



Public Webinar Series

Title: What people with Parkinson's want family and friends to know about movement and speech challenges

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What People with Parkinson Disease Want Friends and Family to Know

Presented by:

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Disclosures

- All of the LSVT faculty have both financial and non-financial relationships with LSVT Global.
- Non-financial relationships include a preference for the LSVT BIG and LSVT LOUD as a treatment techniques.
- Financial Relationships include: Laura Gusé and Angela Halpern are employees of LSVT Global, Inc. All of the LSVT Faculty receive consulting fees, lecture honorarium and travel reimbursement from LSVT Global, Inc.

Objectives of Presentation

1. List common motor and non-motor symptoms of Parkinson disease (PD).
2. Discuss the perspectives shared by people with PD who deal with these common symptoms every day.
3. Briefly review how the LSVT LOUD® and LSVT BIG® address common motor and non-motor symptoms of PD.
4. Learn how caregivers can most effectively support improved speech and movement in people with PD who are receiving LSVT BIG and LSVT LOUD.
5. Discuss perspectives family and caregivers of people with PD would like to share with others.

Brief Overview Of PD and Related Symptoms

Plan for Webinar

Logistics (microphones muted, handouts available, questions – type at any time or ask at the end)

Present webinar

Review resources available

Address your questions and provide time for discussion

Complete survey at end of webinar (five minutes or less to complete)

Primary MOTOR Characteristics

Resting Tremor

Rigidity

Postural Instability

Bradykinesia And Hypokinesia

Hypokinesia Affects Movement AND Speech

- Progressive loss of loudness of speech (hypophonia)
- Progressive loss of amplitude of handwriting (micrographia)
- Progressive shortening of stride length and arm swing during walking
- Progressive loss of speed and amplitude duration with repetitive movements of fingers or limbs.

Koop, Hill, and Bronte-Stewart, 2013

How Do These Non-motor Symptoms Affect Speech And Movement?

Sensory changes: People with PD have soft speech and smaller movements, but they think it is within normal limits

“My voice is fine. My spouse needs a hearing aide.”

“I had no idea my arm was not swinging!”

Fox et al, 2002; Sapir et al, 2011

It takes a lot of EFFORT to move bigger and talk louder!



How do these non-motor symptoms affect speech and movement?

- Internal cueing problems: Bigger movement and louder voice can be cued externally, but internal cueing mechanism is impaired

“If I don’t specifically think about it, I forget to move big and talk louder.”

- Neuropsychological: Slow thinking, slow learning, problems sustaining attention, problems shifting between tasks, and problems in procedural memory.

Primary NON-MOTOR Characteristics

- **Depression**
- **Dementia**
- **Autonomic abnormalities**
 - (hypotension, bowel/bladder, sexual, blurry vision, short of breath)
- **Sleep Disorders**
- **Loss of higher cognitive functions**
 - Slow thinking
 - Retrieval
 - Self-cueing
 - Sustaining attention
- **Emotional Changes**
 - Anxiety
 - Apathy
- **Sensory changes**
 - Pain, tingling, burning
 - Generalized decreased kinesthetic awareness

How do these symptoms affect the lives of people with PD?

Your Feedback

- **Variability** in function from day to day- frustration when people think “not trying” on tough days
- **Increased effort** required to talk, and think about what you want to say
- **Exhausting** to think about “moving correctly” all day

Your Feedback

General words of wisdom for those who wish to be supportive - related to communication and movement:

- **Educate** yourself about PD
- **Be persistent** in involving person with PD in conversation
- **Encourage** independence
- Don't be **overly protective**



Your Feedback

- Off periods are very **challenging**
- **Frustration** at having to repeat, not being able to think of words, not be able to move as want to, at PD in general
- Outward difficulties with speech, **not a reflection of the true person**

The LSVT protocols **SPECIFICALLY and INTENTIONALLY** address the deficits **(MOTOR and NON-MOTOR)** unique to PD

Your Feedback

General words of wisdom for those who wish to be supportive - related to communication and movement:

- **Listen**
- **Be understanding** in general and of the “frustration”
Don't take it personally if loved one “snaps” at you
- **Patience**
Don't rush person
Let them speak at their own pace



Define LSVT LOUD and LSVT BIG

Lee Silverman Voice Treatment

LSVT LOUD – speech therapy to improve communication

LSVT BIG – physical or occupational therapy to improve movements

Poll

How many of you have received
LSVT LOUD?

How many of you have received
LSVT BIG?

Why is this necessary?

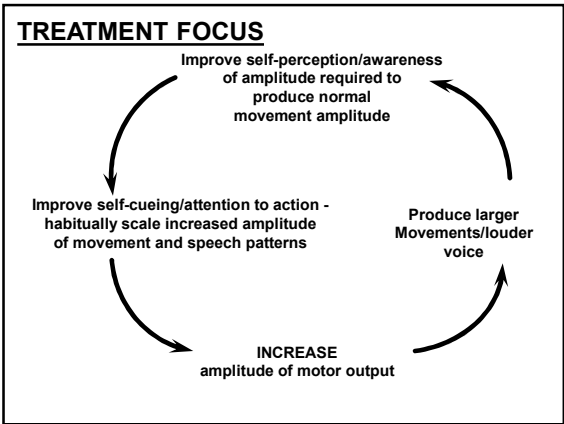
► **NON-MOTOR SYMPTOMS:**

- Apathy
- Slow processing
- Impaired motor planning/motor learning
- Impaired memory and executive functioning
- Impaired internal cueing mechanism

► **MOTOR SYMPTOMS:**

- Deconditioning, weakness, postural changes, require increased direct intervention frequency to resolve or restore

► **Bigger/louder, more normal movement and voice production must be OVER-LEARNED**



It isn't just about the amount of treatment...

The LSVT Protocols are INTENSIVE!!!

- 4 consecutive days a week for 4 weeks
- 60 minute sessions
- Daily homework practice - all 30 days of the month
- Daily carryover exercises - all 30 days of the month
- Establish a life-long habit of practice

EXERCISE IS MEDICINE!

It is also about HOW you hard you work during the treatment and after!

You must keep up the intensity within sessions.

HOW??? ➡ WITH HIGH EFFORT

- Amplitude – keep it BIG/LOUD all 60 minutes every session
- Repetitions – increase the reps over time
- Force/resistance – increase over time
- Accuracy – push to get it correct
- Fatigue – drive to healthy levels: heart rate, sweating, breathing hard during entire session improves brain function as well as cardiovascular function

Calibration

Self-monitoring = Sign of success!

The patient uses larger amplitude movements or louder voice -
“automatically”
in everyday living.

The **LEVEL** of calibration will be reflected in the automaticity of bigger movements or louder voice in daily life:

- Early: Spontaneously (self-cue) with no conscious awareness
- Mid: Partially self-cue (or correct) in familiar environments
- Late: Requires caregiver cueing

CAVEAT: These levels are general estimations, not absolutes. For example, people with later stage PD can be cognitively intact and can self-cue; or people with early PD can show emerging cognitive impairments and require partial cueing.

Calibration

Addresses Barriers to Generalization

Sensory disorder: People with PD have soft speech, but they think it is within normal limits (world needs a hearing aide).

Internal cueing: Physiological substrate for movement is present – not being activated.

Neuropsychological: Slow thinking, slow learning, problems sustaining attention, problems shifting cognitive set, problems internally cueing, and problems in procedural memory.

Fox et al, 2002; Sapir et al, 2011

ROLE OF SPOUSE / FAMILY

Operating principle:
EMPOWER PATIENT 1ST!



Signs of successful calibration

- Reports functional impact and use outside of treatment
- “Internally cues” self
- Requires less effort or accepts the effort it takes to move bigger or talk louder

The Patient takes Responsibility and Reaps Rewards of improved Self-confidence



HOWEVER...

Sometimes use of family is necessary



Recommendations From the LSVT Experts

➤ **If it recommended that you serve as a coach**

- Give ample time for processing information
- Be positive, encouraging, yet compassionate
- Seek to understand how the problems with sensory awareness/perception are affecting your loved one
- Ask questions! Therapists are eager to help!

Sometimes use of family is desirable



Your positive, persistent energy gives the confidence and power of moving **BIG and talking **LOUD!****



Recommendations From The LSVT Experts

➤ **If it recommended that you serve as a coach**

- Practice the exercises to feel effort for “BIG” or “LOUD”
- Learn how to model
- Limit your “words” when coaching. Keep focus simply on “BIG “ and “LOUD”

How can families, friends and caregivers be most helpful when people with PD partake in LSVT LOUD or LSVT BIG?

Your Feedback

Suggestions for those who wish to be supportive of their spouse during LSVT LOUD/LSVT BIG:

- **“Encouragement! The best gift”**
 - Encourage (NOT nag) to practice
 - Encourage – don’t belittle
 - Do the exercises together, cheerlead, be the “timer”

Your Feedback

Patience with caregiver

- Can only do certain things at certain times
- Caregivers get tired
- Caregivers are not trying to take away independence, but foster safety

Your Feedback

Suggestions for those who wish to be supportive of their spouse during LSVT LOUD/LSVT BIG:

- **Support**
- **Feedback**
- **Become educated** about LSVT Treatments
- **Patience**

“Empower Me”

Your Feedback

Communicate

As a caregiver, you want the person with PD to talk more about feelings, struggles, discomfort



Desire to be able to understand the pain and movement challenges

Desire to understand fears and frustrations

What do families, friends, and caregivers want people with PD to know?

Open Mic Time

- What advice would you like to share with other people who have PD who have not yet received LSVT LOUD or LSVT BIG?
- What recommendations would you like to share with other friends, family and caregivers of people with PD?
- Caregivers, friends and family, what words of wisdom would you like to share with others?

Summary

We are in This Together!!!!

Important to have open dialogue between therapists, PWP and caregivers

We have the highest admiration for the people we meet who are daily working hard to enhance and improve their quality of life and the quality of life of those they care for!

Thank you!

Questions???



info@lsvtglobal.com

Please complete the survey that will launch when you close the program.
It will take five minutes or less to complete!

How to get started with LSVT LOUD and LSVT BIG

- Ask your doctor for a referral and a prescription for a speech or physical/occupational therapy **evaluation** and **treatment**
- Visit www.lsvtglobal.com to find an LSVT LOUD or LSVT BIG Certified Clinician in your area
 - Click on "Find a Clinician"
 - Select the desired type of clinician and enter location information
- Videos available to introduce you to voice and movement exercises used in LSVT LOUD and LSVT BIG programs: www.lsvtglobal.com/products

Further Information And Resources

- LSVT Before/After Videos
<http://www.lsvtglobal.com/news/video>
- Webinars – FREE for the PD Community!
- LSVT LOUD Companion Home Edition

