AGING: AN OVERVIEW OF DIAGNOSIS, SYMPTOMS AND FUNCTIONAL TREATMENT OPTIONS FOR ALS AND PARKINSON'S GUIDELINES FOR CAREGIVERS

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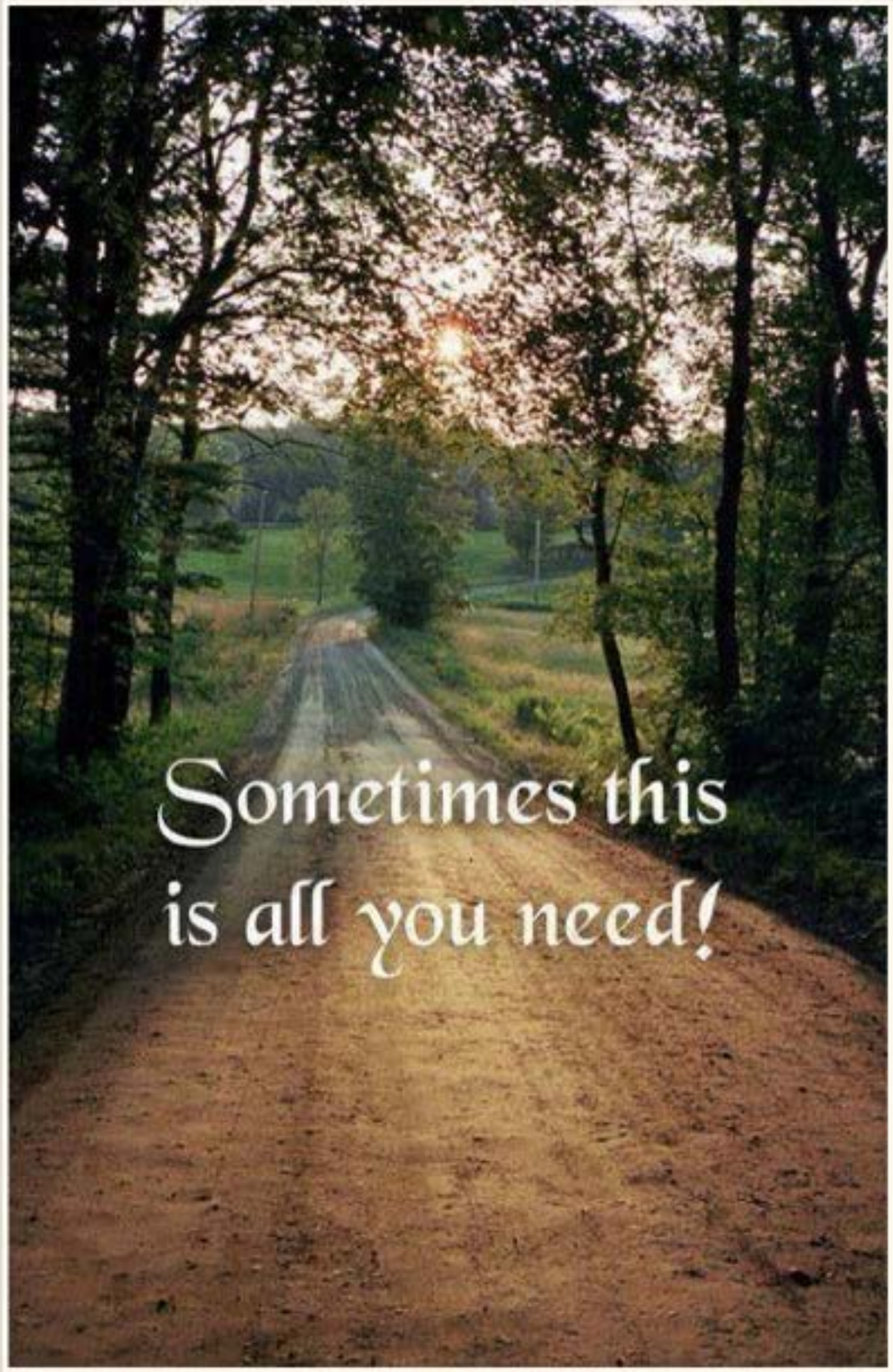
OBJECTIVES

- Participants will be able to discuss the diagnostic definition and aging characteristics for ALS and Parkinson’s Disease.

- Participants will be able to discuss three symptoms affecting function for ALS and Parkinson’s Disease.

- Participants will be able to discuss functional treatment options for ALS and Parkinson’s Disease.

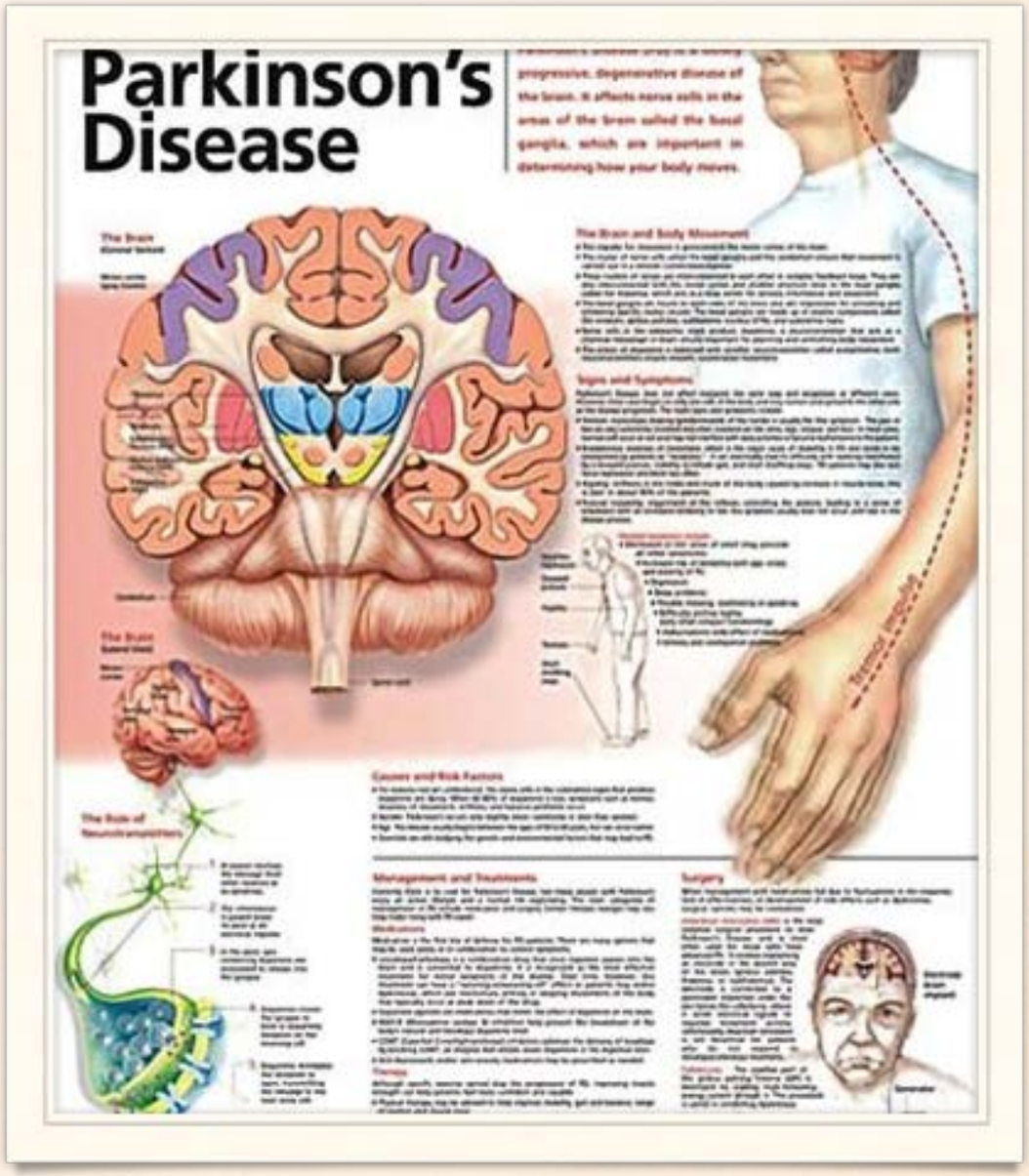

Sometimes this
is all you need!

PARKINSON'S DISEASE (PD)

- A chronic and progressive movement disorder

- Malfunction and death of nerve cells in the brain: neurons, substantia nigra

- Dopamine, decreases as the disease progresses affecting movement and coordination



DIAGNOSIS OF PD

- No blood or laboratory tests that diagnose PD
- Diagnosis is based on reviewing medical history and a neurological examination
- Typical age of onset is 60 years of age
- Four primary symptoms of PD; tremors, rigidity, bradykinesia, and postural instability
- Symptoms typically begin on one side of the body

- Loved ones are usually the first to report symptoms such as slow movement or a masked face

- Other symptoms or affects of PD included depression, difficulty with chewing and swallowing, difficulty with speech, urinary issues, constipation, skin problems, cognitive issues, dementia, dystonia, fatigue and pain

- There are other diseases that produce PD like symptoms and there have been studies linking to the effects of environmental exposure

PD SCALES

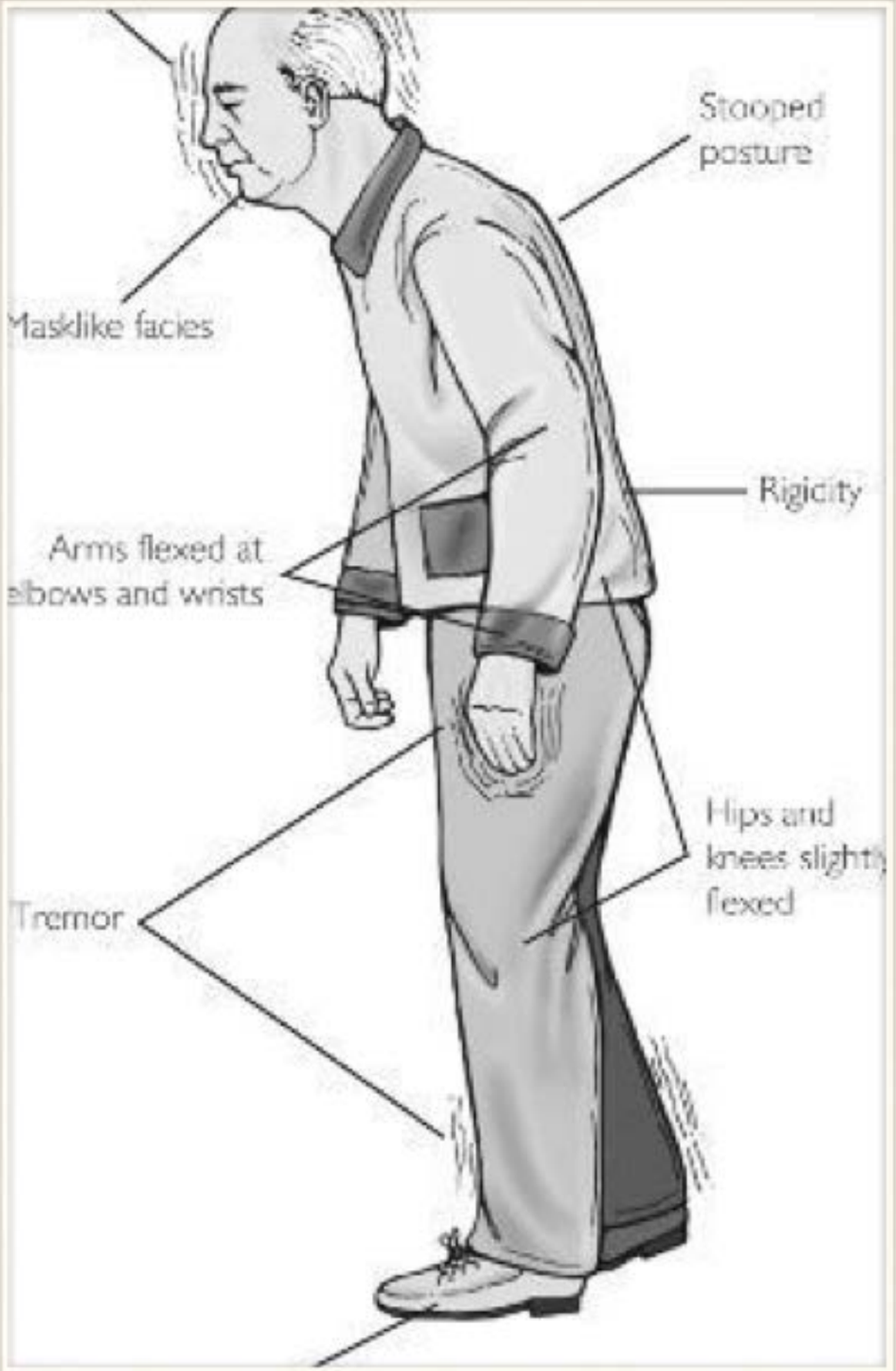
- Neurologist use two scales in the description of the progression of PD; the Hoehn & Yahr scale and the Movement Disorders Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)

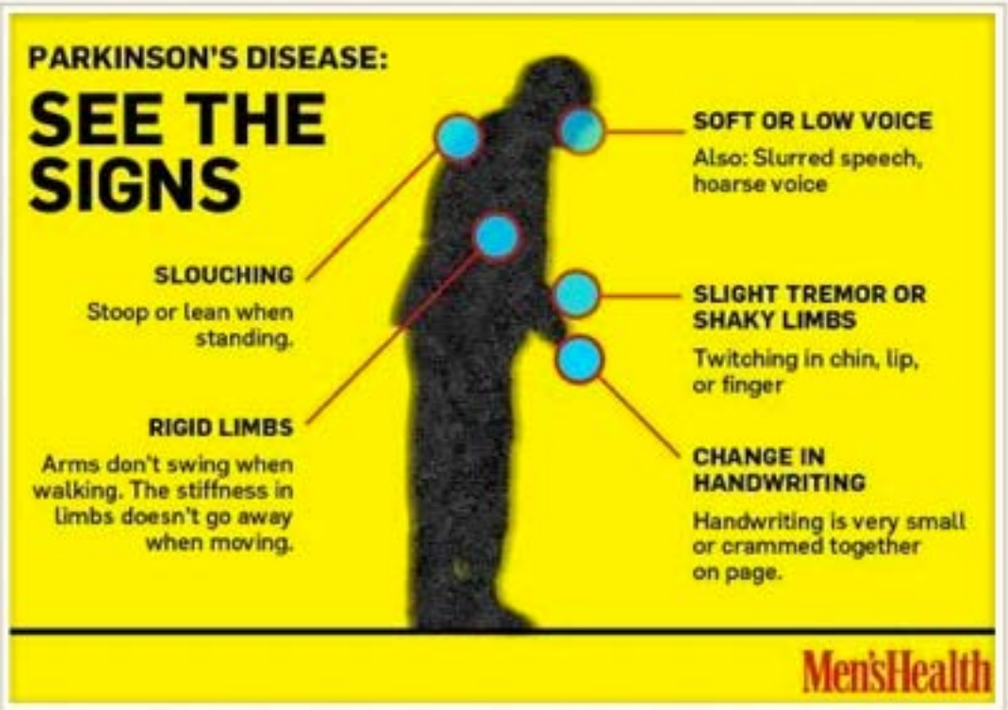
- The Hoehan & Yahr scale stages the progression of PD using a five scale system

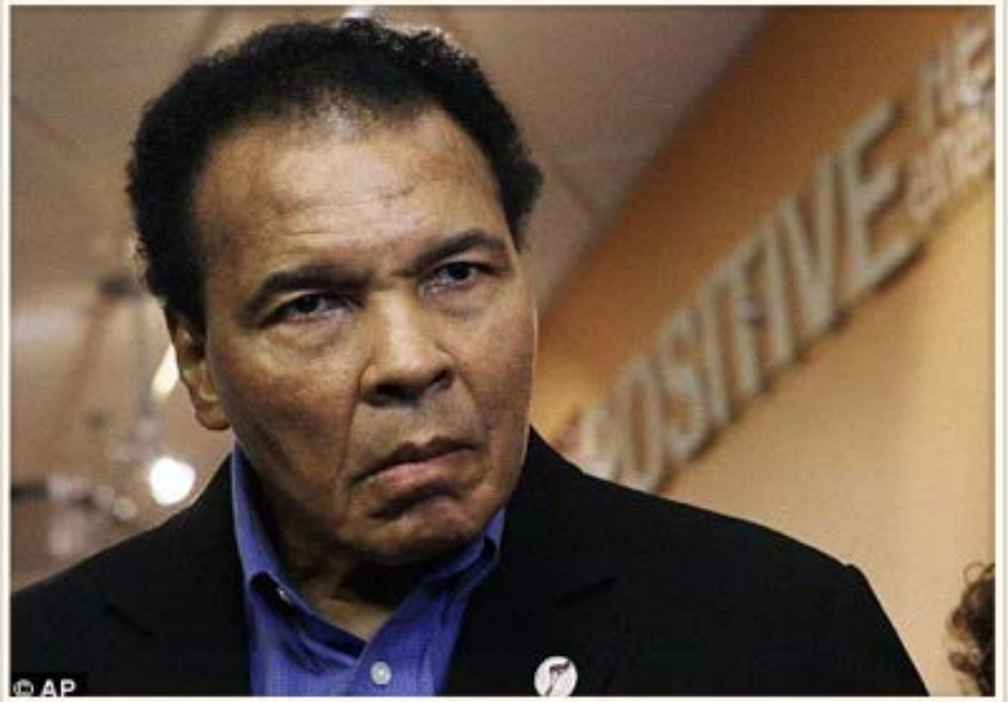
Annex 1. Scale of Hoehn & Yahr staging (1967), modified[10].

Name: _____ I: _____
Neurologist: _____
Date: ___/___/____

STAGES	SIGNS
Stage 0	No disease sign.
Stage 1	Unilateral disease.
Stage 1.5	More axial unilateral access.
Stage 2	Bilateral disease, without an access to postural reflexes.
Stage 2.5	Slight bilateral disease, with a recovery in postural reflex tests.
Stage 3	Bilateral disease from slight to moderated. There is a postural instability, regardless of daily activities.
Stage 4	High degree of inability; they can still walk or stand up with help.
Stage 5	Restricted to a bed or a wheel chair, unless they are helped.


Stooped posture
Masklike facies
Rigidity
Arms flexed at elbows and wrists
Hips and knees slightly flexed
Tremor


PARKINSON'S DISEASE:
SEE THE SIGNS
SOFT OR LOW VOICE
Also: Slurred speech, hoarse voice
SLOUCHING
Stoop or lean when standing.
SLIGHT TREMOR OR SHAKY LIMBS
Twitching in chin, lip, or finger
RIGID LIMBS
Arms don't swing when walking. The stiffness in limbs doesn't go away when moving.
CHANGE IN HANDWRITING
Handwriting is very small or crammed together on page.
MensHealth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CONNECTION WITH AGING

- “While PD is a chronic progressive disorder, the most important determinant of clinical progression is advancing age rather than disease duration.” Levy, G. (2007)

- “…aging may be critical for PD” Rodriguez et. al (2015)

- “…the incidence of postural and gait disorders increased significantly with aging.” Nagaynama et. al (2000)

FUNCTIONAL TREATMENT

- LSVT BIG AND LSVT LOUD
- Boxing
- Dancing
- Occupational, Physical and Speech Therapy

LSVT LOUD

- LSVT LOUD improves both the voice and speech of individuals with Parkinson disease by treating the underlying physical pathology associated with disordered voice.
- Treatment focuses on improving vocal loudness and immediate carryover into daily communication enabling patients to maintain and/or improve their oral communication.
- The LSVT LOUD is administered on an intensive schedule of 16 individual, 60-minutes sessions in one month’s time.

LSVT BIG

- LSVT BIG improves amplitude of limb and body movement which leads to improvement in balance, gait and function

- LSVT BIG is administered in 16 sessions over a single month (four individual 60 minute sessions per week)

ROCK STEADY BOXING

- Rock Steady is a non profit that trains facilitators to deliver this program-with fundraising, free of charge in most communities

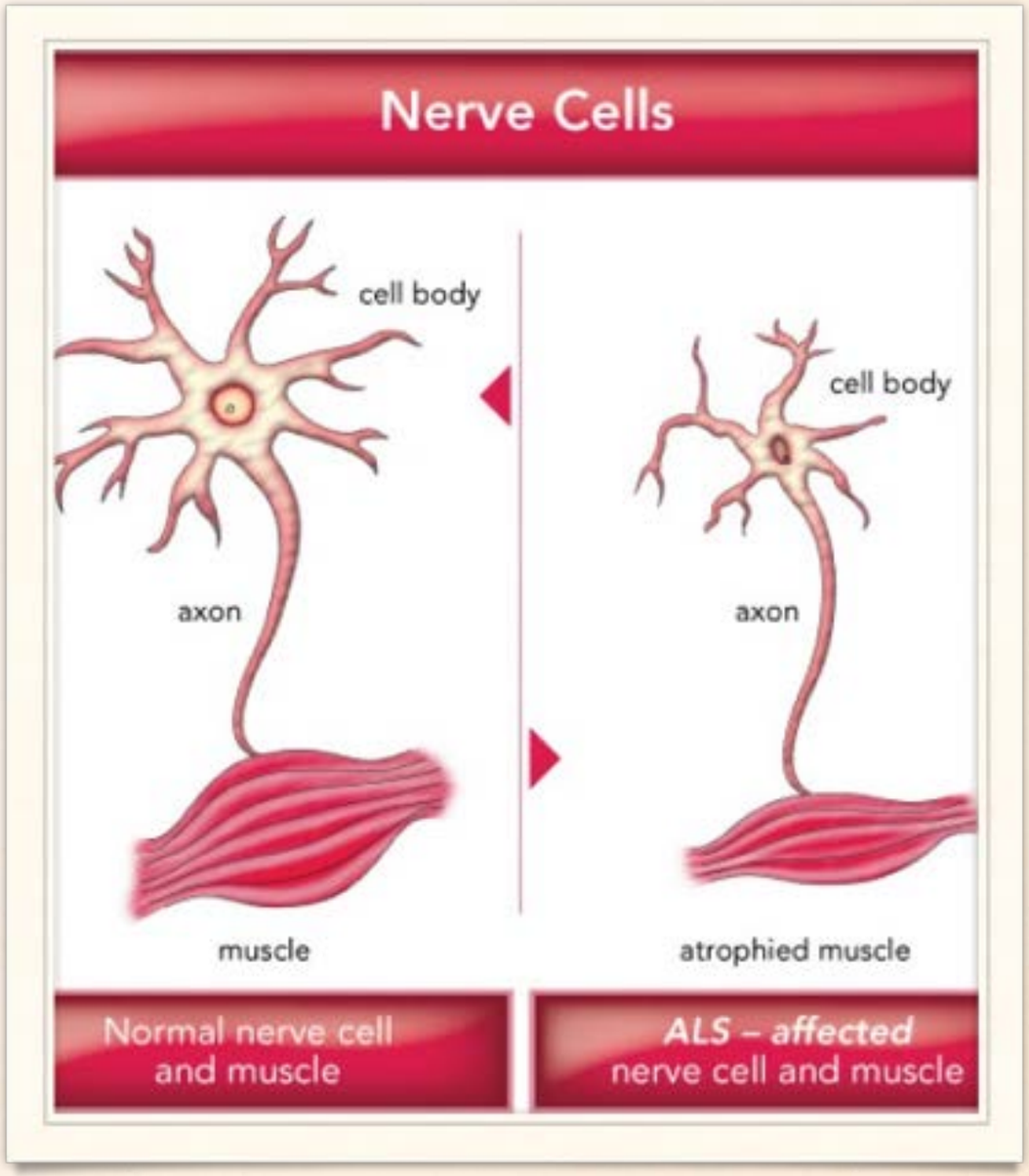
- Exercises are adapted from boxing drills and focus on speed, endurance, accuracy, eye-hand coordination, footwork and overall strength

DANCING

- Research has shown that dance improves gait, balance and quality of life
- Although more research is needed, it is noted that those with mild to moderate Parkinson's that follow this 'exercise program" longterm, benefit from dance

ALS

- ALS is a rare group of neurological diseases that target neurons responsible for voluntary movement
- There is no cure
- Rituzole is the only drug available for ALS which can extend life by a few months and in some cases slow the progression of the disease



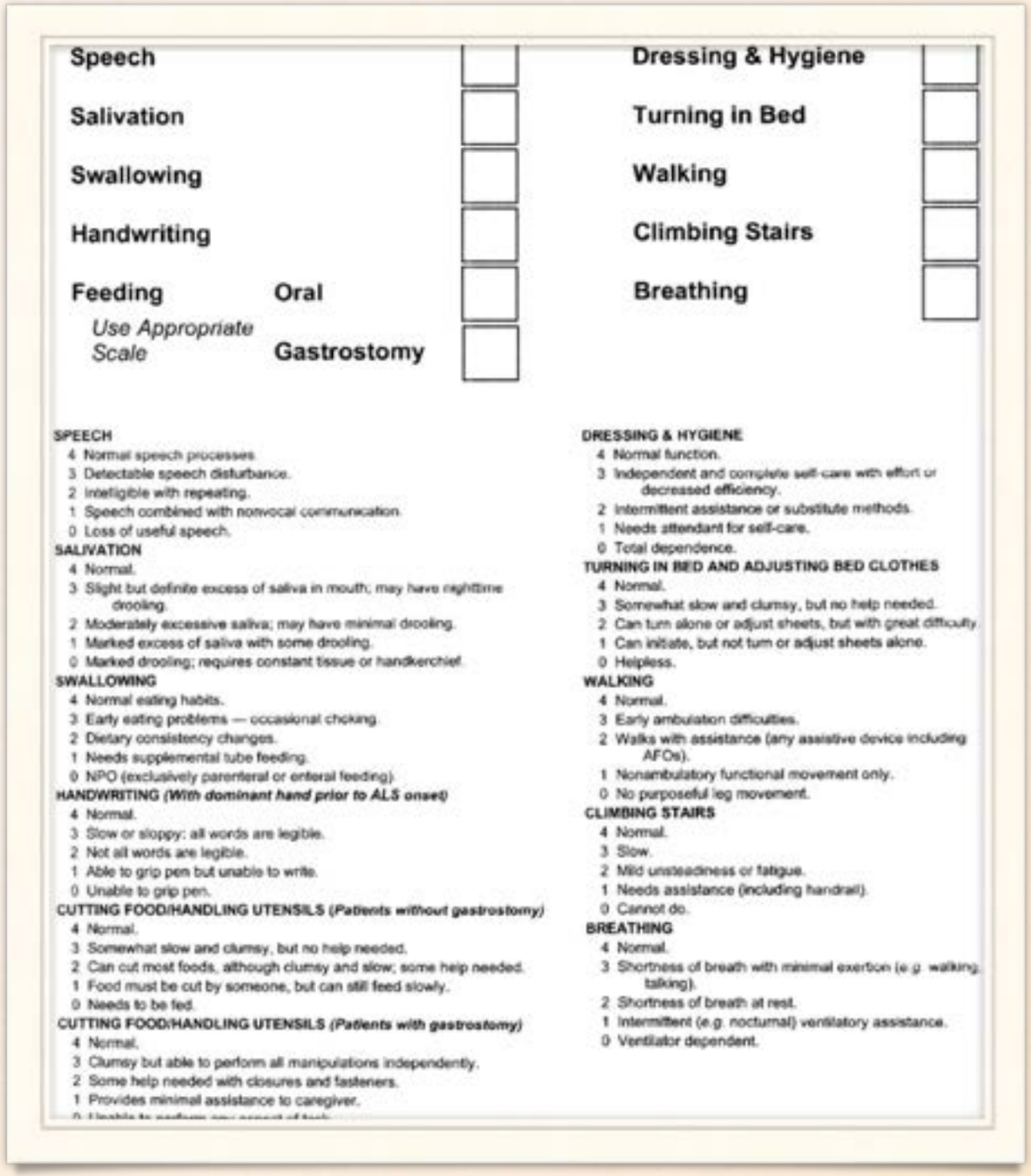
DIAGNOSIS OF ALS

- No one test exists to diagnosis ALS, a physical exam and tests ruling out other diseases and the presence of upper and lower motor neuron involvement suggests ALS
- Typical age of onset is 55-75 years of age
- Primary symptoms include fasciculations, muscle cramps, spasticity, weakness, slurred or nasal speech and difficulty chewing or swallowing

- Sporadic verses familial
- Limb onset verses Bulbar onset
- Respiratory decline is the primary cause of death
- Life expectancy averages 2 years, however 10% of those diagnosed with ALS live 10 years

ALS SCALES

- A measuring tool of the functional status for those living with ALS
- Used to measure change in function as the disease progresses
- Shows agreement with measurements of strength and pulmonary function



Speech			Dressing & Hygiene	
Salivation			Turning in Bed	
Swallowing			Walking	
Handwriting			Climbing Stairs	
Feeding	Oral		Breathing	
Use Appropriate Scale	Gastrostomy			

SPEECH
4 Normal speech processes.
3 Detectable speech disturbance.
2 Intelligible with repeating.
1 Speech combined with nonvocal communication.
0 Loss of useful speech.

SALIVATION
4 Normal.
3 Slight but definite excess of saliva in mouth; may have nighttime drooling.
2 Moderately excessive saliva; may have minimal drooling.
1 Marked excess of saliva with some drooling.
0 Marked drooling; requires constant tissue or handkerchief.

SWALLOWING
4 Normal eating habits.
3 Early eating problems — occasional choking.
2 Dietary consistency changes.
1 Needs supplemental tube feeding.
0 NPO (exclusively parenteral or enteral feeding).

HANDWRITING ***(With dominant hand prior to ALS onset)***
4 Normal.
3 Slow or sloppy; all words are legible.
2 Not all words are legible.
1 Able to grip pen but unable to write.
0 Unable to grip pen.

CUTTING FOOD/HANDLING UTENSILS ***(Patients without gastrostomy)***
4 Normal.
3 Somewhat slow and clumsy, but no help needed.
2 Can cut most foods, although clumsy and slow; some help needed.
1 Food must be cut by someone, but can still feed slowly.
0 Needs to be fed.

CUTTING FOOD/HANDLING UTENSILS ***(Patients with gastrostomy)***
4 Normal.
3 Clumsy but able to perform all manipulations independently.
2 Some help needed with closures and fasteners.
1 Provides minimal assistance to caregiver.

DRESSING & HYGIENE
4 Normal function.
3 Independent and complete self-care with effort or decreased efficiency.
2 Intermittent assistance or substitute methods.
1 Needs attendant for self-care.
0 Total dependence.

TURNING IN BED AND ADJUSTING BED CLOTHES
4 Normal.
3 Somewhat slow and clumsy, but no help needed.
2 Can turn alone or adjust sheets, but with great difficulty.
1 Can initiate, but not turn or adjust sheets alone.
0 Helpless.

WALKING
4 Normal.
3 Early ambulation difficulties.
2 Walks with assistance (any assistive device including AFOs).
1 Nonambulatory functional movement only.
0 No purposeful leg movement.

CLIMBING STAIRS
4 Normal.
3 Slow.
2 Mild unsteadiness or fatigue.
1 Needs assistance (including handrail).
0 Cannot do.

BREATHING
4 Normal.
3 Shortness of breath with minimal exertion (*e.g.* walking, talking).
2 Shortness of breath at rest.
1 Intermittent (*e.g.* nocturnal) ventilatory assistance.
0 Ventilator dependent.


WDSU


because you can

CONNECTION WITH AGING

- Research has shown that longevity is tied to younger onset

- ALS in the aged population can influence the course of treatment intervention including placement of PEG, invasive ventilation and involvement in meaningful occupations

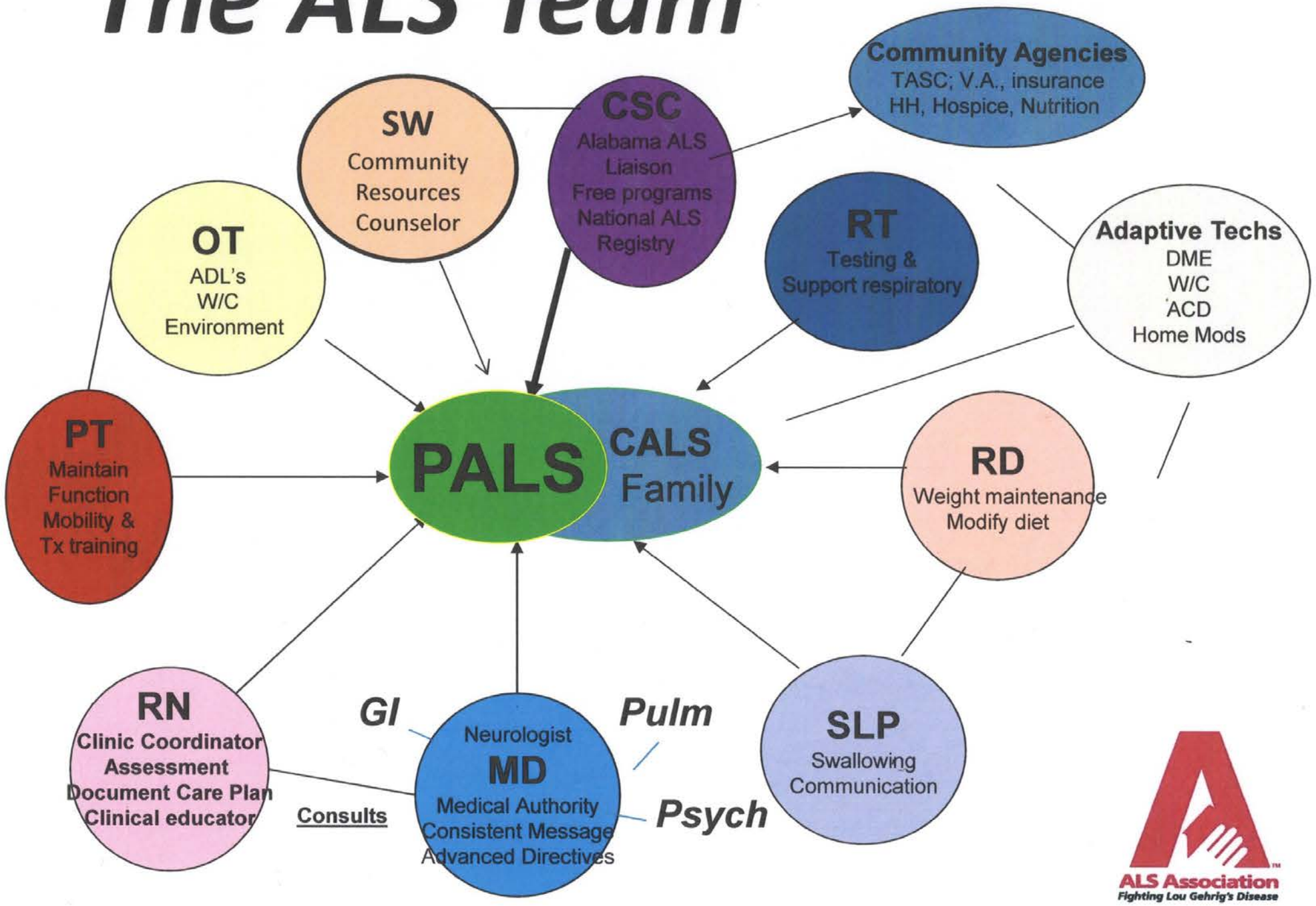
FUNCTIONAL TREATMENT

- Best practice in the care and management of those living with ALS is via a Treatment Center

- In Huntsville at Crestwood Medical Center, we have a Certified Treatment Center of Excellence

- In Birmingham at Alabama Neurology Associates, we have a Treatment Center

The ALS Team



ALS Association
Fighting Lou Gehrig's Disease

CLINIC COORDINATOR

- Coordinates pre clinic and day of clinic operations
- Provides education to team and pALS/cALS
- Provides case management for each patient/each neurologist
- Primary contact for all vendor, referral sources, insurance representatives, Hospice and Respite Care needs

CLINIC NURSE

- Completes pre-assessment system review
- Provides nursing management clinic day
- Assesses head to toe needs and reviews medication management
- Post clinic, screens nursing/medical issues via phone calls as needed

NEUROLOGIST

- Medical Director of the ALS Care Clinic
- Provides care direction during the progression of the disease
- Provides initial and secondary diagnosis

OCCUPATIONAL THERAPIST

- Provides continuous adaption to areas of self-care, work, leisure, play and IADL's
- Completes power wheelchair evaluations and modification as the disease progresses
- Recommends and trains in use of adaptive devices

DIETITIAN

- Conduct a thorough nutritional assessment/reassessment to identify malnutrition.
- Assess nutritional needs and recommend changes in the diet to assist the patient in meeting those needs.
- Adapt consistency of foods and liquids based on swallowing function as assessed by the speech pathologist.
- Guide patients on the use/abuse of vitamins, minerals, and supplements.
- Introduce the topic of enteral nutrition support early so the patient can be prepared to make the decision later if necessary.
- Recommend alternate forms of nutrition, such as tube feeding, and educate patients on the care and administration of tube feeding.

PHYSICAL THERAPIST

- Evaluates and provides recommendations for stretching and exercise
- Provides recommendations for mobility and transfer needs
- Reviews and modifies positioning needs

RESPIRATORY THERAPIST

- Educates patients and families regarding the effect of ALS on the respiratory system and the importance of early intervention
- Evaluates breathing by measuring the strength of respiratory muscles
- Treats pulmonary diseases which may worsen
- Discusses ventilatory support to assist with poor breathing

SPEECH AND LANGUAGE PATHOLOGIST

- Evaluates and treats swallowing, communication

- Works in collaboration with Dietitian for nutrition discussing texture changes, foods rich in calories and PEG

- Works in collaboration with OT to train in and adapt ACC

PATIENT CARE SERVICES COORDINATOR(PCS)

- The PCS who assists with the National Amyotrophic Lateral Sclerosis (ALS) Registry

- The PCS also ensures coordination of services including support groups, advocacy days, fundraising events and educational events

- Our PCS are Social Workers who also provide social work services

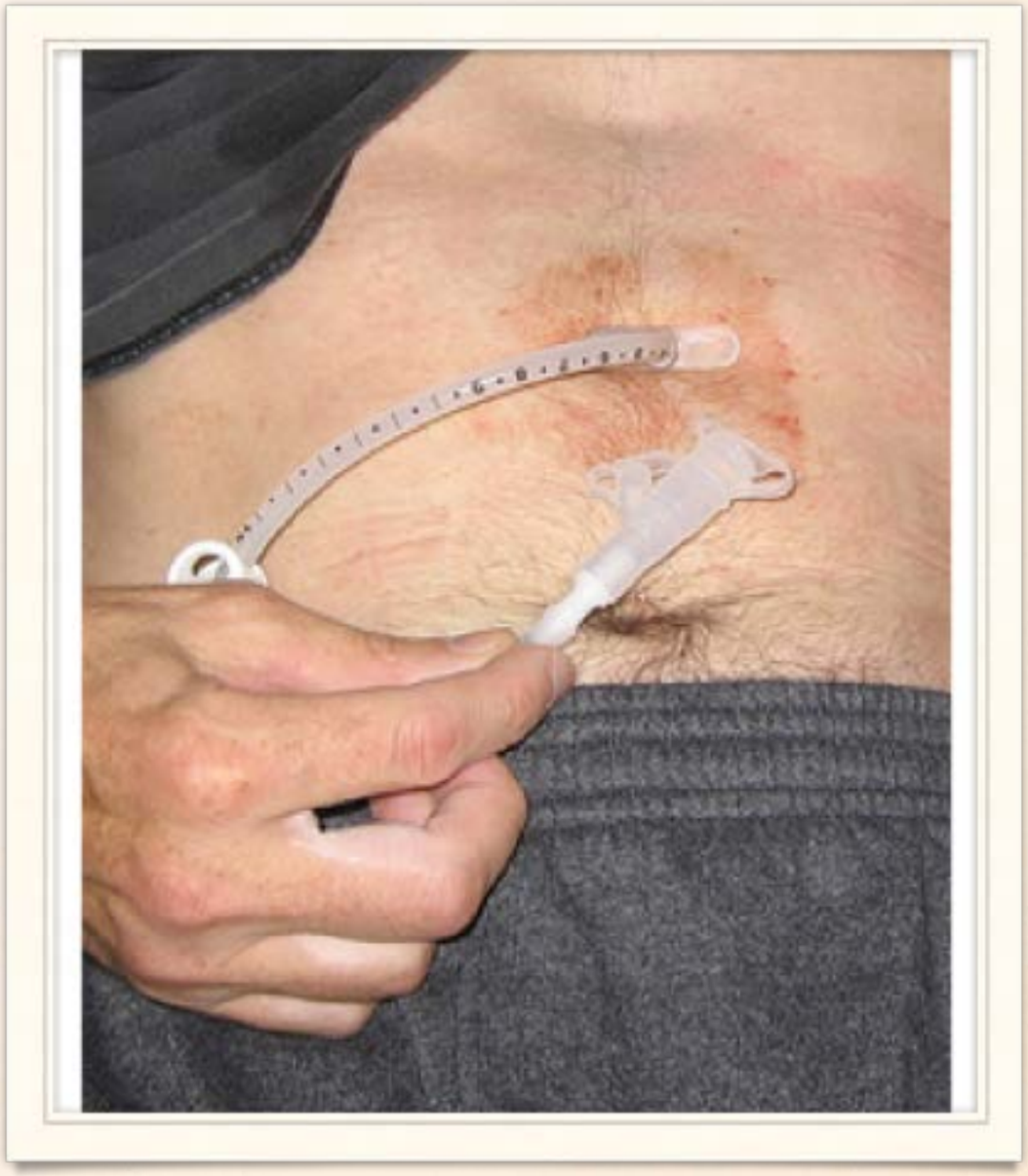
ALS ASSOCIATION
Alabama Chapter

VENDORS

- Present at every clinic are vendors, their role is to provide initial education on equipment ordered as recommended by the clinical team
- ATP, Pulmonary, Nutritional Support, Home Care and Hospice are available as needed
- Critical that we provide a “one stop shop”

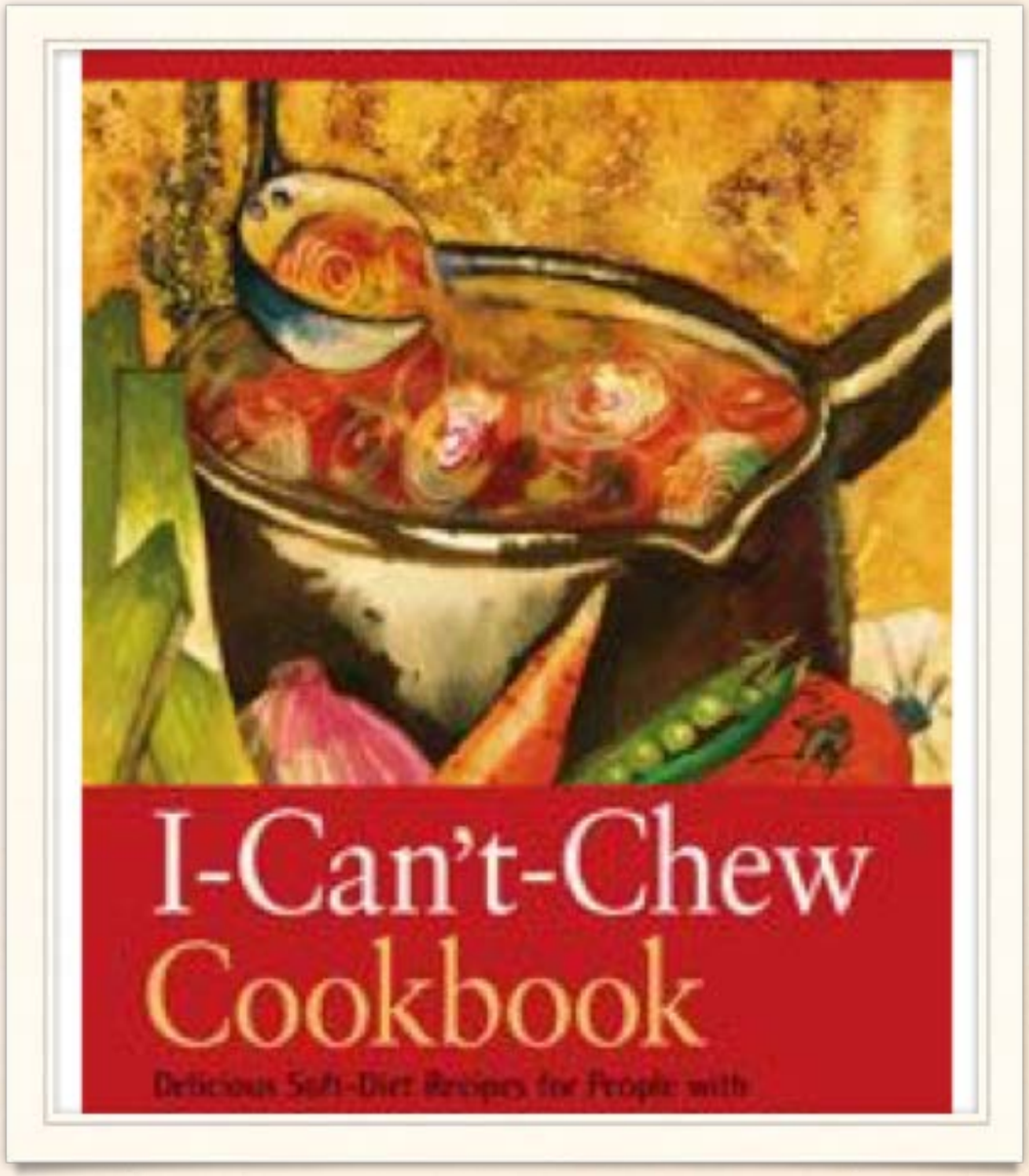
DYSPHAGIA MANAGEMENT

- Malnutrition, aspiration pneumonia
- Signs: drooling, coughing and excessive time to eat
- Altering textures
- PEG: at or soon after 10% weight loss, when FVC is still above 50%



NUTRITION MANAGEMENT

- Thickeners, Blenderize
- High Calorie and Protein Shakes
- Appetite Stimulants
- Ensure, Boost, Carnation Instant Breakfast



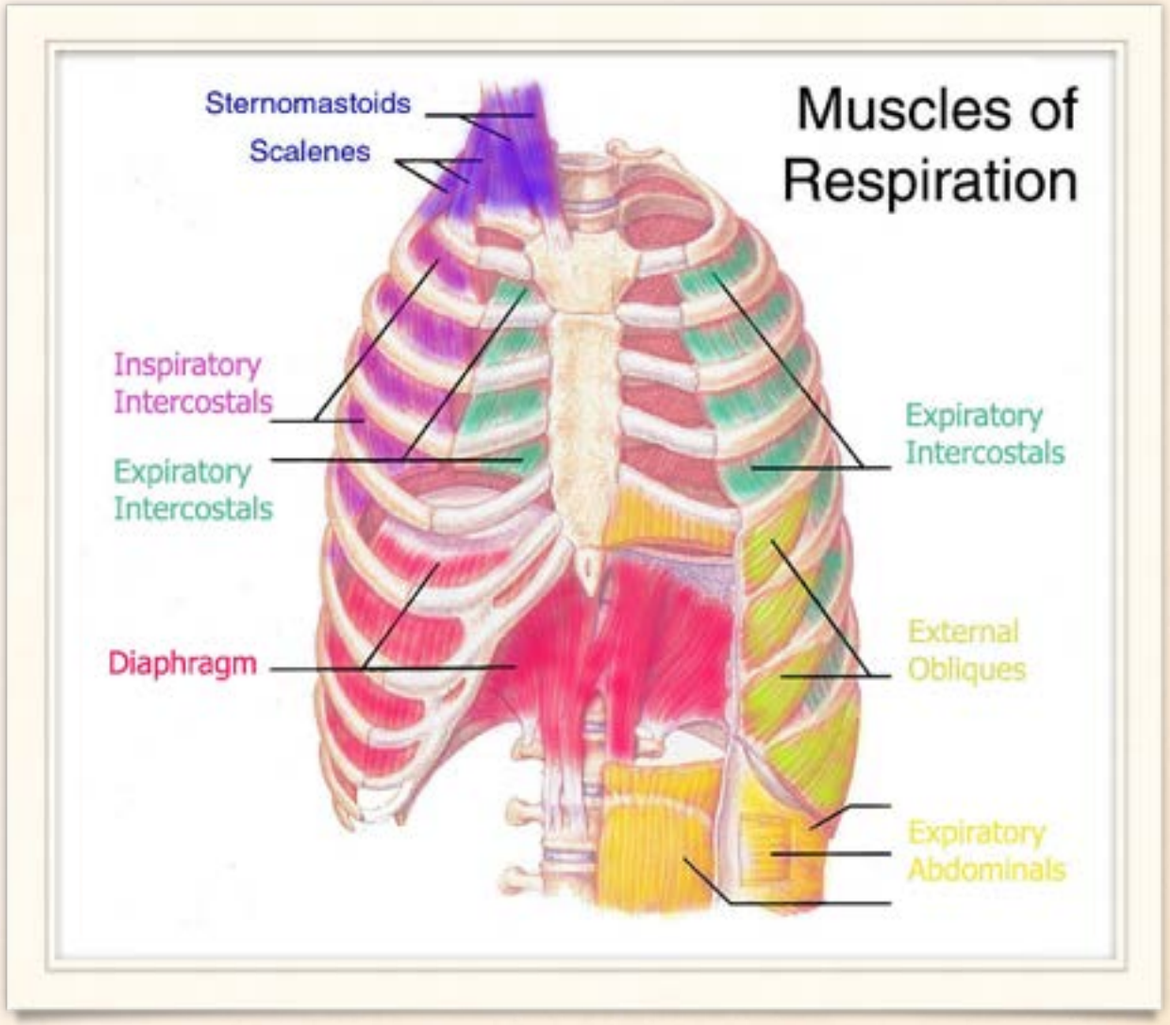
FEEDING AND ASSISTIVE DEVICES

- ADAPT, ADAPT, ADAPT
- Thick handled utensils, built-up foam, universal cuffs, long straws, arm support systems, plate guards, dycem, nose cups
- Environment analysis then ADAPT/MODIFY
- PEG with feeding pump

RESPIRATORY MANAGEMENT

- Initial symptoms: Insomnia, Headaches, Orthopnea, Frequent Sighing, Shallow Breathing, Weak Cough, Short Phrase Speech

- 3 major disorders: Hypoventilation, Pneumonia and RESTRICTIVE APNEA



- Use of Respiratory Aids is critical for support of ventilation, airway clearance and lung volume recruitment

- Diaphragm strength is assessed by FVC (forced vital capacity/volume), and NIF(Negative Inspiratory Force/strength) OR the Modified Borg Scale

PULMONARY CLEARANCE

- Suction machine and oral hygiene
- Cough assist: insufflator-exsufflator device
- Large pressure, pause , expiratory effort
- It coughs
- Treatment: 3-4x/day/5 rounds

NON-INVASIVE VENTILATION

- BIPAP:bilevel positive airway pressure- is the name brand of a non-invasive positive pressure ventilator (NIPPV or NIV). Used with a mask that must be snuggly strapped to the patient's head. There are several different types of masks, some over the mouth and nose and some just over the nose.

- Positive pressure means air is pushed in; bilevel means there are different pressures for inhaling and exhaling, referred to as IPAP and EPAP. Some bipap units, labeled "ST", can have a rate set on them so that the patient gets a set number of breaths.

- AVAPS: Avaps-average volume pressure assured support. Similar to the bipap ST, but also has a volume setting so the air that it provides is more consistent with the amount an individual needs (based on weight. Found to be more effective and better tolerated by ALS patients.

- TRILOGY: is a mechanical ventilator that provides both volume and pressure ventilation and delivers the therapy either invasively (via a trach) or noninvasively (via a mask).

- Advantages over bipap or avaps: Can be more finely tuned to patient’s needs Has an internal battery that can last up to 6 hours. Bipap and avaps do not have batteries- they must always be plugged into an outlet or with an adapter into the cigarette lighter in a car or hooked to a portable battery that weighs about 40 pounds.

- Disadvantages over bipap and avaps:More costly. Some insurance will not approve for non-invasive use unless the patient is nearly 100% dependent on it (20-24 hours per day).More costly for hospice to pay for.

INVASIVE VENTILATION

- Difficult decision for those with ALS
- 24 hour care is more intense with constant monitoring by the caregiver due to the need for suction
- Can decide to turn the vent off, O2 will provide some support but death is imminent
- NO O2 except for terminal use

CAREGIVERS

- Eric Obermann was diagnosed with ALS at 19 years of age
- He, along with four others and their families founded the ALS Association of Alabama
- The majority of caregivers are middle-aged (35-64 yrs)

RESOURCES

- Parkinsons:Parkinson’s Foundation Helpline: 1-800-4PD-INFO (473-4636)

- Caregiver Action Network: 202-454-3970; Check out the Family Caregiver Toolbox

- Connecting with Caregivers : APA

- Family Caregiver Alliance 800-445-8106

PD: PATIENT ACCESS NETWORK

The Patient Access Network (PAN) Foundation is an independent, nationwide 501(c)(3) organization dedicated to providing help and hope to underinsured patients who are unable to afford the out-of-pocket expenses for their prescribed medications. Since 2004, PAN has provided 400,000 underinsured patients with over $880 million dollars in much needed financial assistance to cover out-of-pocket medical expenses across nearly 60 disease-specific programs. For applications and eligibility questions, call 866-316-PANF (7263). To learn more, visit **www.PANfoundation.org**.

RESOURCES

Home Visit Program
Patient Services staff offer one-on-one personal visits to the home to provide personalized information, referrals, and site assessment for home modification and other needs.

ALS Care Clinic
The Chapter supports the first multidisciplinary ALS Clinic in Alabama, which sees patients monthly at Crestwood Medical Center in Huntsville. The ALS Care Clinic is conveniently located in the Crestwood Therapy Services Building, located at 610 Airport Road, Suite 100.

Respite Care
Enables primary family caregivers to have time away from their patient care duties to prevent burnout and to promote well-being for both the caregiver and person living with ALS.

Information Services

We provide educational and practical information on ALS to patients, caregivers and the community. Return often to our website at www.alsalabama.org for information and a calendar of upcoming events.

Support Groups

Dealing with ALS is physically, emotionally and financially devastating for the ALS patient and their family. Monthly Support Groups provide many opportunities to learn more about **living with ALS** from others who understand the challenges and establishes a network of sustained support.

RESOURCES

Equipment Loans
We maintain a loan closet of durable medical equipment for patient care and comfort, as well as specialized augmentative communication equipment. The equipment is available for loan to those who do not have insurance coverage or for those who are awaiting insurance approval.

Home Modification
ALS patients often need significant home modifications such as wheelchair ramps and patient lifts, to continue to live independently in their own homes. ALSA helps with the installation and funding of many of these important projects.

Transportation Assistance
ALS families may require aid for out of town specialist appointments or general transportation expenses. It is important that patients have access to physician and therapist appointments for managing symptoms and also be able to attend support group functions and other quality of life events.

THANK YOU

Questions