The Role of Occupational Therapy with the ALS patient

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Disclosure Statement

- I have the **following relevant financial relationship(s)** in the products or services described, reviewed, evaluated or compared in this presentation.
- University of Louisville Office of Continuing Medical Education and Professional Development
- Financial compensation for speaking
- Frazier Rehab Institute
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AOTA Definition

- "In simplest terms, occupational therapists help people of all ages participate in the things they want and need to do through the therapeutic use of everyday activities (occupations).

- "...Occupational Therapy helps people function in all of their environments (home, community, etc.) and addresses the physical, psychological and cognitive aspects of their well being through engagement in occupations." www.AOTA.org/aboutoccupationaltherapy/professionals.

Main function of Occupational Therapy with the ALS patient

- The occupational therapist strives to enable and enhance meaningful function for the ALS patient.
- Strengthening and improvement of function is often a therapy goal.
- This goal is not appropriate with the ALS patient.
- Compensatory measures not remediation drive the treatment process with ALS patient.

Need to correctly identify the functional stage of the ALS patient

- 1. The Early Stage – Patient experiences generalized fatigue and specific localized weakness to one side of the body, one limb, or upper vs lower trunk. ADLs are specifically impaired.
- The Disability Stage- ADLs and function are very limited. All extremities and trunk show significant signs of limitation. Caregiver role takes on significant importance.
- The End Stage- Patient become nearly fully dependent on caregiver for most if not all ADLs. Very minimal to no function in all extremities. The patient positioning is limited to the bed or to the wheelchair (preferably power w/c).

Need to correctly identify the functional stage of the ALS patient

- These stages are the general trends of the ALS disease process on the functional performance of the patient.
- They should not be taken as absolutely distinct stages. Rather they should be seen as interacting stages on a continuum.
- When you accurately stage the patient you can more accurately and realistically address the patient's present needs and assist both the patient/family anticipate future needs before they occur.

Functional Adaptive Equipment

- Adaptive equipment can be a helpful tool for the patient for accomplishing their functional goals. But often adaptive equipment is thrown in a closet.
- The more the patient is allowed to be involved in the problem solving process, the more invested they will become in using the adaptive equipment and making it work for themselves. Refer to article on feeding harness. It is an excellent case study of patient creativity in collaboration with the therapist to design of unique piece of adaptive equipment.
- According to a research(Arbesman,M. et al) review, ALS patients have a unique preference and satisfaction level with different pieces of adaptive equipment than other patients.

Adaptive Equipment

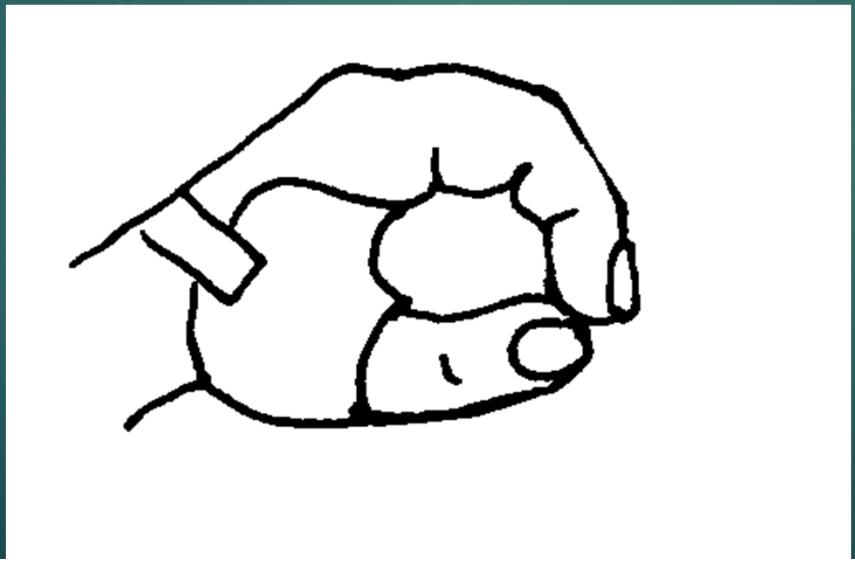
- Dressing equipment such as reachers, sock aids, dressing sticks and button hooks are found to be the least useful to ALS patients. This equipment is typically only useful for a brief during the initial stage of the disease process.
- Feeding/grooming equipment (large grip utensils, built up foam, scoop dish, universal cuff, electric toothbrush, Dycem) are typically the most enduring adaptive equipment from early stage to the end stage of the disease process.
- Shower chair/bench and grab bars should be installed early in the disease process in anticipation of ambulatory deterioration even before the first fall occurs. Bathroom modification (i.e. open shower area) should be considered early in the disease process.

Adaptive equipment

- Computer use adaptive equipment- voice activated/eye gaze technology, use of stylus to operate computer keyboard.
- Cell phone use- Use of stylus to press keys. Fabrication of orthoplast cell phone cuff to compensate for decreased grip strength.
- Be creative. Many problems can be solved with ingenuity and a square of orthoplast.

Splints/Orthotics

- Two types of splints
- A. Functional Splints
- 1. C-Splint- Positions thumb and index to compensate for thenar atrophy and to allow performance of fine motor tasks.

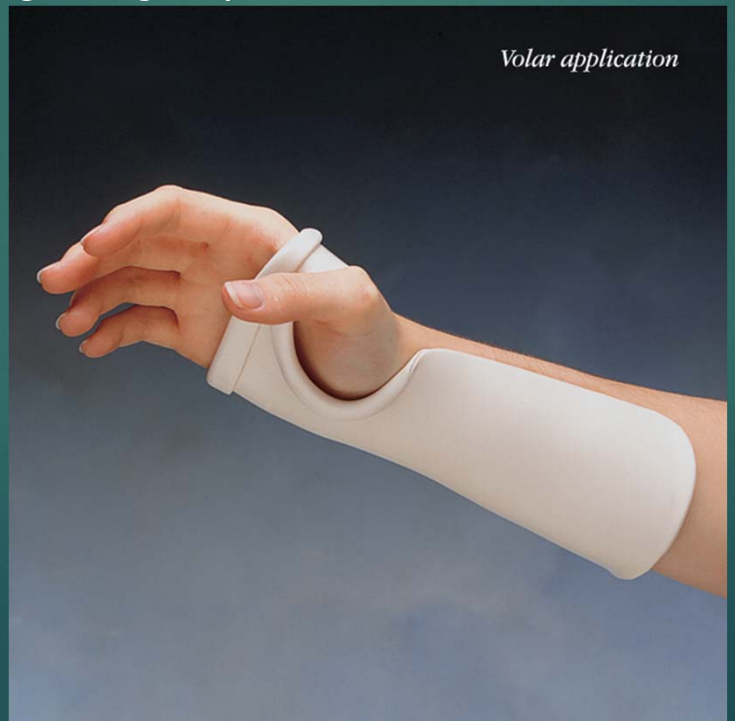


Splints/Orthotics

- 2. Thumb spica splint- provides stability of thumb for fine motor tasks.

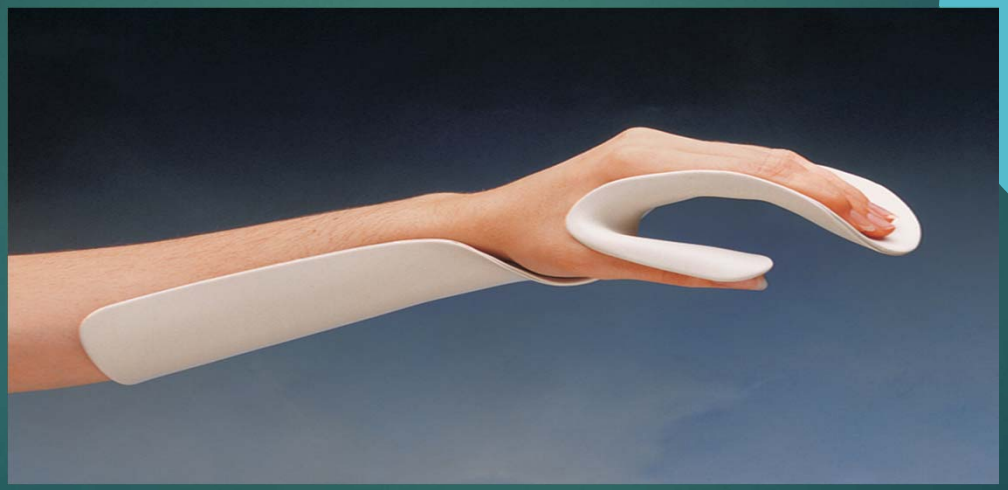
Splints/Orthotics

- 3. Wrist Cock-up Splint- To compensate for wrist drop and allow the patient to perform gross grasp task with wrist extensor muscle atrophy.



Splints/Orthotics

- Contracture prevention splints – Resting hand splint and anti spasticity ball splints.



Splints/Orthotics

- Recommendations
- In order for patient to “buy into the splint,” functional splints will often require some training to facilitate effective use by the patient.
- Splints must be lightweight, easily donned and doffed, and low profile to insure patient compliance. Use lightweight splinting material such as X-lite thermoplast, Polyform and Aquaplast especially for functional splints. More durable material such as Ezeform may be needed for a resting hand splint.
- Custom fitted splints are often a better choice for function than pre-fab splints as they are often too bulky.
- Resting hand splints should not interfere with function and may not be needed if a good stretching program is utilized from the beginning.

Stretching/Passive Range of Motion or Self Range of Motion

- Very important component of the occupational therapy treatment. Emphasize importance to both patient and family to start early in disease process and perform daily.
- Purposes: 1. To prevent contractures (predominately in the shoulder and/or wrist/hand).
- 2. To decrease pain (from contracture, spasticity, cramping).
- 3. To facilitate and increase respiratory function (often overlooked).

Stretching

- Essential stretches listed below-Each stretch must be held 20-30 seconds at least three reps to be effective.
- Shoulder flexion- to prevent adhesive capsulitis and decrease pain
- Shoulder external rotation- to prevent adhesive capsulitis and decrease pain
- Horizontal abduction – to increase rib cage and clavicle mobility and thereby decrease diaphragm workload. Place a vertical towel roll behind upper spine to increase effectiveness.
- Forearm volar and dorsal compartment stretches- to prevent wrist hand contractures and to decrease painful cramping.

Shoulder Care/Subluxations

- Attention to sub-acromial space should begin early, and treatment should begin as soon as a gap is noted.
- Treatment options:
- 1. Shoulder sling- Least desirable not only because it promotes increased contracture but only because the neck and shoulder girdle muscles are often weakened and less able to support the weight of a sling. But sometimes this is the only workable option.
- 2. Kineseotape-Best option for patients with ambulatory mobility. Excellent family teaching however is essential because OT treatment is usually brief for ALS patients. YouTube has many excellent training videos to be used for family teaching.
- 3. Wheelchair arm trough/lap-tray with incline cushion. Best option for wheelchair bound patients.

Driving

- Many ALS patients may be reluctant to give up independence which driving provides and continue to drive well beyond what is reasonably considered safe.
- Broach the subject early to prepare the patient for future inability to continue to drive.
- Perform driving screening for right lower extremity reaction time and upper extremity simulation motion test for steering wheel control.
- Refer to a Certified Driving Specialist if you feel there is uncertainty whether the patient should be driving or if a adaptive equipment, such as a spinner knob, will keep a patient driving safely for a longer period.
- Consult with patient's physician if it is clear that the patient should not be driving.

Energy Conservation

Due to the nature of the disease, addressing this topic is crucial to optimizing function for the ALS patient. The weaker the patient becomes the more crucial energy conservation becomes.

In the movie, “Running for Jim”, one ALS patient states, “Everyday the disease takes something. Its not a lot. Its just enough for you to wish that you still had that little bit.”

Basic principles to apply

1. Prioritize each day what you truly want to accomplish each day. Save your energy for the activities which are truly meaningful to you.
2. Identify what is not important. Eliminate it or have someone else accomplish it.

Energy Conservation

- 3. Place rest breaks between each activity or within each activity between segments.
- 4. Rearrange your activity and your environment so that everything is close at hand to require the least energy consumption.
- 5. Realize that you only have so much energy available for each day. It is like a bank account in which only withdrawals are made.
- 6. Listen closely to your body. If your body tells you that you need a rest break, then you need a rest break.
- 7. Rule of thumb- If the activities of the day leave you tired the next day, then you have done too much and need to learn to scale back your activities.

Exercise and ALS

- The benefits of exercise for the ALS patient is controversial as only limited but somewhat contradictory results have been obtained from research studies. However, some general conclusions can be gleaned.
- Exercise in this sense refers to aerobic and resistance exercise. Stretching exercise is always beneficial irregardless of the stage of the disease.
- Once ALS has affected muscle group with atrophy and loss of strength, muscle tissue and strength is permanently lost and cannot be regained.
- For muscles which have not yet been affected, exercise holds the same benefits it does for anyone. Patients in the early stage of the disease process fit into this category. AROM exercises are more appropriate for middle and end stages of the disease process.

Exercise and ALS

- Exercise benefits muscle tone, cardio-pulmonary function, digestion and assimilation of nutrients, endurance level, mobility and psychological affect.
- Research has concluded in a cursory way that mild to moderate level of exercise are appropriate for maintaining function. Heavy levels of exercise are contraindicated.
- So how much is too much? This can vary considerably and must be assessed individually for each patient.
- This depends on the premorbid conditioning level of the patient. If pre-morbidly the person leads an active lifestyle, continuing a certain level of exercise is appropriate as long tolerated. Many ALS are pre-morbidly deconditioned. Thus activity level increases must be more modest.

Exercise and ALS

- The rule of thumb is if a certain level of exercise causes fatigue persisting into next day, the exercise program should be scaled back until that balance is achieved.
- The primary benefit of an exercise program is not increased strength but prolonged function. Generally, exercise will not prevent the progression of the disease.
- In a research study, it showed that the exercise group versus the non exercise group showed improvement in function at 3 months from the initiation. However, a six months both groups were equal.

Questions?

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