Ochsner Therapy & Wellness

Communication Support and Speech Therapy in Progressive Neurologic Diseases: Planning and Physician Engagement

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Disclosures

Relevant Financial Relationships :

We are employees of Ochsner Health

No Nonfinancial relationships to disclose

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SLP scope of practice

- SLPs work to prevent, assess, diagnose and treat speech, language, social communication, cognitive-communicative, and swallowing disorders in children and adults.
- ASHA: “SLP’s engage in prevention and wellness, education, advocacy and outreach, assessment, and treatment of communication and swallowing disorders.”

Refer to SLP when individual demonstrates difficulty with:

- Communication (expressing information, word finding)
- Understanding or processing information
- Reading Comprehension and/or Written Expression (following a neurological event)
- Listening (auditory training after hearing loss)
- Swallowing (coughing or choking while eating and/or drinking)
- Voice changes
- Reduced speech intelligibility
- Short Term Memory
- Problem Solving and Executive Functions (organization, multitasking, initiation, self awareness difficulty after neurological event)
- Attention/Concentration
- Early Onset Dementia
- Neurogenic Stuttering (dysfluencies after a neurological event)

How can speech therapy help?

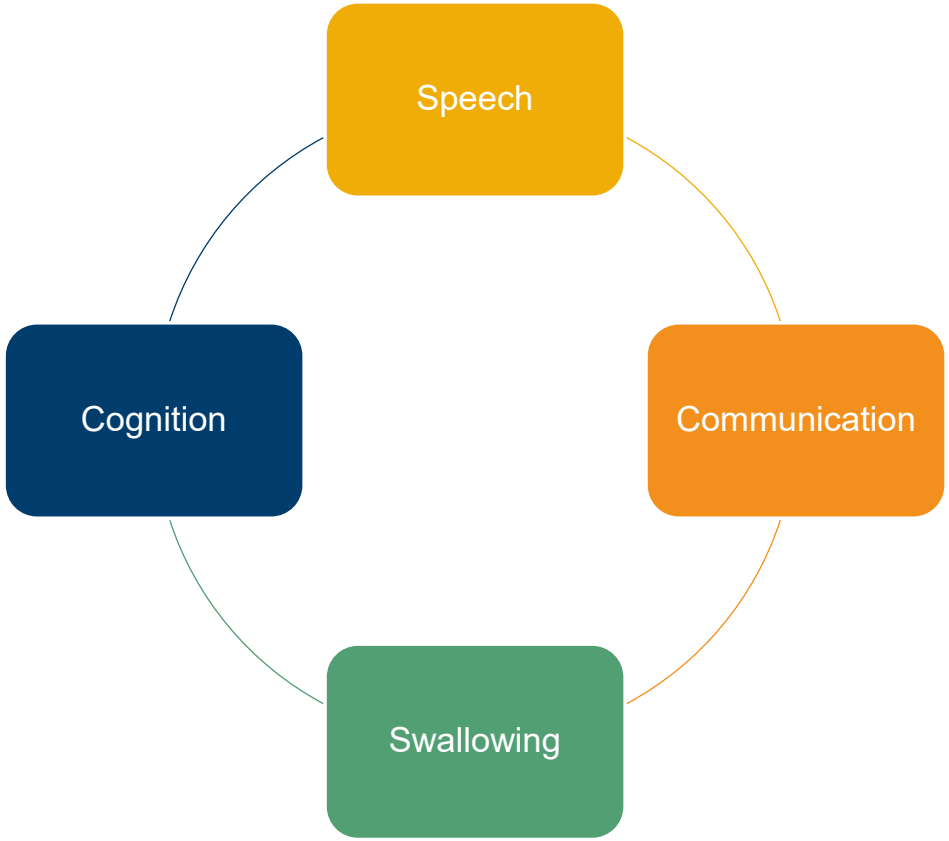
Can improve:

- Safety and efficiency of swallow function
- Communication
- Speech clarity and volume
- Receptive and expressive language
- Ability to express wants/needs
- Ability to be heard & understood
- Ability to manage daily activities
- Executive functions, memory, and attention
- Social interaction, decreases depression, & improves confidence
- Ability to return to work/school

All the above are aimed to improve overall quality of life!

Role of SLPs in progressive neurological diseases

- Provide a thorough comprehensive evaluation of current speech, language, voice, cognition, and swallowing abilities. It's important to establish a baseline to track change over time.
- Provide education and counseling regarding changes in speech/swallowing that may or may not have occurred yet.
- Provide resources to patients and families regarding support groups, educational resources, websites, etc.
- Provide communication partner training to optimize communication in the household.
- Provide rehabilitative and/or compensatory therapy to maintain or improve communication abilities.
- Refer for Neuropsychological Evaluation and/or other discipline input



Supporting communication in progressive neurological diseases

Communication support: anything that promotes effective communication

strategies, resources, supportive attitudes, polices/practices

Treatment principles:

1. "Treatment must be provided over the course of disease progression"
2. Communication partners are important

"AAC timing based on the natural course of the disease is critical. Treatment must start early to ensure adequate time for AAC education, device acquisition, and training. Early referral to a speech-language pathologist is recommended"

Fried-Oken, Mooney, Peters (2015). Supporting communication for patients with neurodegenerative diseases. *NeuroRehabilitation 37* (1) 69-87.

What does therapy look like as a disease progresses?

- Examples:

Parkinsons Disease	
Early	Education, counselling, resources, strategies, may begin Speak OUT! Or LSVT, monitor swallowing function
Mid	Speak OUT! Or LSVT Complete instrumental swallow study
Later	Speak OUT! Or LSVT Amplifiers AAC

ALS	
Early	Education, counselling, resources (Team Gleason, ALS Association of La/Ms), strategies, Voice Banking, monitor for swallowing changes
Mid	AAC evaluation, instrumental swallow study
Later	AAC support, reducing risk for aspiration pneumonia

Dementia (PPA, AD, FTD)	
Early	Comprehensive eval of language/cognition Education, counselling, monitor for swallowing changes
Mid	Communication partner training, strategy use
Later	Communication partner training, external aids, environmental modifications

Proper oral care all stages

- Keep mouth clean to reduce risk of swallowing bacteria.
- Proper oral care includes a toothbrush and toothpaste and/or oral rinse! Suction if needed.
- Problems possibly associated with poor dental hygiene:
  - Heart infections
  - Cardiovascular problems
  - Respiratory infections
  - Systemic infections

Ashford, J.R. (2012, March). Oral Care Across Ages: A Review. *Perspectives in Swallowing and Swallowing Disorders (Dysphagia), 21,* 3-8.

Sheffler, K. (2014, September 4). How to Perform Effective Oral care: Part IV. http://www.swallowstudy.com/perform-effective-oral-care/

Why is early diagnosis important?

Early Diagnosis:

- Diagnosis allows for funding opportunities for communication devices (i.e., ALS and PLS – Team Gleason can help).
- Importance of advanced care planning
- Appropriate referrals to other professionals and organizations/resources
- Realistic goal planning and expectations

Early Intervention:

- Voice preservation opportunities such as voice banking and message banking should be done early when voice is strong, and speech is clear
- Education and counselling regarding course of disease
  and speech/swallow prognosis.
- Establish a plan of care for communication support and swallowing
  - Dx impacts course of treatment
    (i.e., Exercise is contraindicated in ALS whereas could be helpful in PD)
  - Stage/severity impacts course of treatment

Communication oriented treatment

Speaker Strategies

- •Get the listener's attention
- •Convey how communication should take place
- •Set the context and identify the topic
- •Modify sentence content, structure, and length
- •Gestures may help
- •Monitor listener comprehension
- •Alphabet supplementation
- •Maintain eye contact

Listener Strategies

- Listen attentively and actively
- Modify the physical environment
- Maximize hearing and visual acuity
- Schedule important interactions

Interaction Strategies

- Selective a conducive speaking and listening environment
- Maintain eye contact between speaker and listener
- Identify breakdowns and establish methods for feedback
- Repair breakdowns
- Establish what works best when

Compensatory communication strategies

- **Family members and other communication partners can help by encouraging the speaker to:**
  - speak more slowly
  - say one word at a time
  - repeat the word or sentence when necessary
  - rephrase the sentence
  - exaggerate the sounds
  - speak louder (taking a deep breath before speaking)
  - describe what he or she is trying to say if he or she can' t think of the word or indicate the first letter of the word
  - use gestures
  - keep sentences short
  - use alternative techniques, such as word boards, alphabet boards, picture boards, or electronic devices, communication apps
  - Use accessibility features on mobile phones and tablets

Compensatory communication strategies

- **The following are some suggestions for the listener:**
  - eliminate distractions (TV's, radio, large groups of people)
  - keep questions/statements simple
  - ask one question at a time
  - use yes/no question format as much as possible
  - pay attention to gestures and facial expressions/changes
  - if you do not understand what is being said, don't pretend that you do; ask for clarification or repeat what you think was said in the form of a question, such as, "Did you say...?"
  - try to keep to familiar topics
  - encourage the speaker to use his/her specific compensatory strategies
  - allow enough time for the person to convey his/her message
  - most important, be patient with the speaker
  - Speak to the patient! Not about the patient.

Augmentative-Alternative Communication (AAC)

- Communication system for individuals with severe expressive communication and/or language comprehension disorders, such as Autism Spectrum Disorder, Aphasia, Progressive Neurological Disorders.
- AAC includes all forms of communication other than oral speech e.g., communication boards, speech generating devices

Who could benefit from AAC?

- Anyone with a progressive neurological disease can benefit!
- AAC should not be considered a last resort but used to supplement speech!
- AAC can be implemented at any stage – but should be introduced early to allow for learning and habitual use.

- Londral, et. Al determined that early introduction of AAC devices in patients with ALS correlated with higher quality of life scores from both the patient and their caregivers when compared to patients who received AAC later.
  - Early = upon entry to the study (ALFSRS-R between 2-3)
  - Late = ALFSRS-R between 0-1

Londral, et. Al (2015). Quality of life in amyotrophic lateral sclerosis patients and caregivers: Impact of assistive communication from early stages. *Muscle and Nerve 52;* 933-941

National Joint Committee for the Communicative Needs of Persons with Severe Disabilities

- The right to **interact** socially, maintain social closeness, and build relationships
- The right to **request** desired objects, actions, events, and people
- The right to **refuse** or reject undesired objects, actions, events, or choices
- The right to **express** personal preferences and feelings
- The right to **make choices** from meaningful alternatives
- The right to **make comments** and share opinions
- The right to **ask for and give information**, including information about changes in routine and environment
- The right to **be informed** about people and events in one's life

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. American Journal on Intellectual and Developmental Disabilities, 121(2), 121-138

National Joint Committee for the Communicative Needs of Persons with Severe Disabilities continued

- The right to **access interventions and supports that improve communication**
- The right to have **communication acts acknowledged and responded to** even when the desired outcome cannot be realized
- The right to have **access to functioning AAC** (augmentative and alternative communication) and **other AT (a**ssistive technology) services and devices at all times
- The right to access environmental contexts, interactions, and opportunities that **promote participation** as full communication partners with other people, including peers
- The right to be **treated with dignity and addressed with respect** and courtesy
- The right to be addressed **directly and not be spoken for or talked about in the third person** while present
- The right to have **clear, meaningful, and culturally and linguistically appropriate communications**

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. American Journal on Intellectual and Developmental Disabilities, 121(2), 121-13

The importance of attendance for all patients

Jack et. Al 2010

Poor adherence to therapy:

Low levels of physical activity at baseline or in previous weeks
Low in-treatment adherence with exercise
Low self-efficacy
Depression, anxiety, helplessness, poor social support/activity
Greater perceived number of barriers to exercise
Increased pain levels during exercise

Jack, K, McLean, S.M., Moffett, J.K., Gardiner, E. (2009). Barriers to treatment adherence in physiotherapy outpatient clinics: A systematic review. *Manual Therapy, (15),* 220-228

Physician engagement: How can physician's help with their patient's rehabilitation prognosis?

- We know that consistent compliance with therapy improves patient outcomes and reduces health care costs.
- "Making clear the link between the treatment and the illness could enhance the likelihood of a better compliance"
- Patient centered care may increase compliance
- By collaborating with clinicians, physicians can "make the clear link" thus improving adherence, improving patient outcomes, and lowering costs of readmissions and other preventable adverse events.

Hayden HA, van Tulder MW, Tomlinson G. Systematic review: strategies for using exercise therapy to improve outcomes in chronic low back pain. Annal of Internal medicine 2005; 142

Physician engagement: How can physician's help with their patient's rehabilitation prognosis?

- Refer early to learn compensatory strategies
- Encourage consistent attendance
- Encourage caregiver involvement
- Check in with patient frequently
- Collaborate with clinician
- Review clinician’s therapy progress notes

Physician engagement: Interprofessional practice (IPP)

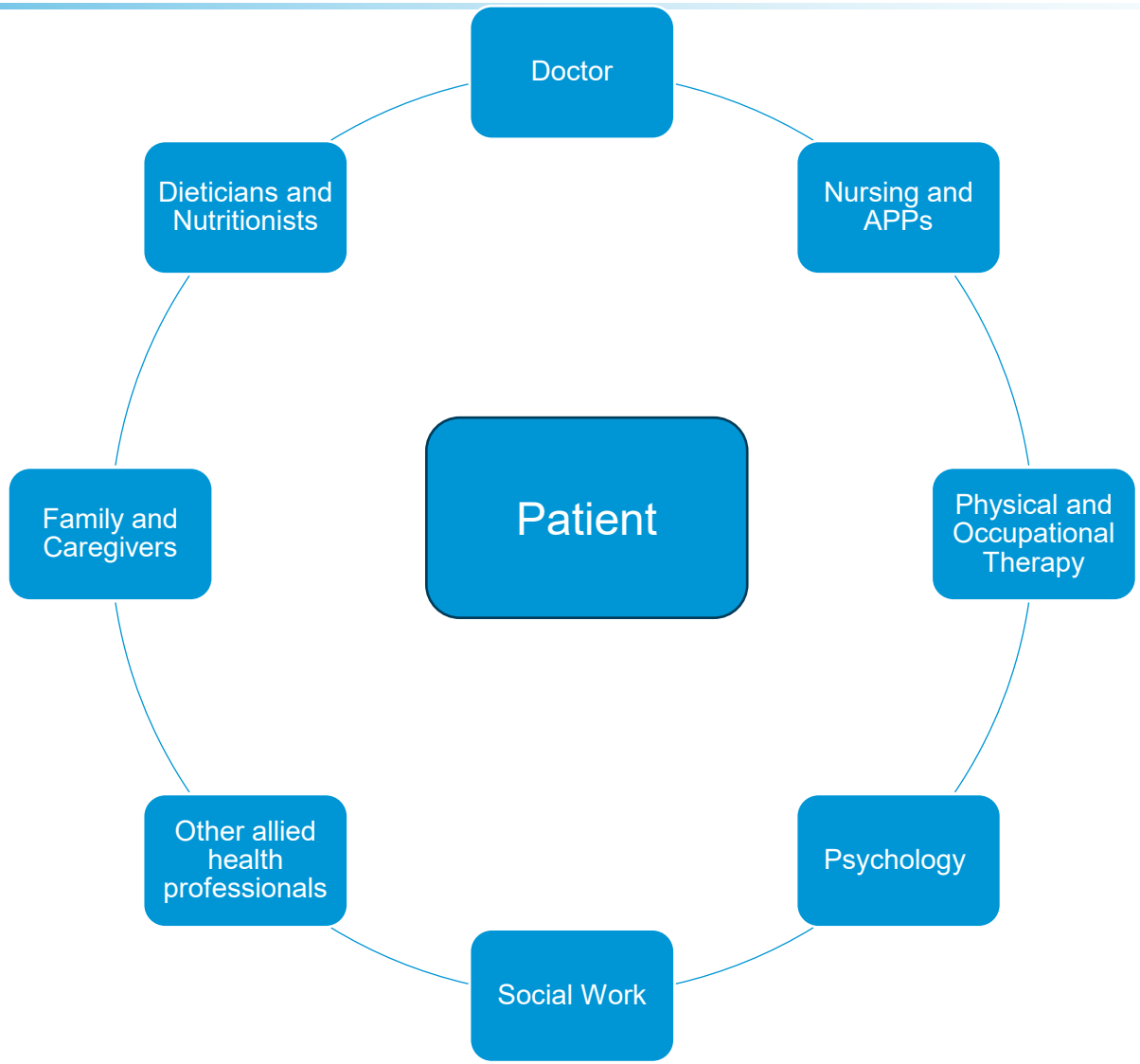
- “As SLPs, we always strive to improve outcomes for the people we serve. In today’s world of specialized care, this requires collaboration with professionals in other disciplines—as well as with families and caregivers. **Interprofessional practice (IPP)** is a framework that makes this collaboration more successful.
- SLPs regularly collaborate with other educational and medical professionals. But IPP isn’t just having more meetings or sending more emails. It’s an intentional approach to collaboration. The IPP framework helps professionals learn about, from, and with colleagues from different specialties.
- On successful IPP teams, each member provides their professional expertise and works together on an assessment and treatment plan that centers around the person and their family. Teams collaborate on planning and developing solutions, taking into account each member’s perspective.
- Participating in an IPP team can take many forms. In some cases, the collaboration is short term; other times, it requires ongoing support over an extended period. In some instances, more professionals are added to the IPP team for a specific need or when existing team members want additional expertise.”

- ASHA

- The main benefit of **interprofessional practice** (IPP) is that it improves outcomes for the people we serve. In fact, that’s the reason nearly 95% of audiologists and speech-language pathologists (SLPs) gave for practicing IPP when asked in a recent survey.
- **Interprofessional education** (IPE) is equally as important. Working on a team involves skills that audiologists and SLPs need to learn. Through classes and professional development opportunities, IPE helps students and working professionals develop the skills to work on IPP teams.
- The vast majority of audiologists and SLPs in a school, hospital, or private clinic think that IPP improves care and outcomes. The exact benefits differ depending on whether you work in health care or education settings.
- In health care settings, a move toward interprofessional teams is an important part of the transition to value-based care, which pays for value and results rather than volume of services delivered. IPP plays a huge role in helping medical teams become more efficient.
- In order to make this new payment model a success, health care professionals—including audiologists and speech-language pathologists— need to collaborate. IPP helps them better coordinate services and track patient outcomes. IPP teams are critical to reducing gaps in patient care, lessening the opportunity for clinical errors and redundant services.
- American Speech-Language-Hearing Association. (n.d.). Team uses therapy and smartphone app to help a woman recover after a fall. https://www.asha.org/practice/ipe-ipp/case-studies/case-study-13/

Resources

Physician engagement: The patient is at the center of interprofessional care



Community Resources

- American Speech-Language-Hearing Association (ASHA)- www.asha.org
- Huntington's Disease Society of America
- Huntington's Disease Youth Organization
- Movement Disorder Society
- National Institute of Neurological Disorders and Stroke
- Mayo Foundation for Medical Education and Research
- International Dysphagia Diet Standardization Initiative (IDDSI) – www.iddsi.org
- Family Caregiver Alliance (https://caregiver.org)
- Multiple System Atrophy Coalition – www.multiplesystematrophy.org
- Huntington’s Disease – www.huntington’sdisease.org
- ALS Association of Louisiana/Mississippi (ALSA) – www.alsa.org
- Team Gleason (for ALS, PLS) – www.teamgleason.org

Resources for ALS

- ALS Association (National); (202) 407-8580; www.alsa.org (webinars, manuals, resources)
- ALS Association – Louisiana/Mississippi Chapter; 1 (800) 891-3746 or (225) 343-9880; info@alsalams.org (includes respite care, durable medical equipment and assistive technology loan closet, support groups)
- ALS Survival Guide; www.lougerigsdisease.net
- Alternative ALS Treatments: www.alsuntangled.com
- Community Choice Waiver; 1 (877) 456-1146; www.dhh.louisiana.gov (assists individuals to remain at home, return home, and in the community; must qualify by meeting Medicaid eligibility AND be 21+ AND be eligible for a nursing facility's level of care)
- Facebook page: "Patients like me"
- For Caregivers: www.caregiver.org (Family Caregiver Alliance)
- Legal Resource: www.ochsner.org (look up: Five Wishes – Prepare for the Future); or contact Meredith Miceli (504) 416-6360; meredith.miceli@ochsner.org
- Medication assistance for Nudexta: www.nudexta.com/savings
- Social Security Administration; 1 (800) 772-1213; www.ssa.gov (retirement, disability, Medicare, Supplemental Security Income)
- TED Talk: www.ted.com/talk ("Nancy Frates: Meet the mom who started the Ice Bucket Challenge")
- Youtube: www.youtube.com ("ALS First Video What it is and Who it Affects"); also offers many educational options on a variety of related subject matters

- **BOOKS**
- "Amyotrophic Lateral Sclerosis – A Guide for Patients and Families", written by Hiroshi Mitsumoto, MD, 2009**
- "ALS Caregivers Guide & Journal", written by Sandra Donalds, 2013**
- "Last Flight Out: Living, Loving, and Leaving", written by Phyllis Langton, 2011
- "Passages in Caregiving: Turning Chaos into Confidence", written by Gail Sheehy, 2011
- "Until I Say Goodbye", written by Susan Spence-Wendel, 2014**
- **Available for loan in Clinic (please see Jayne, our social worker)

Resources for Huntington’s Chorea

- American Speech-Language-Hearing Association (ASHA)- www.asha.org
- Huntington's Disease Society of America
- Huntington's Disease Youth Organization
- Movement Disorder Society
- National Institute of Neurological Disorders and Stroke
- Mayo Foundation for Medical Education and Research
- International Dysphagia Diet Standardization Initiative (IDDSI) – www.iddsi.org

Resources for MSA

- https://www.mayoclinic.org/diseases-conditions/multiple-system-atrophy/symptoms-causes/syc-20356153
- https://www.ncbi.nlm.nih.gov/pmc/articles
- https://www.ncbi.nlm.nih.gov/pubmed

- American Speech-Language-Hearing Association (ASHA), www.asha.org.
- National Movement Disorders Society
- National Institute of Neurological Disorders and Stroke
- Multiple System Atrophy Coalition, multiplesystematrophy.org
- National Center for Biotechnology Information (NCBI)
- National Library of Medicine - National Institutes of Health (NLM-NIH)

Resources for Parkinson's Disease

- Education & Training (parkinsonvoiceproject.org)
- Gulf Coast Chapter | Parkinson's Foundation
- Louisiana Support Groups - PMD Alliance
- Davis-Phinney Foundation for Parkinson's www.davisphinneyfoundation.org
- Parkinson's Circle of Friends Support Group
- National Parkinson's Association
- LSVT Global, Inc (LSVT LOUD and BIG)
- American Speech-Language-Hearing Association (ASHA), www.asha.org

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