

# PHYSICAL THERAPY INTERVENTION WITH ALS

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Amyotrophic Lateral Sclerosis (ALS) provides a challenge to those physical therapists charged with the care and treatment of patients affected by this condition. Though the disease course may vary in its progression, body areas affected, and symptoms (spasticity vs. flaccidity), the trend is an inevitably downward one with the likelihood of severe disability preceding death. There are significant therapy interventions to benefit mobility, independence, safety, comfort, and quality of life throughout the course of care. Special attention must be made by the physical therapist to identify the skilled intervention provided and appropriate goals with awareness of the treatment setting from acute care, rehab, outpatient, home health or hospice.

It is helpful to begin with frank recognition of the terminal nature of ALS. Each person with this disease will die. Having that clearly in mind, we can then think in terms of what are the end goals that will be considered in the last weeks and months. Hospice care is appropriate at such a time and sets goals of:

- safe and comfortable dying
- self determined life closure
- effective grieving
- patient and family self care and independence
- maximize quality of life
- aggressive symptom management despite lack of cure

Understanding these goals must be the foundation on which all care is ultimately based.

## PRACTICE PATTERNS

The progressive decline in physical and functional status requires unique approaches to the practice patterns used for physical therapy. Beyond a traditional rehab approach which is likely to be of benefit in the very earliest stages of ALS, 'Rehabilitation in Reverse' is recognized as an appropriate treatment approach. If one can visualize the progressive impairment of motor strength which occurs with ALS, there are many opportunities when a physical therapist could intervene for gait and balance training with a cane, using AFOs, fitting and gait training with a walker, on levels, steps, and a variety of indoor and outdoor surfaces. A caregiver may also be instructed and trained to assist for safe ambulation. As ambulatory ability declines, a manual or power wheelchair will need to be properly fitted. Transfers become a more significant issue, initially needing only standby assistance, but over time progressing to moderate or maximal assistance, even completely dependent with the use of a mechanical lift. All of this patient and caregiver training is skilled physical therapy intervention, but it is

occurring in the reverse order for a traditional rehabilitation situation. New goals of safety, independence, and equipment use can be written at each new level of function. Depending on the rate of physical loss, the visit or treatment frequency for 'Rehabilitation in Reverse' will vary from several times in a week, to once a week, or even less often.

A second model of practice that becomes evident and necessary is 'Case Management' which is covered and recognized under the Medicare Home Health Benefit. This model is applicable for cases with co-morbidities and/or secondary diagnoses, where care is complex, and there may be multiple caregivers involved. Ongoing re-evaluation with instruction to the caregivers, modifying the care plan, and updating a home exercise and activity program are the skilled care provided by the therapist, even when direct patient treatment is not the focus of intervention. This model provides for optimal prevention of complications which might require hospitalization, knowledge and safety for the caregivers, and quality of life for the patient. Case Management visits might be scheduled once per 30 or 60 days, and are also opportunities to identify needs for short term direct intervention to solve new care issues.

A third model of care that can be considered is 'Skilled Maintenance,' another practice that is recognized under the Medicare Home Health Benefit, and can be used in the hospice environment as well. Some functional activities such as walking and transferring become impaired to the point where it is no longer safe for a caregiver to provide adequate assistance. At times the skill of a physical therapist may be sufficient to provide enough facilitation, assistance with balance and weight shift, and cuing to allow completion of the transfer or walking. While these efforts do not resolve the underlying condition and would otherwise be considered maintenance activities, the requisite skill required allows for intermittent performance as one part of the physical therapy program.

A fourth model is 'Supportive Care' which includes manual care such as massage, range of motion, joint mobilization, modalities, and instruction of caregivers in performance and follow through with these activities. Also part of Supportive care is the psycho-social-spiritual support that is ongoing throughout the entire course of care for people with ALS.

## GOALS

Goal setting is a continuously evolving process, due to the changing condition of the person with ALS. Short term goals may be revised weekly or monthly. Long term goals are more reflective of the eventual disabling nature of the disease, increased care needs, and end of life concerns which transcend the physical body.

### Short Term Goals (examples)

- Increase Strength by ½ grade
- Increase Range of Motion 10 degrees

- Decrease Pain by 2 on 10 scale
- Independent Gait with ....
- Assisted Gait with ...
- Independent Transfers to ....
- Assisted Transfers to ...
- Improved productive cough, vital capacity
- Independence with home exercise program

#### Long Term Goals (examples)

- Maximize Strength
- Maintain adequate Range of Motion for function, mobility, and care
- Minimize discomfort and pain
- Safe Bed Mobility with assistance as needed
- Safe Transfers with appropriate equipment and assistance as able
- Safe Ambulation with appropriate equipment and assistance as able
- Maximize respiratory function
- Adequate pressure relief in sitting and lying positions
- Knowledge of an appropriate level home exercise program as desired
- Caregivers are knowledgeable and safe assisting with functional mobility

## EXERCISE

The role of exercise is important to consider. Recent studies have shown that limited and targeted exercises can help maximize and preserve strength during the decline and loss of strength, although some consider just the strenuous nature of normal activity to be sufficient. Ultimately the person with ALS can choose which provides the best sense of control and quality of life. Neither excessive repetition nor heavy resistance is recommended so as not to cause further motor impairment. A modest home exercise program can be designed for the person who desires one and can thus maximize their strength through a declining course. In later stages a passive range of motion program is essential to prevent contractures that might limit the caregiver's ability to provide assistance (plantar flexion for weight bearing during transfers) or personal care (hip or shoulder adduction to allow bathing access). More specific range of motion along with joint mobilization techniques can help manage the painful joints that can occur as a secondary condition from immobility. Caregivers can be instructed in these specific activities depending on their capability and availability.

## TREATMENT ISSUES

A number of unique treatment issues arise in the course of care for a person with ALS. This section will outline specific interventions that may be applicable.

Maximizing surface heights for transfers becomes essential so as to allow the use of efficient body mechanics as strength wanes. Inversely, carefully lowering the height of assistive devices for ambulation can conserve energy and prolong mobility through the use of more extension in the upper extremities, and thus less energy costs.

Primary upper extremity involvement affecting one or both limbs may severely limit the use of assistive devices for ambulation.

Positioning for comfort becomes extremely difficult with a person who lacks any significant motor function yet retains full sensation. All of those small motions we make as we settle into bed at night, allow us to relax and decrease stimulus to our bodies as we try to fall asleep. The ALS person cannot move in such ways and is likely also limited in communication which compounds this task for a caregiver. The eyes, knowledge, and hands of the physical therapist can be essential tools in training family caregivers in the nuances of positioning.

Positioning to assist breathing is also essential. Relieving the resistance to diaphragmatic contraction can be achieved by elevating the head of the bed. Along with elevation, the patient must be positioned such that the hips are aligned with angle of the bed. If the person has slid down in bed, the flexion of the trunk will obstruct the respiratory pattern. Elevation of the lower end of the bed as well will minimize this sliding from occurring.

Other respiratory care issues include maximizing breathing capacity and strength, use of various breath techniques, coughing, and clearing of secretions.

Pressure relief both in sitting and in bed become significant issues. Again, the knowledge and experience of the therapist can provide caregivers the best seating system or mattress surfaces (foam vs. alternating pressure vs. low air loss) for comfort and mobility.

Massage is often useful for inhibition of spasticity, and to provide pain relief and comfort. Caregivers can be taught appropriate massage techniques to perform to ease discomfort by providing a normal stimulus and enhance quality of life.

## EQUIPMENT

Adaptive equipment and aids are essential to be considered. A partial list of possible equipment includes:

Cane: Standard, Small or Large Based Quad, Hemi  
Walker: Pick-up, Front Wheeled, or 4 Wheeled  
Crutches: Axillary or Lofstrand  
Ankle Foot Orthoses  
Sliding Board

Floor to Ceiling Pole  
Commode: Standard, Drop Arm  
Wheelchair: Manual, Transport, Recliner, Power  
Cushion/Seating System  
Lap board  
Bath Seat: Bench/Chair, Tub Transfer, Rolling Shower Chair  
Electric Lift Chair  
Electric Hospital Bed  
Mattress: Foam, Alternating Pressure, Low Air Loss  
Mechanical Lift  
Head/Neck supports/collars  
Slings, Splints

## PSYCHOLOGICAL, SOCIAL, SPIRITUAL ISSUES

The psychological, social, and spiritual dimensions of care must always be considered by the therapist, along with the physical care. Having the support of an interdisciplinary team common to palliative care and hospice programs can assist in addressing these issues. Because the physical losses are often recognized by the physical therapist (changing strength levels which preclude an activity or no further adaptation being possible) the questions around loss and meaning of life are often first confided and heard during a therapy treatment session. Being able to listen and offer support with sensitivity becomes paramount in the persons ability to continue the struggle of both living and letting go of life at the same time. At times the therapist can be helpful in 'giving permission' to let go of activity that is no longer physically possible. Education about the disease process in relation to function and physical changes from ALS, a co-morbid, or a secondary condition is often helpful as the knowledge allows for an increased sense of control. Re-framing activity around maximal effort and performance, as well as exploring the dimensions of self beyond the physical body are also useful in coping with these changes. The physical therapist, often seen by the patient and family as a source of hope, can gently broach these issues when appropriate during the course of care.

### THE ESSENTIALS:

- Physical therapy has an important role in management of ALS at any stage.
- The physical therapist needs to understand the various stages of decline and different practice patterns to provide and document appropriate care.
- Communication with the patient and family caregivers provides direction and choices about the interventions they want.
- Identify unique treatment and adaptive equipments issues.

- Education of patient and caregiver are essential through the course of care.
- Psychological, social and spiritual issues must be considered and addressed.

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