LSVT LOUD® Professional Webinar Series

Title: **Atypical and Advanced Parkinsonian Disorders: An Overview and Discussion of Application to LSVT LOUD**

Presenters: Elizabeth Peterson, MA, CCC-SLP

Cynthia Fox, PhD, CCC-SLP

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Contact Us:

Web: www.lsvtglobal.com Email: info@lsvtglobal.com

Phone: 1-888-438-5788 (toll free), 1-520-867-8838 (direct)

Atypical and Advanced Parkinsonian Disorders: An Overview and Discussion of Application to LSVT LOUD

Elizabeth Peterson, MA, CCC-SLP
LSVT LOUD Training and Certification Faculty
LSVT LOUD Expert Clinician
LSVT Global, Inc.

Cynthia Fox, PhD, CCC-SLP
LSVT LOUD Training and Certification Faculty
LSVT LOUD Expert Clinician
Co-Founder
LSVT Global, Inc.

www.lsvtglobal.com
info@lsvtglobal.com

Instructor Biographies

Elizabeth Peterson, MA, CCC-SLP
Ms. Peterson received her master's degree in Speech, Language and Hearing Sciences from the University of Colorado-Boulder. She began working with Dr. Lorraine Ramig's research team while completing her master's thesis. Ms. Peterson is LSVT LOUD certified and primarily delivers LSVT LOUD in the research setting. She has worked as a research associate at the National Center for Voice and Speech-Denver and the University of Texas Health Science Center, San Antonio. Ms. Peterson is currently involved in Dr. Ramig's research investigating the short and long-term impact of LSVT LOUD on neural underpinnings of speech in Parkinson disease.

Cynthia Fox, PhD, CCC-SLP
Dr. Fox is a research associate at the National Center for Voice and Speech and Co-Founder of LSVT Global. She is an expert on rehabilitation and neuroplasticity and the role of exercise in the improvement of function consequent to neural injury and disease. Dr. Fox is among the world's experts in speech treatment for people with Parkinson disease. She has multiple publications in this area of focus, as well as numerous national and international research and clinical presentations. Dr. Fox pioneered the application of LSVT LOUD pediatric populations.

Disclosures

All of the LSVT LOUD faculty have both financial and non-financial relationships with LSVT Global.

Non-financial relationships include a preference for the LSVT LOUD as a treatment technique.

Financial Relationships include:

Ms. Peterson is an employee of and receives lecture honorarium and travel reimbursement from LSVT Global, Inc. Dr. Fox is an employee and Co-Founder of LSVT Global, Inc. She receives honorarium and has financial interest in the company.

Information to Self-Report Activity

- This LSVT Global webinar is **NOT** ASHA or state registered for CEUs, but **it may be used for self-reported CEU credit** as a non-registered CEU activity.
- If you are a speech, physical or occupational therapy professional and would like to self-report your activity, e-mail webinars@lsvtglobal.com to request a certificate after completion of the webinar which will include your name, date and duration of the webinar.
- Licensing requirements for CEUs differ by state. Check with your state licensing board to determine if your state accepts non-ASHA registered CEU activities.
- Attendance for the full hour is required to earn a certificate.

Plan for Webinar

Logistics (questions, handouts)

Discuss application of LSVT LOUD to individuals with atypical and advanced PD

Survey will automatically launch at the conclusion of the webinar (less than 5 minutes to complete)

Objectives

Upon completion of this webinar, participants will be able to:

- Define advanced Parkinson disease (PD) and typical features that characterize advanced PD
- Describe several atypical parkinsonism disorders and their features
- Discuss the application of LSVT LOUD and how the LSVT LOUD protocol can be customized to meet the needs of individuals with advanced or atypical PD

Polling Question

- Who is in our audience today?
  - Individuals with Parkinson's disease (IPD), or atypical PD
  - Family members or care providers for individuals with PD or atypical PD
  - LSVT LOUD Certified Clinicians
  - Speech-language pathologists (not LSVT LOUD)
  - Other

Advanced PD...

What is considered "Advanced"?

Not necessarily how long you have had PD, but the severity of symptoms (often correlated).

Rating Parkinson Disease Severity

Modified Hoehn and Yahr Scale

STAGE 0 = No signs of disease.
STAGE 1 = Unilateral disease.
STAGE 1.5 = Unilateral plus axial involvement.
STAGE 2 = Bilateral disease, without impairment of balance.
STAGE 2.5 = Mild bilateral disease, with recovery on pull test.
STAGE 3 = Mild to moderate bilateral disease; some postural instability; physically independent.
STAGE 4 = Severe disability; still able to walk or stand unassisted.
STAGE 5 = Wheelchair bound or bedridden unless aided.

Goetz CG, Poewe W, Rascol O, et al. Movement Disorder Society Task Force report on the Hoehn and Yahr staging scale: status and recommendations. Mov Disord. 2004;19(9):1020-28.

Limb Motor characteristics of Advanced PD

- Increased severity of bradykinesia, hypokinesia, & rigidity, akinesia/freezing
- Difficulty walking; wheelchair
- Not able to live alone, increased falls
- Assistance needed with all daily activities; greater need for assistive devices/aids
- Worsening of posture

Giugni & Okun, 2014; Varanese et al, 2010

Speech characteristics of Advanced PD

- **Imprecise articulation**
- **Vocal tremor, rate**

Repetitive speech phenomena
Dysfluent speech - stuttering like (initiation difficulties, inappropriate silences)

Hyperfluent – palilalia (compulsive, effortless repetition of words and phrases, against a background of increasing rate and loudness; word and phrase repetitions tend to occur at the end of an utterance)

Increased time for processing information and responding

Benke, Hohenstein, Poewe, & Butterworth, 2000; Duffy, 2005 Darley et al, 1969a; 1969b; 1975; Logemann et al, 1978; Cherney et al., 1988

Non-motor characteristics of Advanced PD

- Dementia and increase neuropsychological changes (slow processing, attention, etc.)
- Psychosis and hallucinations
- Depression, Anxiety, and Apathy
- Sleep Disorders
- Autonomic Dysfunction
- Pain

Giugni & Okun, 2014; Varanese et al, 2010

These motor and non motor complications, may dramatically impair quality of life

What Every Social Worker, Physical Therapist, Occupational Therapist, Speech-Language Pathologist Should Know About Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA). (2017). *Cure PSP, Inc. www.curepsp.org*

Atypical Parkinsonisms…

How do they differ from Idiopathic PD?

What makes Atypical Parkinsonism different from Idiopathic PD?

- Have one of more features similar to PD (rigidity, bradykinesia, tremor, postural instability)
- Have added symptoms not seen in PD ("Parkinson's Plus")
- Disease course and underlying pathology differs from PD
- They do not respond well or in the same way to anti-parkinson medications
- Can be difficult to distinguish from PD initially

Atypical Parkinsonisms

PSP	**Progressive Supranuclear Palsy**
MSA	**Multiple System Atrophy**
CBD	**Corticobasal Degeneration**
LBD	Lewy Body Dementia
FTD	Frontotemporal Degeneration

Incidence and Prevalence

Very rare but frequently misdiagnosed as PD
- Rates vary from 1-6 per 100,000 except for LBD at 400 per 100,000

Life expectancy
- Rates vary from 5 – 10 years

Hospitalizations generally due to:
- Urinary tract infections
- Aspiration pneumonia (secondary to swallowing impairment)
- Falls

Levin et al, 2016

Progressive Supranuclear Palsy (PSP)

Remember "FIGS" *to help with differentiating PSP from PD*

F = Frequent, sudden falls early in disease course
- *generally posteriorly*

I = Ineffective Medication
- *anti-PD medications are not particularly helpful*

G = Gaze Palsy
- *vertical loss (downward first)*

S = Speech & Swallow Changes

Speech changes with PSP

- Strained voice
- Speech fluency - slow, labored speech and palilalia
- Emotional lability
- Language and cognitive deficits
- May progress to anarthria (inability to speak)

Multiple System Atrophy (MSA)

1. **MSA-P (parkinsonian):** Striatonigral degeneration implies parkinsonism with some degree of cerebellar dysfunction.
   - *Slow, stiff movements*
2. **MSA-A (autonomic):** Shy-Drager syndrome reflects a predominance of autonomic failure.
   - *Orthostatic hypotension, constipation, urinary incontinence*
3. **MSA-C (cerebellar):** Olivopontocerebellar atrophy indicates primarily cerebellar defects with minor degrees of parkinsonism.
   - *Ataxia, balance, coordination, gait, and speech*
4. Also common is frontal-executive dysfunction. Memory and visual spatial functions can also be impaired.

Speech changes with MSA

MSA-P:

hypokinetic dysarthria (soft, monotone voice, hoarseness, imprecise articulation), sometimes mixed with spastic or hyperkinetic dysarthria

MSA-A:

ataxic or hypokinetic dysarthria, may be mixed with spastic dysarthria

MSA-C:

ataxic dysarthria is most common, may be mixed with spastic dysarthria

Corticobasal Degeneration (CBD)

Remember "CIAO" *to help with differentiating CBD from PD*

C = **Cognitive changes**
- *mild early on and can progress to dementia*

I = **Ineffective Medication**
- *anti-PD medications are not particularly helpful*

A = **Asymmetrical Presentation & Apraxia** (inability to perform coordinated movements or use familiar objects)
- *alien-limb phenomenon*

O = **Odd movements or feelings**
- *slowness, stiffness, shakiness, clumsiness*

Speech changes with CBD

- Hypokinetic and spastic dysarthria
- Progressive apraxia of speech and oral apraxia
- Progressive nonfluent aphasia may occur
- Speech is hesitant and halting with strained voice and slower speech production
- Progresses to anarthria

General Points to Remember

- The atypical Parkinsonisms are not managed well with medication or surgical treatment like in PD
- Symptoms and presentations can vary greatly
- Compensatory strategies may need to be implemented earlier (vs. restorative treatment methods used in idiopathic PD)

Rehab focus in both Advanced PD (H&Y 4 to 5) and Atypical PD

- Maintain or improve physical capacity:
  - Vocal loudness
  - Voice quality
  - Pitch range
  - Speech intelligibility
  - Bigness of movements
  - Quality of movement
  - Posture
  - Balance
  - Range or motion and strength
- Maintain vital functions: swallowing and moving safely
- Functional communication and movement to improve and maintain function, enhance safety and reduce caregiver burden
- Use of external cueing or augmentation (care team)

Multi-disciplinary team is key!

Medical Team
- Neurologist
- Neurosurgeon
- General practice physician
- Nurses
- CNP/PA in Neurology
- Physiatrist
- Pharmacist

Allied Team
- Speech therapists
- Physical therapists
- Occupational therapists
- Clinical neuropsychologist
- Social workers
- Nutritionist

Behavioral intervention is the most EFFECTIVE therapy for improving communication and function!

LSVT LOUD: Considerations and Adaptations

Delivery
- Certified LSVT LOUD Speech-language pathologist
  - 1:1 intervention

Time of Practice
- 4 consecutive days per week for 4 weeks
- 16 sessions in one month
- 60 minute sessions
- Daily carryover assignments (30 days/entire month)
- Daily homework (30 days/entire month)

LSVT LOUD Treatment Session

Daily Exercises
1. Maximum Duration of Sustained Vowel Phonation (Long Ahs) – 15+ reps
2. Maximum Fundamental Frequency Range (High/Low Ahs) – 15 reps each
3. Maximum Functional Speech Loudness (**Functional Phrases**) – 5 reps of 10 phrases

Hierarchy Exercises

Structured reading – multiple reps, 20+ min.

Off the cuff – bridge the gap to conversation

Build complexity across 4 weeks of treatment towards your long-term communication goal

Homework

Includes all daily exercises and hierarchy exercises

Assigned all 30 days

Carryover Exercises

Use loud voice in real life situations outside of the treatment room

Assigned all 30 days

LSVT LOUD: Gold Standard

Individuals with advanced or atypical PD:

- Greater variability in tx effect
- Show improvement
  - Gains not as significant as IPD (H&Y stage 1-3)
  - Difficulty maintaining tx effects
  - May need to:
    - Increase calibration effort and activities
    - Emphasize importance of the home exercise program
    - Educate and train caregivers to provide external cues for increased loudness
    - Use cues for "shout" vs. "loud"
    - Include more frequent follow-ups and refresher sessions (e.g., every 1-2 months)

Stimulability testing

Does "loud" have impact on improving speech and voice

- Maximum duration vowels "ah"
- High/low "ahs"
- Functional phrases (speech)

Try four consecutive initial sessions and evaluate impact

Monitor progress in treatment

Quantify treatment changes

Don't underestimate ability of person with advanced or atypical PD

Everyone deserves a chance!

Evidence Supporting LSVT LOUD for Atypical PD

- Countryman, S., Ramig, L., & Pawlas, A. (1994). Speech and voice deficits in Parkinsonian Plus syndromes: Can they be treated? *Journal of Medical Speech-Language Pathology, 2* (3), 211–225.
- Sale, P., Castiglioni, D., De Pandis, M. F., Torti, M., Dall'armi, V., Radicati, F. G., & Stocchi, F. (2015). The Lee Silverman Voice Treatment (LSVT®) speech therapy in progressive supranuclear palsy. *European journal of physical and rehabilitation medicine*, *51*(5), 569-574.

Adaptations during LSVT LOUD Exercises

Maximum duration sustained vowel phonation

- May have shorter duration times and more repetitions
- Longer rest periods between repetitions
- Clinician may spend more time modeling and shaping to get best vocal productions

Maximum fundamental frequency range

- Pitch range exercises may open the door to improve voice quality in sustained vowel phonation
- Clinician may need to reset the exercise more frequently to ensure client is starting at max “ah”
- Clinician may spend more time modeling and shaping to get best vocal productions

Functional Phrases

- May need family input to create the phrases
- If family is used, clinician will check in to make sure phrases are what client says every day (not what others *want* them to say)
- May utilize increased repetitions (more than the 5 times) as these will be KEY functional outcomes for clients

Speech Hierarchy

- May need to adjust reading material for individuals with language/visual impairments
- Use repetition of words and phrases
- Use picture description
- Allow sufficient time for declined cognitive processing and response
- Use motor start of the “ah” as needed to rev up the system

Calibration

- Can be more challenging, but remains as important
- Education can be more difficult with cognitive impairments
- Differences played back on audio may not be as easily perceived
- Benefits/rewards of improved communication may be harder to establish
- Critical to find those emotionally salient opportunities so clients will feel the reward of improved communication

LSVT LOUD Homework!

- Daily Carryover Assignments (all 30 days of month)
- Exercise practice at home
  - With coach/caregiver as needed
  - With LSVT LOUD Homework Helper video
  - With LSVT Companion Client Edition
  - 1-2 times per day

Considerations: Treatment strategies to maximize LSVT LOUD outcomes

Considerations

- Will likely need support from family, caregivers, nursing staff, etc.
- Include family/caregiver perceptual ratings to help determine functional impact
- Carefully train others on how to cue (helpful not hurtful to treatment goals)
- Islands of lucidity – capitalize on them; have clients at times when they may not be feeling their best
- Motor fluctuations: On/off and dyskinesias

Considerations for Treatment Location

- Cognition
- Distractibility
- Home environment vs. clinic setting
- Transportation issues
  - Consider telehealth sessions (LSVT eLOUD)
  - Consider LSVT Companion for some sessions

Treatment Strategies Adaptations for Cognitive Concerns

- Treatment should be in a room separate from others and with as few distractions as possible
- Clinician will really focus on modeling behaviors as opposed to lengthy clinical explanations
- Repetition, repetition, repetition!!!
- Simple treatment focus! Treatment target remains focused only on loudness, even when other communication deficits are present
- May need treatment beyond the 4 weeks
- Once client is able to follow modeling, care partners may receive education from clinician so they can be a "coach"

Treatment Strategies Adaptations for Physical Concerns

- Consider teleheath sessions to reduce fatigue from traveling

- Clinicians will acknowledge a patient's fatigue within treatment sessions (e.g., validate; longer rest periods)

After LSVT LOUD…

- Daily LSVT LOUD exercise practice at home
  - Once a day forever!!
  - With coach/caregiver
  - With LSVT LOUD Homework Helper video
  - With LSVT Companion System
  - In a group – LOUD for LIFE®!

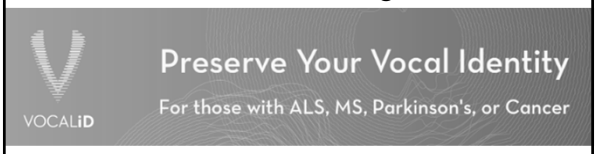
After LSVT LOUD…

- Ongoing maintenance therapy (1/week ongoing)
- "Tune-Ups": check in every 1-3 months, reassess and determine ongoing treatment

Supplemental Strategies

- Voice banking for future augmentative device
- Altered auditory feedback (SpeechEasy; SpeechVive)
- Listener strategies

Voice Banking



- VocaliD is passionate about voice preservation and restoration
- Personalized digital voices enable you to continue to speak as yourself when your voice may be compromised.
- Your VocaliD voice can be used on type-to-speak apps on your phone, tablet, or augmentative and alternative communication (AAC) device.

www.vocalid.co

Supplemental Strategies SpeechEasy

What is SpeechEasy?

SpeechEasy uses delayed auditory feedback (DAF, FAF) to reduce palilalia in advanced PD.

(Hanson & Metter, 1983)

janusdevelopment.com

Supplemental Strategies SpeechVive

What is SpeechVive?

SpeechVive uses the Lombard effect to increase loudness.

(Lombard, 1911; Lane and Tranel, 1971; Adams and Lang, 1992)

speechvive.com

Supplemental Strategies Listener Behaviors

- Eliminate background noise and distractions
- Use yes/no question format
- Ask for clarifications, "Did you say…?"
- When asking to repeat, use the single cue, "Say that with a loud voice."
- Use familiar topics
- Provide choices for responses
- Face the speaker

There is HOPE!

- Don't discount therapy just because the disease is advanced or it is an atypical PD
- People with advanced PD and atypical PD can have amazing outcomes! FUNCTIONAL communication and movement of any kind can dramatically improve quality of life (even if supplementation is required)

Summary

- LSVT LOUD is applicable to all stages of PD and can be customized to each patient's needs and treatment settings
- LSVT LOUD can increase independence, confidence, quality and/or safety with communication, and ADLs
- Restore Function! Improve Function! Maintain Function!
- Atypical and Advanced PD carry unique challenges requiring creative solutions and increased caregiver involvement

Related Organizations

- Cure PSP www.psp.org
- MSA Coalition www.multiplesystematrophy.org
- The Association for Frontotemporal Degeneration www.theaftd.org
- The Lewy Body Dementia Association www.lbda.org
- The Alzheimer's Association www.alz.org

Where are Other Places One Can Learn More About PD?

- Parkinson's Foundation:
  - www.parkinson.org
- American Parkinson's Disease Foundation
  - https://www.apdaparkinson.org
- Michael J. Fox Foundation
  - https://www.michaeljfox.org/
- Davis Phinney Foundation
  - https://www.davisphinneyfoundation.org/
- World Parkinson Coalition
  - http://www.worldpdcoalition.org/

How Do I Locate LSVT Certified Clinicians?

1. www.lsvtglobal.com
2. Find LSVT Clinicians
3. Search Options
   - LSVT LOUD (Speech Therapy)
   - LSVT BIG (Physical Therapy & Occupational Therapy)
4. Enter your location
5. Click on "I agree to the terms and conditions"

Then-Ask your doctor for a referral to one of these clinicians!

LSVT Resources for You!

- Public webinars - live and on demand
- LSVT BIG and LSVT LOUD seminars (locations worldwide)
- LSVT BIG and LSVT LOUD Homework Helper Videos
  - Available on DVD; download; or 1 year streaming ($15)
    - **LSVT LOUD Homework Helper:** https://vimeo.com/ondemand/lsvtloud
    - **LSVT BIG Homework Helper Volume 1**: https://vimeo.com/ondemand/lsvtbig/159619597
    - **LSVT BIG Homework Helper Volume 2**: Seated and Supine; Caregiver Chapter (available only on DVD)
- BIG for LIFE and LOUD for LIFE Groups – Look for designation in clinician profile - OR contact info@lsvtglobal.com
- Ask the Expert! Info@lsvtglobal.com

How to Ask Questions

1. Type in the question box on your control panel

2. Raise your hand! (click on the hand icon in your control panel)
   - Your name will be called out
   - Your mic will be unmuted, then you can ask your question out loud.

3. Email webinars@lsvtglobal.com if you think of questions later!

Please complete the survey!

Upcoming Webinars

Early Parkinson Disease: A discussion on the benefits of exercise and LSVT BIG®

Wednesday, September 19, 2018

2:00 PM - 3:00 PM (EDT)

Early Parkinson Disease: A discussion on the benefits of exercise and LSVT BIG®

Wednesday, October 17, 2018

2:00 PM - 3:00 PM

Eastern Daylight Time (EDT)

Thank you!

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It will take five minutes or less to complete!