

In the name of god

The Role of Occupational Therapy with the ALS patient

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What is ALS?

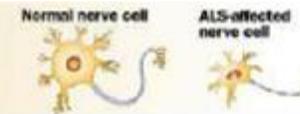
ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's disease, is a fatal disease of the nervous system, characterized by progressive muscle weakness resulting in paralysis.

What are motor neurons?

Motor neurons are nerve cells in the brain and spinal cord that attach to muscles and control voluntary movement.

How does ALS progress?

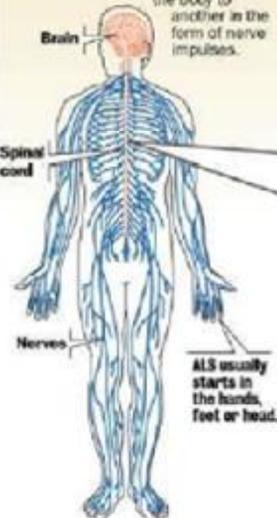
When motor neurons gradually degenerate and die, the muscles no longer receive nerve impulses. As a result of the nerve death, the muscles shrink and waste away.



A closer look at a healthy nervous system

Nervous system

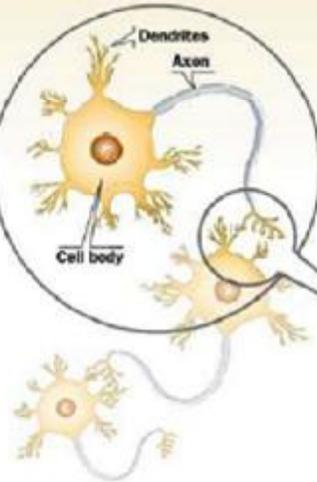
The basic unit of the nervous system is a highly specialized cell, known as a neuron. Its main purpose is to transport messages from one part of the body to another in the form of nerve impulses.



Motor neuron

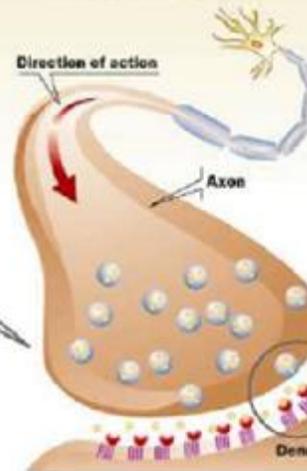
A motor neuron is made up of three main functional parts.

- **Cell body:** biosynthetic center of the cell
- **Axon:** responsible for sending messages
- **Dendrites:** responsible for receiving messages



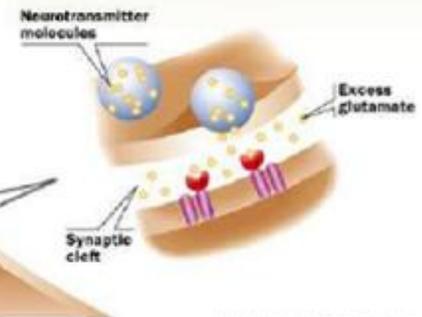
Nerve impulse

A nerve impulse is transmitted when the terminal fibers of one neuron's axon release chemicals called neurotransmitters that attach to dendrites of the receptor neurons.



A possible cause of ALS: Too much glutamate

Scientists aren't sure what causes ALS, but glutamate poisoning is a popular theory. Glutamate is an amino acid that acts as a neurotransmitter, allowing motor neurons to "talk" to one another. After transmitting a message, glutamate is supposed to be vacuumed up by a cell membrane protein. But researchers at Johns Hopkins University in Baltimore suggest people with ALS don't have enough of that protein. Over time, glutamate dogs the synaptic cleft, the space between nerve endings, and chokes motor neurons to death. The drug Riluzole slows the body's production of glutamate and keeps ALS patients alive for an extra two to three months.



Source: Toxicology/Minnesota Times

Motor Neuron Disease

Terminology

Lower motor neuron  Upper motor neuron

This process involves destruction of motor neurons in spinal cord, brain stem and motor cortex. There're both combination of UMN and LMN deficits

Progressive
Muscular
Atrophy

Amyotrophic
Lateral Sclerosis

Primary Lateral
Sclerosis

There are multiple theories regarding the cause of ALS:

- ◆ metabolic disorders of glutamate insufficiency
- ◆ metal toxicity
- ◆ autoimmune factors
- ◆ genetic factors
- ◆ viral infection

Degeneration and death of motor nerves

◆ Upper Motor Neuron

– within brain/spinal cord

- Spasticity, hyperreflexia, weakness

◆ Lower Motor Neurons

– leaves brain (stem)/spinal cord

- Weakness, muscle wasting, hyporeflexia, muscle cramps, fasciculations

◆ Bulbar

-corticobulbar

- Dysarthrititis and dysphagia and weakness of facial and tongue muscles

Amyotrophic Lateral Sclerosis Pathology

Epidemiology

- ◆ Etiology – unknown
- ◆ Average age of onset mid-50's
- ◆ Mode of transmission
 - Sporadic – 90-95%
 - Familial – 5-10% (autosomal dominant)

Amyotrophic Lateral Sclerosis Pathology

Epidemiology

- ◆ Male : Female – 3:2
- ◆ U.S. Prevalence: 30,000
- ◆ Incidence 1-2.5 / 100,000

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.

Need to correctly identify the functional stage of the ALS patient

- § 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).

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.
- § 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.

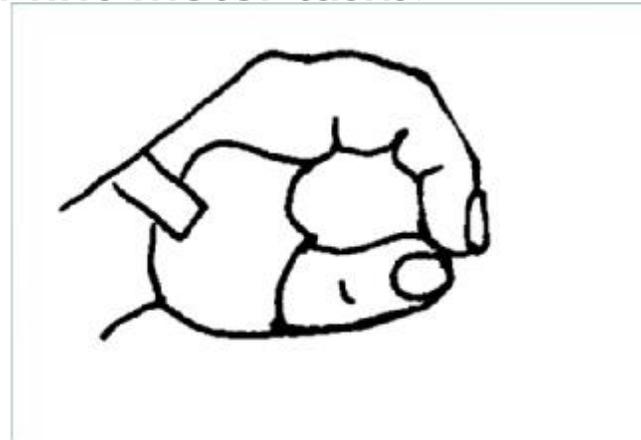


- Computer use adaptive equipment- voice activated/eye gaze technology, use of stylus to operate computer keyboard.
- Cell phone use- Use of stylus to press keys. Fabrication of orthoplast cell phone cuff to compensate for decreased grip strength.
- Be creative. Many problems can be solved with ingenuity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



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



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



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



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 prefab 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

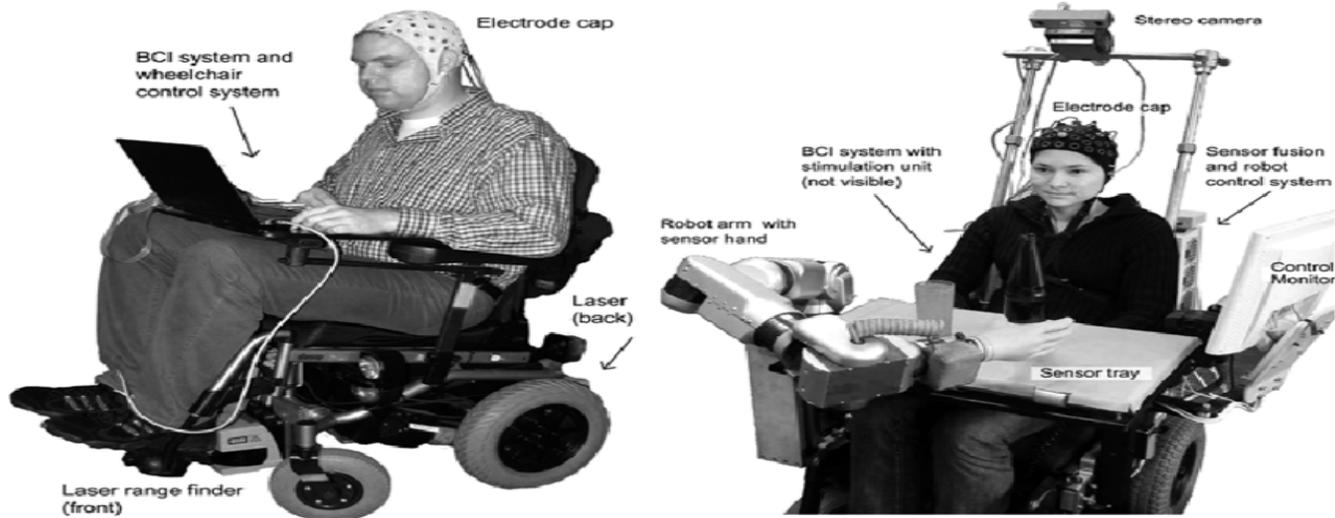
- Attention to sub-acromial space should begin early, and treatment should begin as soon as a gap is noted.
- Treatment options:
 1. Shoulder sling- Least desirable not only because it promotes increased contracture but only because the neck and shoulder girdle muscles are often weakened and less able to support the weight of a sling. But sometimes this is the only workable option.



2. Kinesiotape-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.

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.

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 regardless 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 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.
- This depends on the premorbid conditioning level of the patient. If premorbidly 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.

- The primary benefit of an exercise program is not increased strength but prolonged function. Generally, exercise will not prevent the progression of the disease.

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Parkinson's Disease

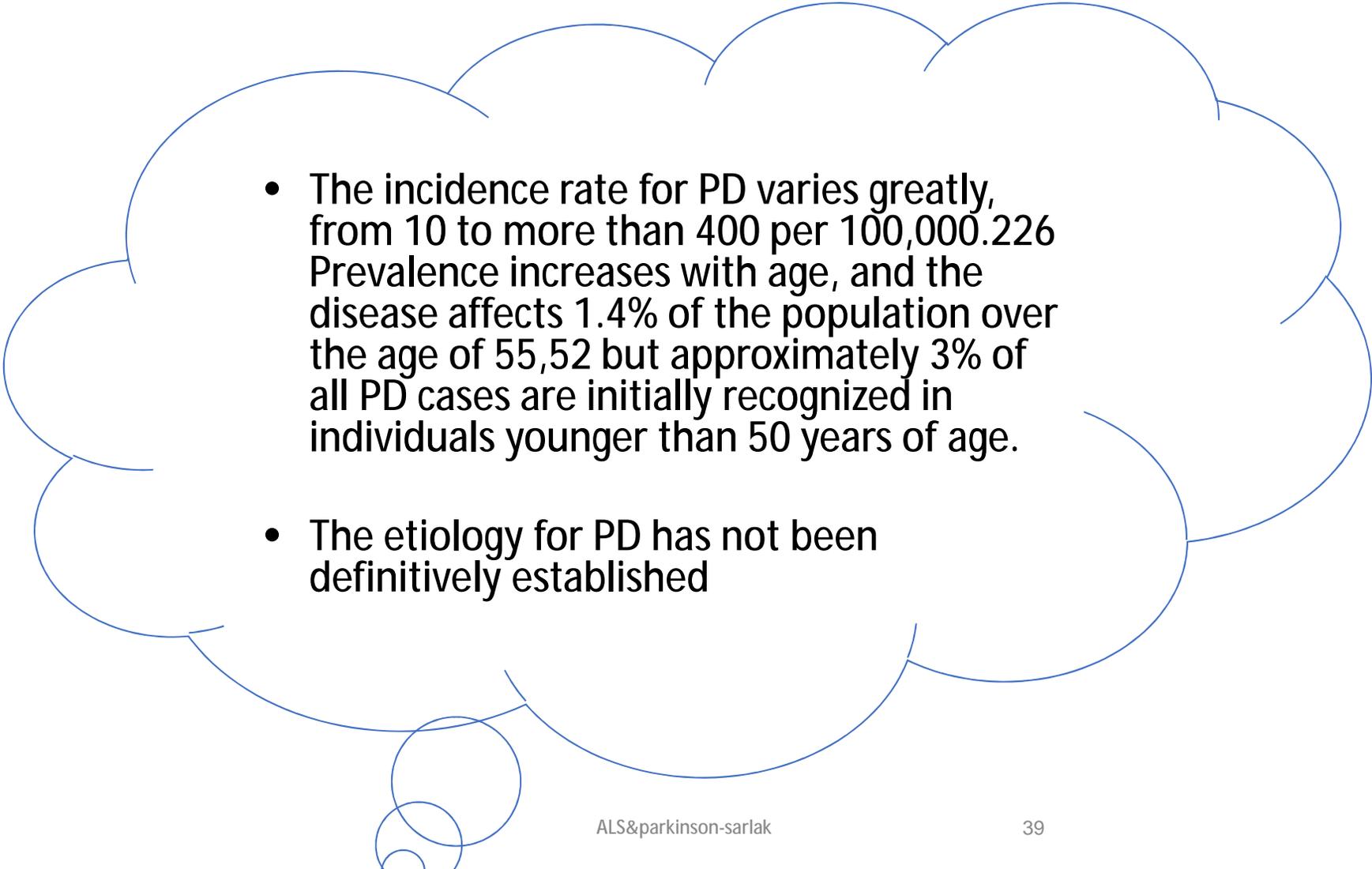
OVERVIEW OF PARKINSON'S

- § Chronic Neurodegenerative disorder
- § 2nd most common movement disorder
- § Onset – typically 55-60 y.o.
- § Cell death occurs causing movement Impairment

Nobody knows why people gets the disease – it is an idiopathic disease



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- The incidence rate for PD varies greatly, from 10 to more than 400 per 100,000.²²⁶ Prevalence increases with age, and the disease affects 1.4% of the population over the age of 55,52 but approximately 3% of all PD cases are initially recognized in individuals younger than 50 years of age.
 - The etiology for PD has not been definitively established

MOVEMENT IMPAIRMENTS



TRAP

- Tremor – resting
- Rigidity
- Akinesia – difficulty with movement
- § Bradykinesia
- § Hypokinesia
- § Shuffling Gait
- Postural instability
- Impaired aerobic capacity

ADDITIONAL SIGNS AND SYMPTOMS

- ! Decreased:
 - § Quality of Life
 - § Function
 - § Mobility
 - § Safety
- ! Emotional & Cognitive problems
- ! Sleep disorders
- ! Fatigue
- ! Depression

People with Parkinson's disease can live many years before symptoms gets severe



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Diagnosis:

- EMG+NCV+MRI+X-ray
 - +blood and urine studies, including high resolution serum protein electrophoresis
 - +thyroid and parathyroid hormone levels
 - +24-hour urine collection to assess for heavy metals
 - +muscle or nerve biopsy

ROLE OF THE OCCUPATIONAL THERAPIST

- Occupational therapy services vary depending on the client's stage of PD .Typically an OT program would provide compensatory strategies, client and family education, environmental and task modifications, and community involvement.

Progression of Symptoms in Parkinson's Disease

Stage	Symptoms	Occupational Therapy Management
I	Unilateral tremor, micrographia, poor endurance for previous occupations, fatigue	Work evaluation if the client is employed; work simplification for work and home settings; develop the habit of taking frequent rest breaks; use of utensils with enlarged handles
II	Bilateral motor disturbances, mild rigidity reported, difficulties with simultaneous tasks, difficulties with executive function	Energy conservation techniques related to ADLs; develop daily flexibility exercises focused on trunk rotation; driving assessment and alternatives for community mobility; use of task analysis to structure sequential tasks
III	Balance problems with delayed reactions, difficulties in skilled sequential tasks	Environmental modifications in the home, including raised toilet seats, chairs with armrests, removal of throw rugs; use of visual cues and supports for sequential tasks
IV	Fine motor control severely compromised, oral motor deficits	Modifications to support participation in self-care tasks, changes in food textures
V	Client severely compromised motorically, dependent with ADLs	Use of environmental controls to allow access to the environment

ADLs, activities of daily living.





**initial
stages**

- During the initial stages of the disease, the occupational therapist should develop an occupational profile with the client and significant others to establish intervention priorities.
- Clients have expressed the desire to retain a **sense of self** and **normalcy** within their family, even in the face of deteriorating abilities. The focus of intervention is developing the **habits** and **routines** to foster participation in desired occupations as the disease process progresses.





Educating the client and significant others regarding the course of the disease is an important step in this process, one that aids in the selection of occupations.

- During the early stages of the disease, the client and family should be informed of **community resources** and **support groups**.
- clients with PD were found to be far more dependent on others for **personal care** and **household activities** than were same-age peers without PD.
- This **dependence** can place additional stress on the family.
- Involvement in a community-based group may provide the support needed to accommodate the changes in family roles and interaction.



Modification of household items may decrease the impact of tremors during the initial stage of the disease process. Built-up handles for eating and writing utensils should be introduced during the initial stages of PD.



- Handwriting often becomes small and difficult to read during the initial stage of PD. Time management techniques should be introduced at this stage.
Paying bills, signing forms, or doing other written work should be completed soon after taking levodopa, using utensils with built-up handles. Even though tremors are not severe during the early stages of PD, clothing fasteners should be modified.



The use of slip-on shoes or Velcro closures for clothing should be considered at this time. Although a client may be able to fasten clothing during this stage of PD, the occupational therapist must consider the amount of energy and time needed to perform such a task.



- In addition to the modification of specific tasks, household changes should be made at this time. Loose rugs should be removed from floors and furniture placed close to the wall to decrease obstacles. Chairs should have **armrests** to allow the client to push up from the chair to stand. Although balance is not significantly compromised during the early stages of PD, the family and client should become familiar with the new arrangement of furniture before this becomes a necessity.

- Bath and toilet railings and a raised toilet seat should be provided within the home. Because **fatigue** is a common complaint, clients should develop the habit of taking frequent breaks during the day. Modifying the household setting early in the course of PD allows the client and family members to adjust to changes and incorporate these changes into daily routines before they become a necessity.



- A work evaluation should be performed during the early stage of the disease process to assess safety risks, potential hazards, and work simplification techniques that could be used.
- An ergonomic assessment of the work site and modifications to the tools would be appropriate.
- A client may have the option of reducing the number of work hours, but that decision may reduce medical benefits. These decisions and available options are part of the OT intervention process during the early stage of the disease.

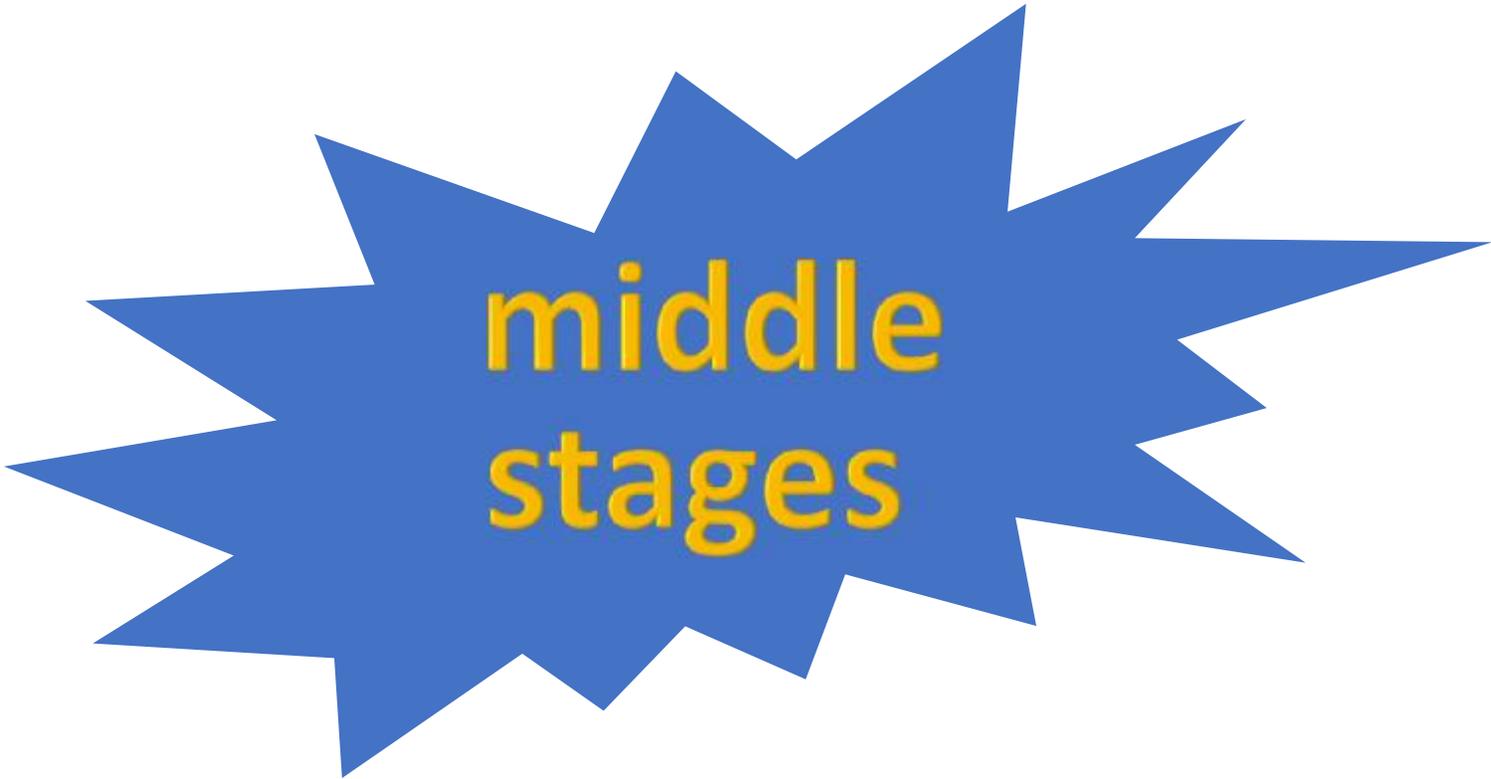
- During the initial stage of PD, the occupational therapist should establish a daily exercise program addressing full range of motion.
- It is preferable to have a client with PD perform a short exercise program for 5 to 10 minutes daily rather than a longer program three times a week.
- Exercises should include alternating movements from various planes, as many clients with PD display difficulties with smooth shifting of movements.

- **Postural flexibility exercises** should be included in the program, with specific attention given to trunk extension.
- The most common postural change noted with the progression of PD is a **stooped posture**.
- In addition to the flexibility exercises, occupational therapists should instruct clients in the use of **relaxation techniques** and **controlled breathing**.

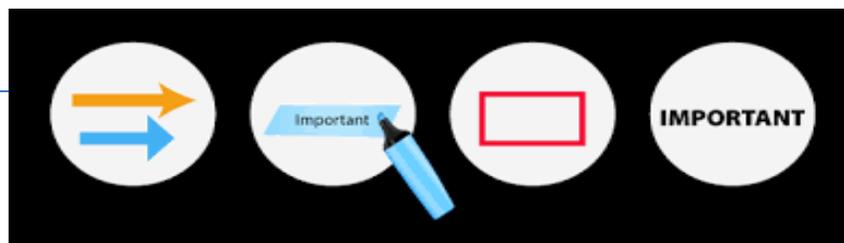


- Inhaling slowly through the nose and exhaling through pursed lips two or three times in succession, combined with improved postural alignment, can promote relaxation.

- As the disease progresses, additional exercises can improve gait.
- **Rhythmic auditory stimulation** in the form of music with an accentuated initial beat has been found to significantly improve stride length and speed in clients with PD.
- **Dancing** can also enhance gait patterns, in addition to providing a social environment for the client with PD.
- As akinesia becomes more apparent, the client with PD should be instructed to use a **rocking motion** to begin movement activities.
- Rocking forward and backward a few times while seated can produce the momentum needed to rise from a chair.



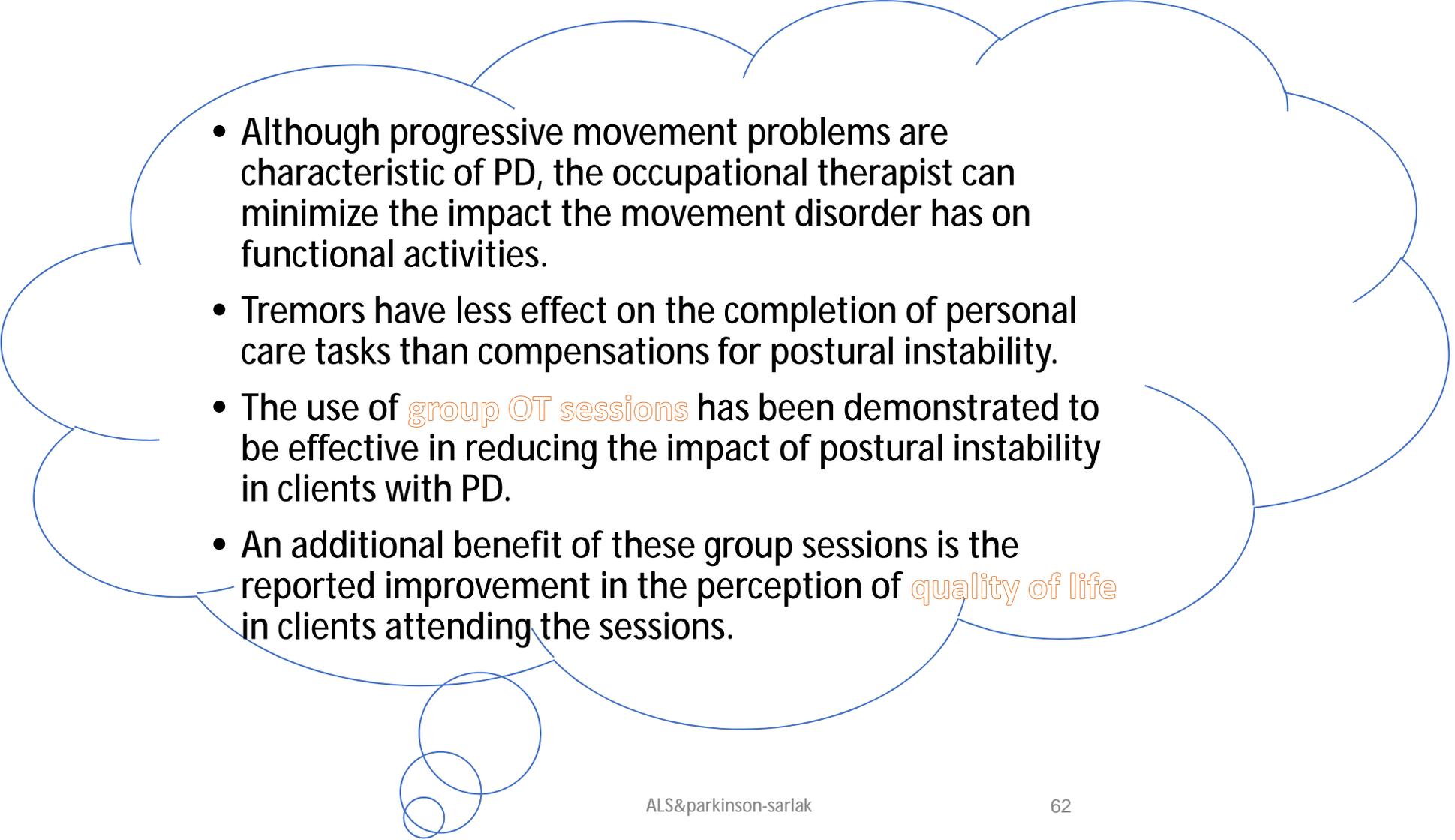
**middle
stages**



- As a person with PD progresses to the **middle stages** of the disease, the client experiences further deterioration of motor skills particularly the execution of skilled sequential movements. These types of movements are needed to complete personal care and household tasks.
- **external cues** improved the speed and sequential performance of novel motor tasks.
- The occupational therapist should suggest modifying activities to include **visual cues, verbal prompts, and rehearsal of movements.**
- These strategies increase a client's ability to perform personal care and household activities.

- During the middle stages of PD, clients may have decreased oral motor control.
- Dysphagia and drooling may embarrass them and further restrict social engagements.
- The occupational therapist should encourage oral motor exercises and provide education regarding food selection.
- Food consistencies can be altered to improve the client's ability to eat.

The ability to complete personal care tasks has been identified as a critical variable in a client's perception of quality of life.

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- Although progressive movement problems are characteristic of PD, the occupational therapist can minimize the impact the movement disorder has on functional activities.
 - Tremors have less effect on the completion of personal care tasks than compensations for postural instability.
 - The use of **group OT sessions** has been demonstrated to be effective in reducing the impact of postural instability in clients with PD.
 - An additional benefit of these group sessions is the reported improvement in the perception of **quality of life** in clients attending the sessions.

- Access to community mobility and support programs should be included in the OT intervention plan during the middle stages of PD.
- A client with PD is often dependent on others for transportation.
- The use of community mobility services can decrease the client's dependence on family members for shopping and errands.



**last
stages**

- During the last stages of PD, movement disorders and rigidity may eliminate the client's ability to perform personal care tasks such as dressing and grooming.
- Depression caused by the decreased ability to perform these tasks can significantly compromise a person's quality of life.
- OT services should be provided to further modify the home environment for **access** and **control**.

- The use of environmental control units, such as a switch-operated television or radio, can be helpful.
- The switch plate should be activated with only light touch. Voice-or sound activated environmental control units may not be as useful because of decreased vocal volume and poor articulation control during speech production.
- The client's ability to control the immediate environment can compensate for the losses experienced during the final stages of PD.
- The client may no longer be able to dress himself or herself, but through the use of various switches the client can select preferred television or radio programs, control room lighting, and operate a computer by using minimal motor action.

Questions?