 2019)



# Exercise

## Results are **positive**:

- The program was **well tolerated and was associated with less functional decline on the ALS Functional Rating Scale (ALSFRS) and the Ashworth spasticity scale** in the exercising group at 3 months following study initiation  
( Drory, et al., 2001)
- A second randomized, controlled trial of moderate resistance exercise in 27 people with ALS also resulted in **better function at 6 months, as measured by total ALSFRS scores and quality of life, without adverse effects**  
( Bello-Haas t al., 2007)
- Aerobic exercise defined by CPET is feasible and **can improve functional outcome in ALS.** (Braga et al., 2018)

# Exercise take home message

*Exercise is beneficial and the patient may use it to cope*  
*Find a modified version that works*



# Name three types of exercise?

- Flexibility
- Strengthening
- Aerobic

# Flexibility

- Indication:
  - Prevention and management of contractures; might also help reduce pain, cramps caused by spasticity
  - Start early in the disease course and incorporate in gentle daily routine with caregiver participation as needed
  - Cramps can interfere with sleep



# Strengthening

- Indication:
  - Potential role in maintaining muscle strength
  - Do not exercise muscles that do not have antigravity strength <3
  - Avoid high-resistance exercise
  - Avoid eccentric exercise (assist concentric and load eccentric)
  - Progress as tolerated (“start low, go slow”)



# Aerobic

- Indications:
  - Potential role in reducing deconditioning and improving mood, sleep, spasticity and quality of life
  - Perform at a moderate, sub-maximum level  
If the patient cannot talk comfortably during exercise, the program is too vigorous
  - Progress as tolerated (“start low, go slow”)
  - Consider community-based programs that encourage social interaction and participation such as adaptive sports program (e.g., adaptive golf)

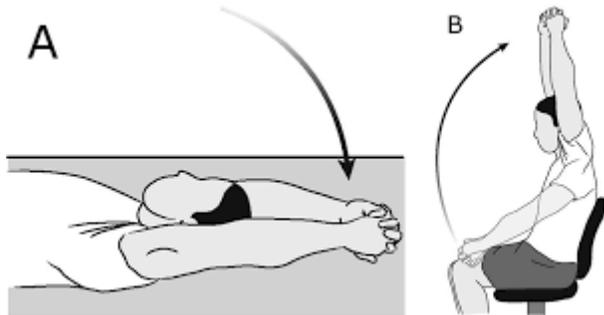
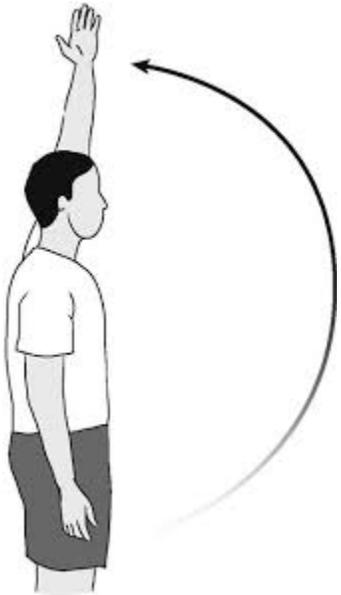


# How to know when to back off?

- Difficulty with activities of daily living after exercise session
  - Ex: difficulty walking back to car after the gym session
- Pervasive fatigue doesn't improve with short rest
- Increase in fasciculations in the muscles that are being exercised
- Cramps are worse at night
- \$100 analogy

# From mover to being moved

AROM > AAROM > PROM



Soum, Carolee Kiser, Linn Allen Oddy, John Bonzani:  
Therapeutic Exercise: Foundations and Techniques, Seventh Edition  
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- Important to maintain a consistent movement practice involving the family or with the care team to avoid pain becoming a more permanent symptom
- This is often a task that becomes lost in the busy day of caregiving

# Ability to move

- While at each clinic we document the inevitable progression of weakness our focus shifts to brainstorming ways to make desired activities possible for as long as possible
- Assistive aids become increasingly used
- Sign of defeat, aids are presented as allowing for independent functional mobility at home and in the community

# Assistive aids

What assistive aids are used with ALS?

# Assistive devices

- Canes
  - mild lower extremity weakness-increases proprioceptive input
  - held on the stronger side of the body while the weight is shifted away from the weaker side.
  - must have adequate grip strength
- Walkers
  - more significant lower extremity weakness
  - axial weakness with respiratory complaints with sufficient strength in triceps
  - walkers with wheels and brakes useful for self-pacing with seated breaks
- Manual wheelchair
  - Severe lower extremity weakness with ability to self propel
- Transport wheelchair
  - useful when long distance mobility is difficult but they are not yet a candidate or do not want a fitted wheelchair



# Assistive devices

- Lower body weakness = less efficient and more energy-consuming gait pattern

(Menotti et al., 2011)

- Proximal leg weakness may compound the problem, making it difficult to get out of a car or rise from a low surface
- Can trigger musculoskeletal pain and can worsen fatigue

# Assistive devices



- Braces use intermittent basis when weakness is mild ( $>3$ ) to help conserve energy and assist at times of demanding activities such as walking long distances (Bean, Walsh & Frontera, 2001)
- The most commonly used braces in ALS are ankle-foot-orthoses (AFOs) - light-weight and customized
- Strength  $< 3$ , AFOs may be needed at all times to help reduce the risk of falling

# Assistive devices

- Sit to stand and transfer patient aid
  - Appropriate for non-ambulatory patient that is able to pull self to standing from wheelchair but is unable to take steps safely
  - Useful to help patient continue toilet in bathroom and avoid diaper use
  - Helps avoid injury to caregiver when giving frequent assistance for sit to stand



# Assistive devices

## Hoyer lift

- Patient requires maximal assistance for transfers
- Transfers become cumbersome and transfer to toilet becomes much less efficient (need special sling and more time consuming with pant wearers)



# Pain

- Common areas include: neck, lumbar, shoulder (Ho, Ruthazer & Russell., 2011)
- Causes of pain?
  - Joint contractures
  - Tendon and muscle contractures
  - Pressure sores
  - Spasticity
  - Cramps
  - Poor positioning
- Pain can occur/be exacerbated after falls



# Pain

- Interventions:
  - Lumbar support in wheel chair
  - Neck bracing for cervical weakness
  - Shoulder approximation sleeves for shoulder weakness ( we use the hand in the pocket)
  - Leg elevation/tilt in space chairs for leg discomfort from edema and gluteal pressure in sitting
  - Resting hand and ankle splints for prevention of contractures
  - Massage
  - AROM▷AAROM▷PROM
  - PREVENT FALLS

# Falls prevention

- Changes arising in the central and peripheral nervous systems –constant adaptation
- Falls linked to
  - lower extremity (LE) weakness
  - muscle fatigability or generalized fatigue
  - spasticity
  - inability to respond to postural changes
  - decreased coordination
  - changes in balance

(Kloos et al., 2004)

# Negative consequences of falls

- Falls lead to negative health outcomes for the patient such as
  - Injury
  - hospital admission
  - loss of functional independence
  - Inactivity
  - premature admission to long term care centers
  - morbidity and mortality

(Schell et al., 2019)

# How do we prevent falls?

- Discussion with patient about physical deficits and how they interact with the environment
- Implementing changes based on factors that predispose patient to falls
- Element of experiential learning of patients coming to understand their limits



**Its not possible to prevent all falls and some patient prefer to take risks**

# Decision making and ALS

Take home message:

**Meet the patients where they are**



# Experiential learning

**Scenario:** Patient with flail arm weakness has a new foot drop requiring an AFO. Patient has not worn it due to added burden on wife. Patient and wife come to physio appointment with history of a recent fall.

**Task:** Teach wife to assist patient to wear AFO

1 group: patient (will be holding something you cannot let go of with both hands behind your back)

1 group: caregiver (you have 4 minutes to complete the task because you need to get to an appointment)

1 group: physio (you think they need the AFO, how can you explain why they need it?)

Questions?

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