

Parkinson's Disease(s) and Dementia

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Parkinson's and Movement Disorders Alliance
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About us...

The Layton Aging & Alzheimer's Disease Research Center at OHSU is one of 31 NIH Alzheimer's Disease Research Centers in the United States and the only one of its kind in Oregon.

The Layton Center conducts studies of caregiving, promising treatments, technologies for patient support, genetics, neuroimaging and pathology.

Along with research, we also provide evaluation and treatment for persons with dementia and their family members.

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Plan for Today

1. Review characteristics of dementia
2. Discuss unique challenges families living with PD and dementia face
3. Q and A



Parkinson's Disease(s) and Lewy Body Disease

Parkinson's disease (PD)

- A neurodegenerative disorder that affects predominately dopamine-producing (“dopaminergic”) neurons in a specific area of the brain called substantia nigra.
- People with PD may experience:
 - Tremor
 - Bradykinesia
 - Limb rigidity
 - Gait and balance problems
- **Approximately 70% of people with Parkinson's develop dementia**

Lewy body disease

- A type of dementia that looks like PD
- First symptoms are cognitive



Criteria for Dementia

(any)

Cognitive impairment which:

1. Interferes with the ability to function at work or at usual activities
2. Represent a decline from previous levels of functioning
3. Not explained by delirium or major psychiatric disorder

Impairment in a minimum of **two** of the following domains:

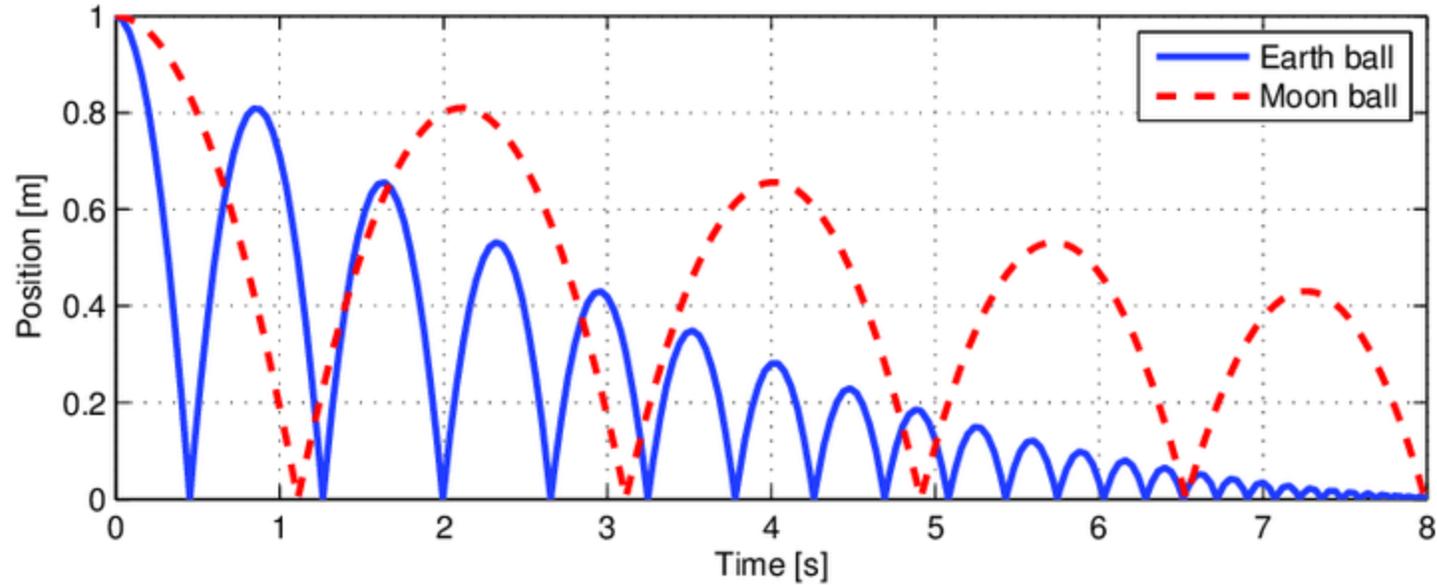
1. Ability to acquire and remember new information (working memory)
2. Reasoning and handling of complex tasks, poor judgment (executive)
3. Visuospatial abilities
4. Impaired language
5. Personality, behavior, or compartment



Alzheimer's disease



LBD

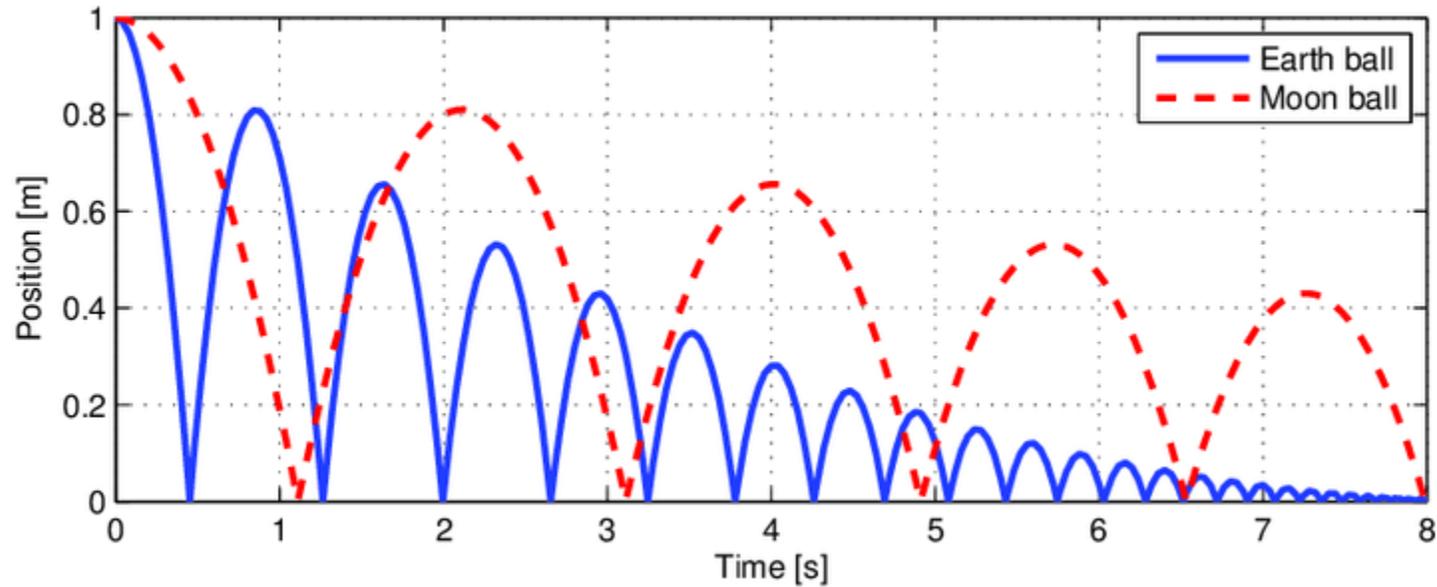


Features of LBD

- Cognitive decline that interferes with normal function
- Memory issues not always first concern
- Attention and judgement often noted to be early problems
- Cognition and alertness fluctuate
- Well formed visual hallucinations
- PD symptoms
- REM sleep disturbances



PD Dementia



Features of PD Dementia

- Parkinson's Disease
- Dementia after diagnosis of PD
- Memory issues (recall)
- Attention and judgement
- Cognition and alertness fluctuate
- Well formed visual hallucinations
- Apathy, anxiety and or depression
- Excessive daytime sleepiness



Progression of Parkinson's Disease vs. Lewy Body Disease



Family Care



Challenges for Families with PD/LBD

- Fluctuations
- Hallucinations
- Mood issues
- Mobility
- Sleep
- Coping with variations on reality
- Physical health
- Behavioral symptoms notable



Who are the Care Partners?

- 36% report high emotional stress
- 17% report high physical strain
- 23% have difficulty caring for their own health
- Almost 30% of those who live with their care recipient feel alone



Who are the Care Partners?

- Up to 25% experienced verbal, physical or sexual abuse by the parent for whom they are caring
- 30% of people with dementia abuse their Care Partners and often, the abuse is reciprocated



Sources of “burden”

- Isolation
- Grief
- Financial strain
- Family conflict
- Uncertain future
- Behavioral symptoms



Care Partners Risks

- Depression
- Pre-death grief
- High blood pressure
- Immune system dysfunction
- Diabetes
- Sleep disturbances
- Memory problems



How are you doing?

Anonymous Poll

Which of these do you experience?

(check all that apply)

- a. Emotional Strain
- b. Physical Strain
- c. Financial Strain
- d. Loneliness/isolation
- e. All of the above



Behaviors



What Do We Mean By Behaviors?

“Behaviors” are tools that help us communicate. Most of the time we use words with the behaviors to deliver a clear message.

smiling, clapping, frowning, yelling



Behaviors



Behaviors

“How many times have I told you to clean your room??”



Anonymous Poll

My family member behaves in ways that upsets me.

- Daily
- Two to three times/week
- Once a month
- Never



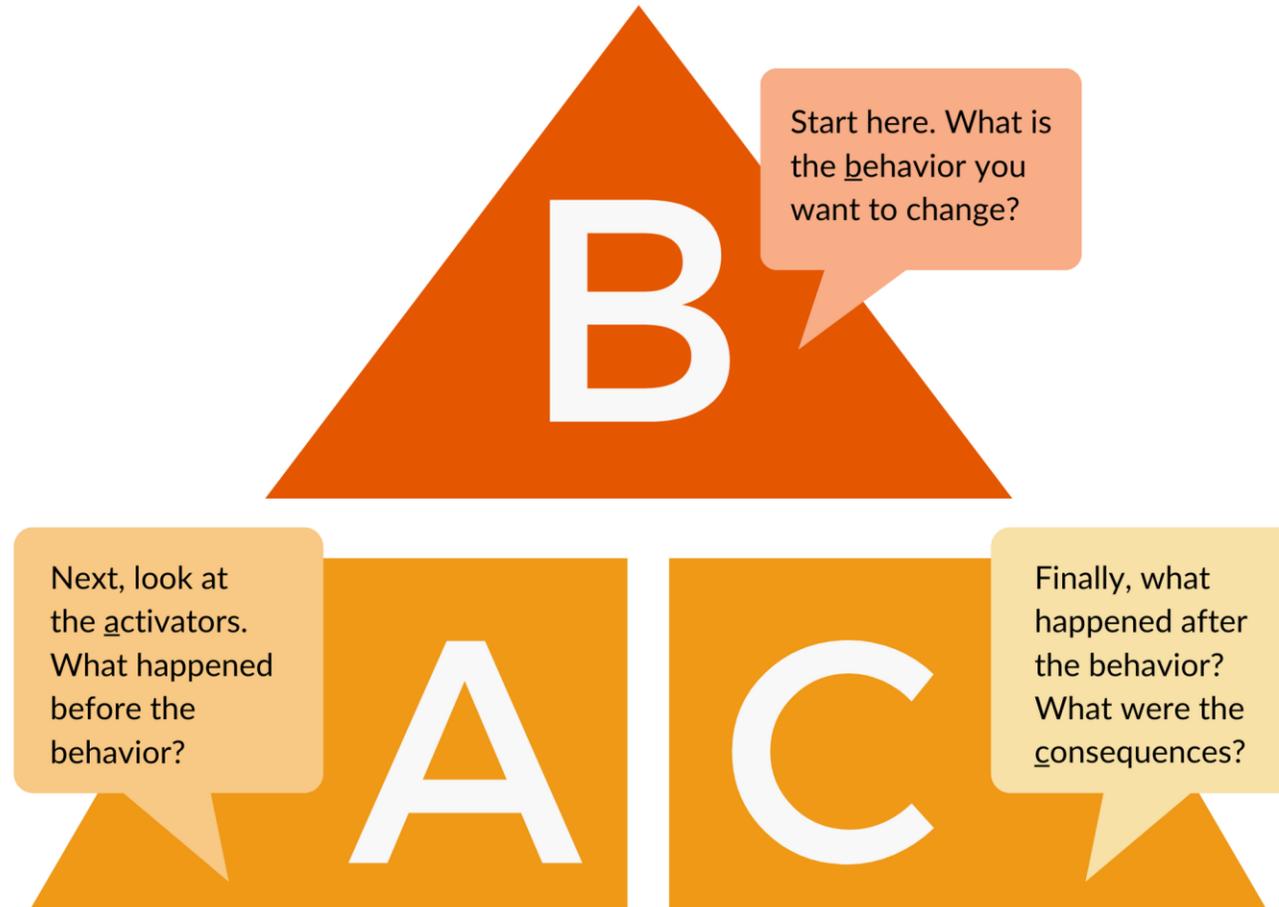
Anonymous Poll

I understand their behavior and know how to cope with it.

- True
- False



Approach to Understanding Behaviors





First, describe the behavior in detail (what do you see and hear?)





Next, think about “A”, Activators. What happens before B, the Behavior?





What are the consequences?

What happens after B, the Behavior?





- Andrea is Ted’s wife. Ted has Lewy Body Disease. About four times a week Ted tells Andrea that she needs to cook extra food for their company.
- Andrea feels angry. She knows that Ted is referring to the little people in his hallucinations, but he doesn’t comprehend that.
- Andrea is grumpy, she has a glass of wine (or three) while making dinner.
- She wants Ted to stop asking to make dinner for the “company.”





Observe

- Andrea takes some time to look, listen and think about Ted's **B**ehaviors
- She notes what happens prior to his requests (the "**A**ctivators")
- She notices how she and Ted feel afterwards

Brainstorm

- Andrea realizes she is demonstrating behaviors too
- She knows she can't control the hallucinations
- She brainstorms ways to cope
- She calls Ted's sister to get ideas

Make a plan

- Ted's sister can make dinner once a week so Andrea can get out of the house.
- Andrea learns to listen to Ted with respect, comfort, and re-direct

Try it!





Key Points

- Understanding and addressing behaviors takes time
- Make a plan—then *TRY* it. If it doesn't work, try again (and again)
- Call your neurologist/nurse/social worker if you aren't making any progress
- Find people to support you
- Make time for yourself



I'm going to think about an ABC plan to help me and my family cope with upsetting behaviors

- Nope
- Maybe
- I think so
- Likely
- Sure!





JOIN THE



Tele-STELLA STUDY

Do you care for a family member with dementia? Would you like to learn more about coping with upsetting behaviors and mood?

Researchers are working to understand how to help family members who care for someone with dementia.

YOU MAY BE ELIGIBLE IF:

- You care for a family member with Alzheimer's disease or a similar dementia.
- Your family member has 2 or more bothersome behaviors. For example, asking the same question over and over, pacing or refusing help with personal care.
- You provide care, such as personal care and/or supervision, for 4 or more hours per week.

STUDY PARTICIPATION INCLUDES:

- 16 visits by video conference to learn how to manage challenging behaviors related to dementia. Each visit lasts about 1 hour.
 - 4 visits will be in private, with a professional Guide
 - 4 visits will be in small groups, with a professional Guide
 - 8 visits will be in a large group, with a professional Guide
- Complete electronic surveys during the study period (about 6 months to 1 year)
 - 6 surveys about mood, coping & family member behaviors
 - Brief weekly surveys about mood and costs of care
- An optional focus group

ADDITIONAL INFO:

- All study activities are done from your home, no travel is needed
- Your family member with dementia does not need to live with you
- If you do not have a computer, we can loan you one for the study
- Gift cards up to \$100 may be provided for completing all study activities

For more information, visit our website www.tele-stella.org



PI: Dr. Allison Lindauer
OHSU IRB # 22288

For caregivers in Oregon, Washington, Kentucky, and Georgia



Review

- Dementia: PD and LBD
- Caregiving
- Strategies to address burden



Last Poll:

How helpful was this presentation for you?

- Not all helpful
- Somewhat helpful
- Helpful
- Moderately helpful
- Very helpful



THANK YOU!

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