The Virtual Assessment in Lewy Body Dementia: Pandemic and Beyond

The approach to clinical care via telemedicine

An LBDA Research Centers of Excellence Webinar

March 4, 2021

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Housekeeping Notes

- The activity is being recorded.
- All attendee mics are automatically muted.
- If you have questions during the presentations, please submit them via the Q&A function

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Welcome

Today's event was organized by the Clinical Care and Professional Education Working Group for LBDA's Research Centers of Excellence (RCOE) Program

Co-Chairs/Course Directors

- Katherine Amodeo, MD, Westchester Medical Center, Poughkeepsie, NY
- Jennifer Goldman, MD, MS, Shirley Ryan AbilityLab and Northwestern University Feinberg School of Medicine, Chicago, IL

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Support Acknowledgement

This activity was supported by an educational grant from
Acadia Pharmaceuticals Inc.

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Accreditation Statement

In support of improving patient care, this activity has been planned and implemented by the Postgraduate Institute for Medicine and Lewy Body Dementia Association. Postgraduate Institute for Medicine is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

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Designation Statement

Physicians

Postgraduate Institute for Medicine designates this internet live activity for a maximum of 1.0 *AMA PRA Category 1 credit™*. Physicians should claim only the credits commensurate with the extent of their participation in the activity.

Allied healthcare professionals

Participants will receive a Certificate of Attendance stating this program is designated for 1.0 *AMA PRA Category 1 Credit™*. This credit is accepted by the AANP and the AAPA.

PIM Postgraduate Institute for Medicine
Professional Excellence in Medical Education

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Disclosures

Jennifer Goldman, MD, MS *Contracted research:* Acadia Pharmaceuticals Inc., Michael J. Fox Foundation, Parkinson's Foundation. *Honoraria:* International Parkinson and Movement Disorders Society, Medscape, Parkinson's Foundation

Katherine Amodeo, MD *Contracted research*: Genentech Roche Ltd., EIP Pharma Inc, Michael J. Fox Foundation, NINDS, Acadia Pharmaceuticals Inc, and Biogene through July 2020.

Jori Fleisher, MD, MSCE *Consults* for UCB Pharmaceuticals, Inc.

Karen Marder, MD, MPH *Consulting fees:* CHDI, Parkinson Foundation; *Contracted Research*: NIH: U01 NS100600, U24 NS107168, UL1TR001873 LBDA, Parkinson's Foundation, Michael J Fox Foundation, HDSA, CHDI, HSG, Site investigator: Genentech, Prilenia, Triplet Therapeutics; *Section Editor:* Springer LTD

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Agenda

- **Brief Background**
- **Case 1**: Making and Delivering the Diagnosis Remotely
  - Approach to diagnosis in remote setting
  - Approach to remote delivery
- **Case 2:** Addressing Challenges/Limitations of Remote Encounter
  - Engaging care partners and providing support
  - Working through technology challenges
- Followed by Panel Discussion with Questions and Answers

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Educational Objectives

At the conclusion of the activity, learners should be able to:

- Demonstrate an increased knowledge of LBD symptoms.
- Discuss the approach of virtual care in LBD with respect to in-person visits.
- Discuss the challenges when assessing motor and non-motor features via telehealth.
- Discuss how to deliver a diagnosis via a telehealth appointment.
- Compare and contrast the differences in delivering a case via telehealth via an in-person diagnosis.
- Outline the various technology challenges a person living with LBD or their care partners may encounter when being seen via televisit
- List solutions to challenges of telehealth appointments and technology challenges.

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Background: Call for Virtual Assessment

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Background

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- Parkinson's disease dementia (PDD) and dementia with Lewy bodies (DLB) collectively termed Lewy body dementia (LBD)
- LBD is characterized by dementia with parkinsonism (slowness of movement, rest tremor, rigidity, postural instability), psychosis, fluctuations in cognition and consciousness
- Diagnosis requires thorough history, cognitive assessment and physical examination

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Lewy Body Dementia

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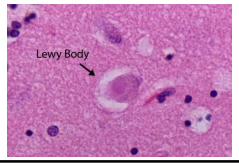
- Umbrella term to include Parkinson's disease with dementia (PDD) and dementia with Lewy bodies (DLB)
- Neurodegenerative disorders involving abnormal alpha-synuclein protein→ Lewy bodies



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Dementia with Lewy Bodies and Parkinson's Disease: *Shared Characteristics*

- Neurodegenerative disorders involving abnormal alpha-synuclein protein
- Premotor features: **REM behavior disorder** (dream enactment), anosmia, constipation
- Parkinsonism
  - bradykinesia, rest tremor, rigidity
  - postural instability and gait dysfunction
- Cognitive and Behavioral disturbances
- Autonomic Dysfunction: Orthostatic Hypotension

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Dementia with Lewy Bodies and Parkinson's Disease: *Distinguishing Clinical Characteristics*

PD

- Parkinsonism is initial presentation
- Over time (years), may develop cognitive impairment → Dementia
- Over time, may develop psychosis (most often in setting of dopaminergic therapy)

DLB

- Cognitive impairment (Dementia) is core feature and presents early
  - 'one year rule'- either prior to parkinsonism or within one year of parkinsonism
- Psychosis (VH +/- delusions) is spontaneous and presents early in disease course

*Main difference is the timing of onset of dementia in relation to motor symptoms ('*one year rule*').

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Background: Call to Telemedicine

- In March 2020, the World Health Organization declared a pandemic attributable to the outbreak of novel COVID-19.
- "Stay at home" orders to "flatten the curve"
  - Older adults at increased risk
  - LBD represents a particularly vulnerable population
    - (more on this in our 3rd webinar of this series! Stay tuned!)
- Call for conversion to telemedicine to keep our patients safe

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Survey Among LBDA RCOE Clinicians

- Survey was sent to 26 LBDA RCOE centers over a 2 week period in June 2020
- 14 of 37 Investigators responded
- All respondents were delivering care virtually for both new and established patients with LBD since declaration of pandemic

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Case Presentation 1: Making and Delivering the Diagnosis Remotely

Drs. Amodeo and Marder

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Case 1 - Presentation

- 89 years old man presenting via televideo for evaluation in setting of cognitive impairment and falls
  - Accompanied by daughter
- HPI:
  - Gradually progressive changes in cognition over the past 4 years
    - Forgetful, has gotten lost when driving
    - Impact on Function: missed bills, missing doses of Medications, lost when driving, trouble with organization
  - Shaking of hands (at rest) over the past 4 years
  - Less steady when walking, rare falls. Short steps
  - Sleeps "a lot."
  - Times in which he seems to be "staring off" and less responsive

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Case 1 - Presentation

- Rest tremor present “all the time” in both hands. Impacts his hand-writing.
- No exposure to dopamine blocking agents.
- At night, he sees people and animals.
  - Knows they are not real. They “run” away.
- Constipation
- Postural light-headedness
- Wife reports dream enactment

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Case 1 - Presentation

- Examination by Video
  - MOCA-BLIND: 14 out of 22 (Normal is ≥18).
    - Lost points across domains (notably attention, fluency, abstraction, delayed recall)
    - MOCA-BLIND does not test Executive/Visuospatial Function
  - Mild hypomimia and mild hypophonia. No jaw tremor.
  - Mild-moderate bradykinesia with finger taps, hand opening/closing, toe and heel taps bilaterally. Mild, rare tremor at rest with emergence with posture.
  - Able to arise to standing with no assistance but is slow. Feels momentarily dizzy with standing but passes. Gait is narrow based and steady but with reduced stride length and absent arm swing

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Let’s pause here:
Does this meet diagnostic criteria for LBD?

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VIEWS & REVIEWS

Diagnosis and management of dementia with Lewy bodies

Fourth consensus report of the DLB Consortium

OPEN

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ABSTRACT

The Dementia with Lewy Bodies (DLB) Consortium has refined its recommendations about the clinical and pathologic diagnosis of DLB, updating the previous report, which has been in widespread use for the last decade. The revised DLB consensus criteria now distinguish clearly between clinical features and diagnostic biomarkers, and give guidance about optimal methods to establish and interpret these. Substantial new information has been incorporated about previously reported aspects of DLB, with increased diagnostic weighting given to REM sleep behavior disorder and ^{123}Iodine-metaiodobenzylguanidine (MIBG) myocardial scintigraphy. The diagnostic role of other neuroimaging, electrophysiologic, and laboratory investigations is also described. Minor modifications to pathologic methods and criteria are recommended to take account of Alzheimer disease neuropathologic change, to add previously omitted Lewy-related pathology categories, and to include assessments for substantia nigra neuronal loss. Recommendations about clinical management are largely based upon expert opinion since randomized controlled trials in DLB are few. Substantial progress has been made since the previous report in the detection and recognition of DLB as a common and important clinical disorder. During that period it has been incorporated into DSM-5, as major neurocognitive disorder with Lewy bodies. There remains a pressing need to understand the underlying neurobiology and pathophysiology of DLB, to develop and deliver clinical trials with both symptomatic and disease-modifying agents, and to help patients and carers worldwide to inform themselves about the disease, its prognosis, best available treatments, ongoing research, and how to get adequate support. *Neurology*® 2017;89:88–100

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DLB: Clinical Diagnostic Criteria

Essential Criterion	Dementia occurring before or concurrently with parkinsonism (usually with early and prominent deficits in attention, executive function, visuoperceptual ability; memory impairments usually evident w/ progression)
Diagnostic Categories	1. Probable DLB: 2 or more core clinical features, with or without indicative biomarkers OR 1 core clinical feature + 1 or more indicative biomarkers 2. Possible DLB: 1 core clinical feature with no indicative biomarker evidence OR 1 or more indicative biomarkers is present but no core clinical features
Core clinical features	1. Fluctuating cognition with pronounced variations in attention and alertness 2. Recurrent visual hallucinations (usually well-formed and detailed) 3. REM sleep behavior disorder (may precede cognitive decline) 4. One or more spontaneous features of parkinsonism (rest tremor, rigidity, bradykinesia)
Indicative biomarkers	1. Reduced basal ganglia dopamine transporter uptake on SPECT or PET 2. Abnormal (low uptake) 123iodine-MIBG myocardial scintigraphy 3, Polysomnographic confirmation of REM sleep without atonia
Supportive clinical features	1..Severe sensitivity to antipsychotic agents, 2. postural instability, 3. repeated falls, 4. syncope or other transient episodes of unresponsiveness, 5. severe autonomic dysfunction (e.g. constipation, OH, urinary incontinence) 6. hypersomnia, 7. hyposmia, 8. hallucinations in other modalities, 9. systematized delusions, 10. apathy, anxiety, and depression
Supportive biomarkers	1. Relative preservation of medial temporal lobe structures on CT/MRI scan, 2. generalized low uptake on SPECT/PET perfusion/metabolism scan with reduced occipital activity & the cingulate island sign on FDG-PET imaging, 3. prominent posterior slow-wave activity on EEG with periodic fluctuations in the pre-alpha/theta range

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Making the diagnosis

- Patient's presentation is consistent with probable DLB
  - Dementia by history
    - Need for more formal neuropsychological testing?
    - Parkinsonism, Visual Hallucinations, Hx of RBD
      - RBD is now core clinical feature- screen for with bed partner report (McKeith et al, Neurology 2017)
      - If there is doubt, refer to sleep specialist for PSG
        - If PSG demonstrates REM sleep without atonia in patient with dementia, there is a >90% likelihood of synucleinopathy (Boeve et al. Sleep Med. 2013).
- Review of consensus criteria
  - Two core criteria are needed for diagnosis
  - Remote examination may make detection of mild parkinsonism difficult (or parkinsonism may not be present). This is not necessarily needed for diagnosis if other features are there

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Making the diagnosis remotely

- History, history, history
  - Perhaps more reliant on a good history remotely as there may be limitations on examination
  - Understanding the profile of Cognitive impairment in LBD can aide in diagnosis
    - Characterized by disproportionately worse executive function, attention, and visuospatial function over other domains (McKeith et al, 2017; Bronnick et al, 2007)
  - History of RBD
    - Women may have less dream-enacting behaviors, (Zhou et al. Sleep Med. 2015)
  - Supportive criteria can be helpful
    - Autonomic dysfunction, hypersomnolence, etc.
- Utilization of diagnostic biomarkers
  - DATSCAN, PSG

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Comfort Among Experts Assessing LBD Virtually

- Survey results indicate that 8/14 (57%) respondents felt very comfortable or comfortable in *making* the diagnosis of LBD virtually
- 6/14 (43%) felt very comfortable or comfortable with *delivering* the diagnosis virtually.
- Ten (71%) respondents felt very comfortable or comfortable with determining the presence of moderate-severe parkinsonism virtually, but only 4/14 (29%) felt very comfortable or comfortable with determining the presence of trace-mild parkinsonism.

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Remote Cognitive Assessment

- No Standardized Approach at this time
- Validation studies in this population do not exist
  - Remote use of MoCA validated in PD (Abdolahi et al. Health Inform. 2016)
- Expert survey indicated MoCA BLIND as most utilized tool
  - Lacking for visuospatial/executive function
- Normal scores on MoCA and MoCA-BLIND
  - MoCA-BLIND ≥18 out of 22
  - MoCA ≥ 26 out of 30
  - Add 1 pt if ≤ 12 years education
- Referral for formal neuropsychological testing
  - Do what you can be done virtually, but may need follow-up in-person testing

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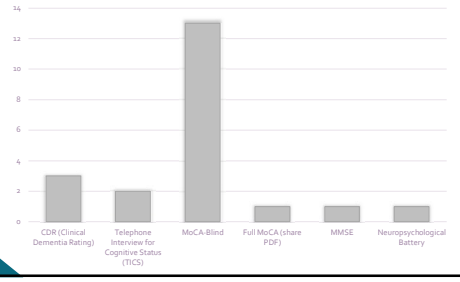
Figure 1 Preferred Virtual Cognitive Assessment



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Remote Motor Assessment

- Feasibility studies in PD patients
  - Cubo E et al Movement Disorders 2012
  - Dorsey ER et al Parkinsons Dis 2015
  - Dorsey ER et al Mov. Dis. 2010
  - Lacking studies that validate against in-person examination
- Recent Survey among experts indicated most use modified part 3 of MDS-UPDRS
  - No assessment of tone or postural stability
- What elements are “needed” to make diagnosis
  - May have patient “come in” if possible for follow-up examination

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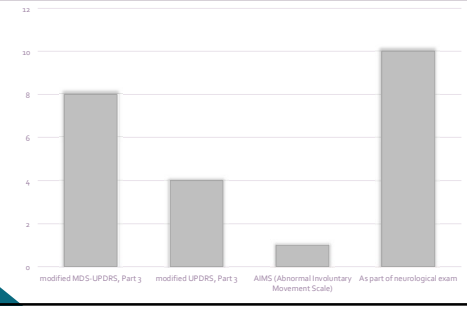
Figure 2 Preferred Virtual Motor Assessment



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The Delivery of Diagnosis Virtually

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Concern for delivery of diagnosis in remote setting

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- In our survey, 50% respondents indicated concern for delivery of the diagnosis (or "bad news") in the home setting versus in-person.
- Some respondents (21%) indicated concern with the virtual encounter negatively impacting the mental status of the person with LBD
  - e.g., the "distorted reality" of interacting via a screen or phone contributing to worsening confusion/disorientation).

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Delivery of diagnosis in remote setting

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- Are they Supported?
  - Presence of care partner, family, friend
    - Need for more work-up and in-person follow-up (if possible) to discuss more
- Assess whether they are ready to hear diagnosis
  - "I'm going to tell you what I think is going on - is that okay?"
- Explain diagnosis with empathy
- Empower
  - Diet and exercise should be considered
    - Recommendations based on benefits in PD (LBD patients often excluded from these trials)
      - Inskip et al. Exercise for Individuals with LBD: Systematic Review. 2016)
  - While no cure, have treatments that can help symptoms
- Provide information on education materials, support groups

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Case Presentation 2:
Addressing Technology Challenges/
Limitations of a Remote Visit

Drs. Amodeo and Fleisher

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Case 2 - Presentation

- 78 years old man follow-up for probable DLB
  - ~4 years of visuospatial disorientation, executive dysfunction, impairment in attention and delayed recall
  - Parkinsonism, rare hallucinosis
  - Impairment of high-level function (ie: driving, finances, managing appointments)
- Follow-up via televideo
  - Accompanied by wife and daughter who is a nurse
  - Patient really enjoyed not having to come to the office, but he and wife state they only could do the visit because their daughter was present
  - Visit went well but unable to see entirety of patient for thorough exam
  - Wife had concerns about his seemingly lack of motivation (apathy)

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Survey Results: Advantages of the Remote Visit

- Addresses travel and mobility limitations (100%)
- Allows providers to deliver care safely during times of pandemics or natural disasters (100%)
- Allows for evaluation of urgent issues outside of the emergency department (71%)
- Makes it easier for family members who live remotely from the patient to join then encounter (14%)
- Provides insight into the patient's home environment (7%).

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Survey Results: Limitations of the Remote Visit

- Technology failures (93%)
- Lack of familiarity with the applications or platforms among the patients or care partners (e.g., may take time in encounter to teach patient or care partner how to use) (79%)
- Many respondents (86%) found that the inability to perform a complete physical exam was a notable challenge.
- 50% of the respondents indicated concern for delivery of the diagnosis (or "bad news") in the home setting versus in-person.
- 21% indicated concern with the virtual encounter negatively impacting the mental status of the person with LBD (e.g., the "distorted reality" of interacting via a screen or phone contributing to worsening confusion/disorientation).

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Telemedicine: Challenges in this Population

- Only 55% of older adults own a smartphone or have internet access
- Only 60% able to find a website or send an email

Nouri S et al NEJM Catal Innov Care Deliv 2020.

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Overcoming Challenges/Limitations

Pre-Visit

- Choose a platform that is easy to use
  - Reliability, security/privacy
- Practice Runs
- Staff to check in prior to scheduled visit
- Tech Savvy family member present if possible
- Email instructions/expectations prior to patients/caregivers prior to visit
  - Demonstrate how to position camera
  - Tips for optimization of visit

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Email Instructions - Example

Telehealth Visit – Dr. Katherine Amodeo

Please follow the link below to your Telehealth visit from Dr. Katherine Amodeo. **Please log in 15-30 minutes early.**

https://doxy.me/drkatherineamodeo

- Ensure you are in the part of the house with the best internet connection.
- Position camera 6 to 8 feet away.
- Frame video so as mush of you as possible is visible.
- To avoid a dark silhouette, ensure a light source is in front of you/behind camera if possible

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Encourage Advanced Preparation Before Visit

	Cognitive Symptoms
	Forgetfulness
	Trouble with problem solving or analytical thinking
	Difficulty planning or keeping track of sequences (poor multi-tasking)
	Disorganized speech and conversation
	Difficulty with sense of direction or spatial relationships between objects
	Fluctuations
	Fluctuating levels of concentration and attention
	Unexplained episodes of confusion
	Excessive daytime sleepiness
	Parkinson's-like Symptoms
	Rigidity or stiffness
	Shuffling walk
	Tremor
	Slowness of movement
	Behavior and Mood Changes
	Hallucinations - Seeing things that are not really present
	Sleep Concerns
	Acting out dreams during sleep, sometimes violently, falling out of bed

Patient Instructions
Add a check mark next to any symptoms you are experiencing. Bring this form with you to your next appointment or send it to the doctor in advance. For more information on Lewy body dementia please visit www.lbda.org.

For Physicians: There are two clinical diagnoses that fall within the Lewy body dementia spectrum. ***This form may be helpful in diagnosing one of those disorders, dementia with Lewy bodies (DLB).*** The other form of LBD is Parkinson's disease dementia (PDD).

www.lbda.org/LBD-Diagnostic-Symptoms-checklist

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Overcoming Challenges/Limitations
During Visit

- To help with comfort of visit
  - Introduction is important
    - Why telehealth is being used
  - Affirm session is happening in "real time"
  - Provide reassurance
    - Security
      - Information will not be on internet
    - Establish visual context

Gough F et al. Telemed J E Health 2015.

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Overcoming Challenges/Limitations
During Visit

- Clarify roles, expectations, how encounter will be organized
  - Example: "I will start by hearing from you...then if it is okay, I may turn to your spouse for additional questions."
  - Clarify how others will be included (care partners, etc)
- May need separate follow-up call with care partner to ensure supported

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Telemedicine and LBD:
Tips for Patients Lewy Brief

Lewy Briefs: Telemedicine and LBD

www.youtube.com/user/LBDAtv

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Telemedicine and LBD:
Tips for Patients Handout

Telemedicine and LBD

The COVID-19 pandemic has greatly increased the use of telemedicine. For those living with LBD, it is now easier to get medical care.

Authored by: Jori Fleisher, MD, MSCE
Associate Professor, Movement Disorders, Rush Medical College, Rush University

www.lbda.org/Telemedicine-and-LBD-Lewy-Brief-Companion-Article

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Overcoming Challenges/Limitations

- Have a backup plan if connection is lost
  - Phone visit
- Summaries, Post-visit communication
  - Arranging for follow-up
  - Sending after visit summaries
- It may be best to arrange for in-person follow-up if video exam was inadequate

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Conclusions/Discussion Points

- The call for telemedicine during pandemic is clear, but has a role going forward
  - There are clear advantages and limitations
- Need for validation studies/new standards in making a diagnosis of LBD virtually
  - What is needed for motor exam, etc
- Setting Expectations/Pre and Post Communication may lend to successful visits

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Panel Discussion and Q&A

Moderator:
Katherine Amodeo, MD

Panelists:
Jori Fleisher, MD, MSCE
Karen Marder, MD
Jennifer Goldman, MD, MS

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Thank you!

- A follow up email will be sent to you at the end of this activity.
- Please complete the evaluation using the instructions in that email.
- After you complete the evaluation, you may download and print the CME credit/Certificate of Participation or save it to your computer in your files.

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CME Activities

- Webinar Series:
  - The Virtual Assessment in Lewy Body Dementia: Pandemic and Beyond
    - April 8, 2021: Understanding Current Research on Virtual Assessment
    - May 27, 2021: Impact of COVID-19 in those with LBD
- Medscape and LBDA collaboration
  - On demand: An Introduction to Lewy body dementia
  - More Medscape partnerships in development

Watch your inbox for more information about these activities!

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LBDA's Research of Excellence Program

A program consisting of 26 of the nation's leading LBD clinicians to which LBD patients and their families can turn for advanced LBD diagnosis and treatment.

Through our combined efforts we are connecting many experienced physicians and respected institutions that are committed to conducting LBD research, providing advanced LBD care, community outreach, and support.

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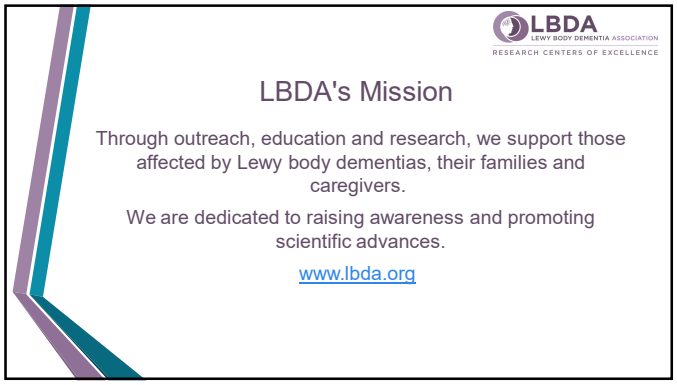
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LBDA's Mission
Through outreach, education and research, we support those affected by Lewy body dementias, their families and caregivers.
We are dedicated to raising awareness and promoting scientific advances.
www.lbda.org

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