

# Understanding and Living with Lewy Body Dementia

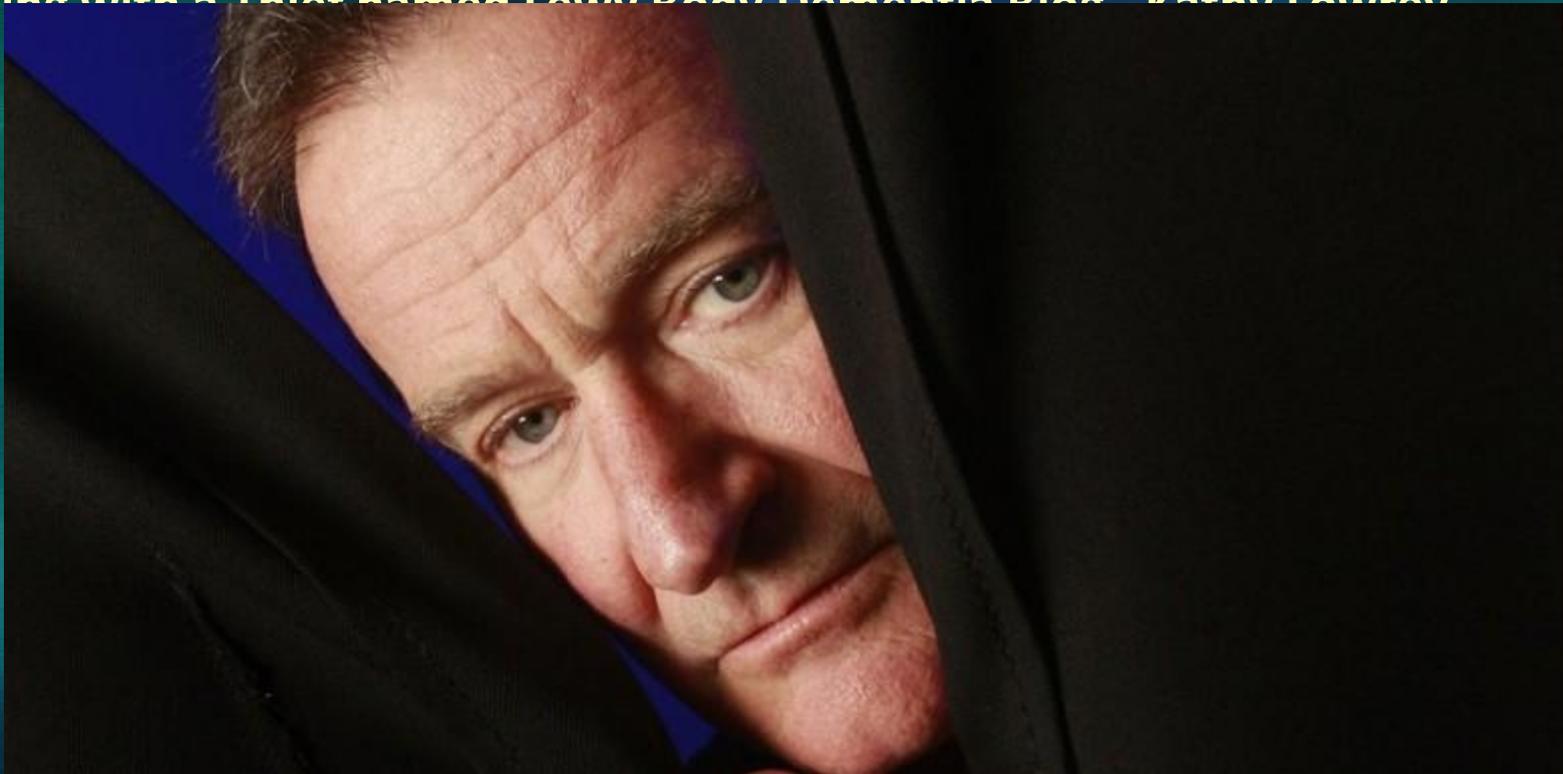
Tracy Sherman MD



The ride on the Lewy Body Roller coaster ended.

The seat belt that had us held prisoner was removed and we exited the car.

Living with a Thief named Lewy Body Dementia Blog - Kathy Lewrey



# Understanding and Living with Lewy Body Dementia

What is Lewy Body Disease?

What are the symptoms and why do they occur?

What are the current treatments available?

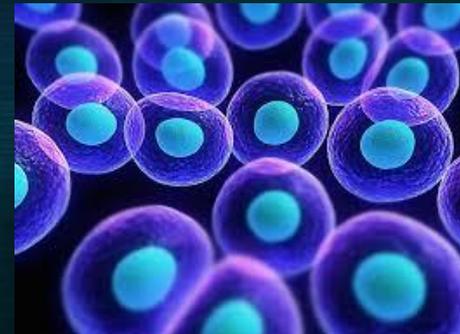
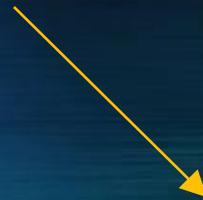
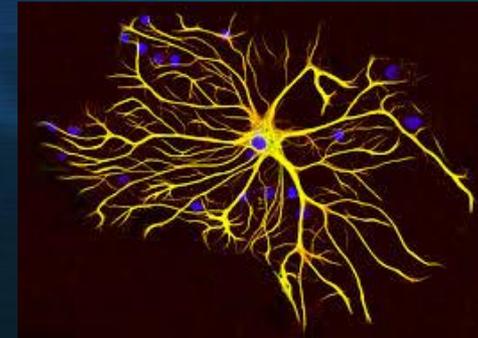
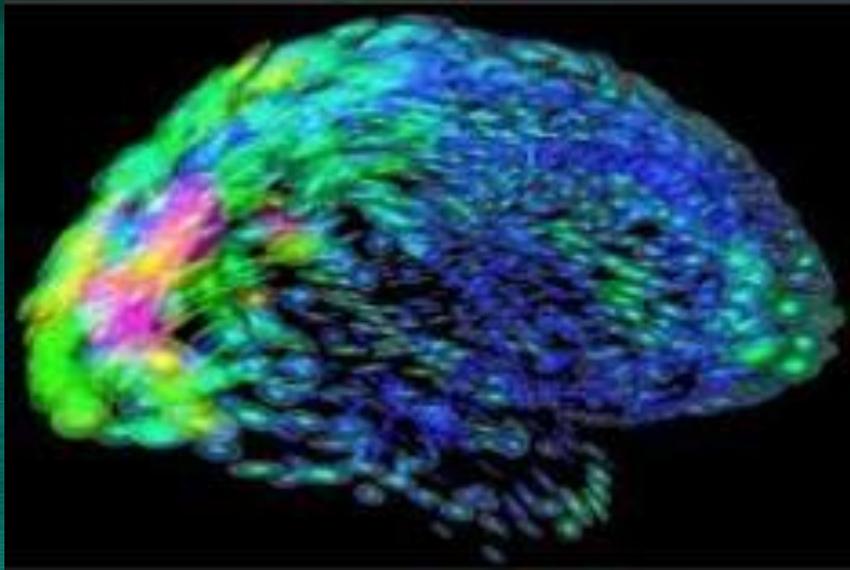
How can we best live with Lewy Body Dementia

What does the future hold?

Lewy  
What?



# Understanding and Living with Lewy Body Dementia



# Understanding and Living with Lewy Body Dementia



86 billion neurons in the brain

Every neuron communicates with up to 10,000 other neurons via neurotransmitters, degenerative dementias cause disruption of neurotransmitters.

Neurons do not replicate (decrease with age)

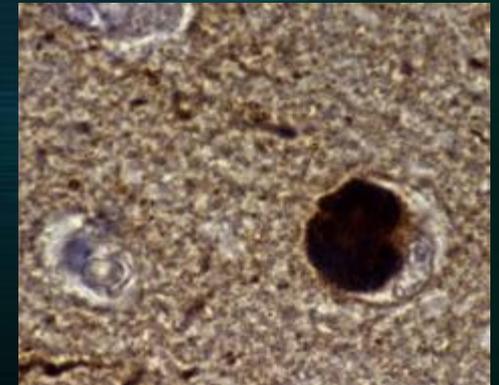
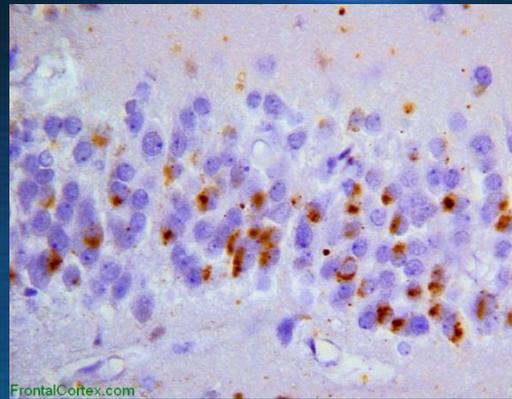
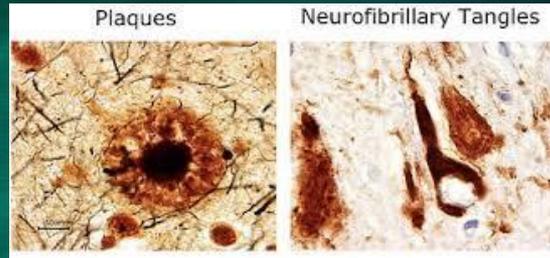
Are the cells most disrupted and are the cause of symptoms of degenerative dementias

# Understanding and Living with Lewy Body Dementia

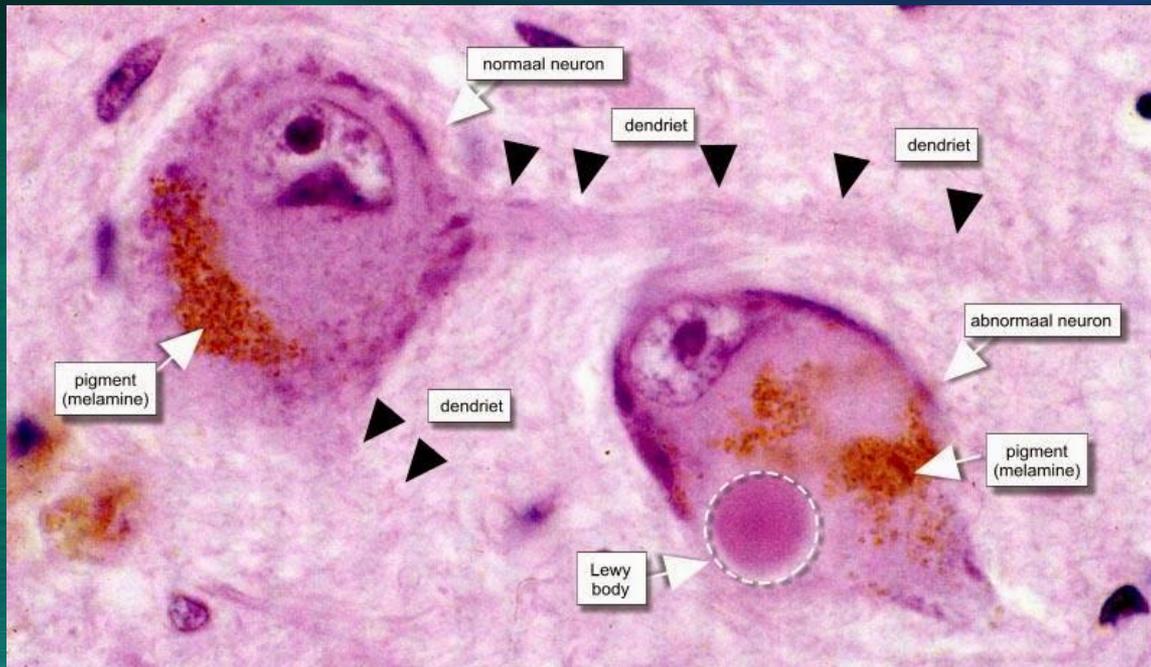
Alzheimer's disease

Frontal Temporal Dementia

Lewy Body Dementia



# Understanding and Living with Lewy Body Dementia



First discovered by  
Dr. F H Lewy in  
1912 with  
studying with Dr.  
Alois Alzheimer

Made up of  
protein known as  
alpha synuclein

Also the  
abnormality found  
in Parkinson's  
disease

# Understanding and Living with Lewy Body Dementia

- Understanding the Term “**Lewy Body Disease**”
  - **Dementia with Lewy Bodies** (what we refer to as Lewy Body Dementia) – second most common form of dementia
  - **Parkinson’s disease**

# Understanding and Living with Lewy Body Dementia

## Timeline for Lewy Body Dementia



?RBD

MCI

DLB

# Understanding and Living with Lewy Body Dementia

Criteria for diagnosing probable Lewy Body Dementia

Core symptoms

fluctuating attention and concentration

recurrent, well formed visual  
hallucinations

spontaneous signs of parkinsonism

(? REM sleep behavior disorder?)

# Understanding and Living with Lewy Body Dementia

Suggestive symptoms of Lewy Body Dementia

- \*REM sleep behavioral disorder

- \*Sensitivity to neuroleptic medications

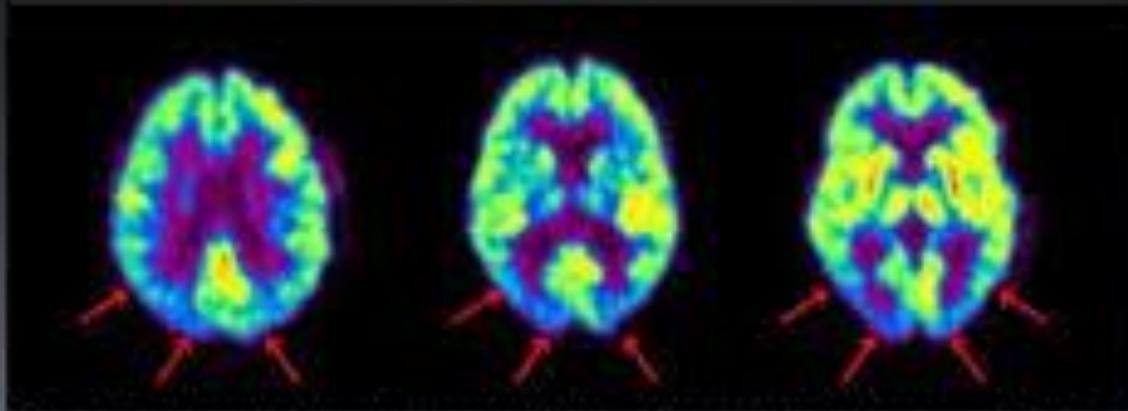
Delusions, Illusions (misidentification) and other forms of Hallucinations

Autonomic Dysfunction

Frequent Falls

# Understanding and Living with Lewy Body Dementia

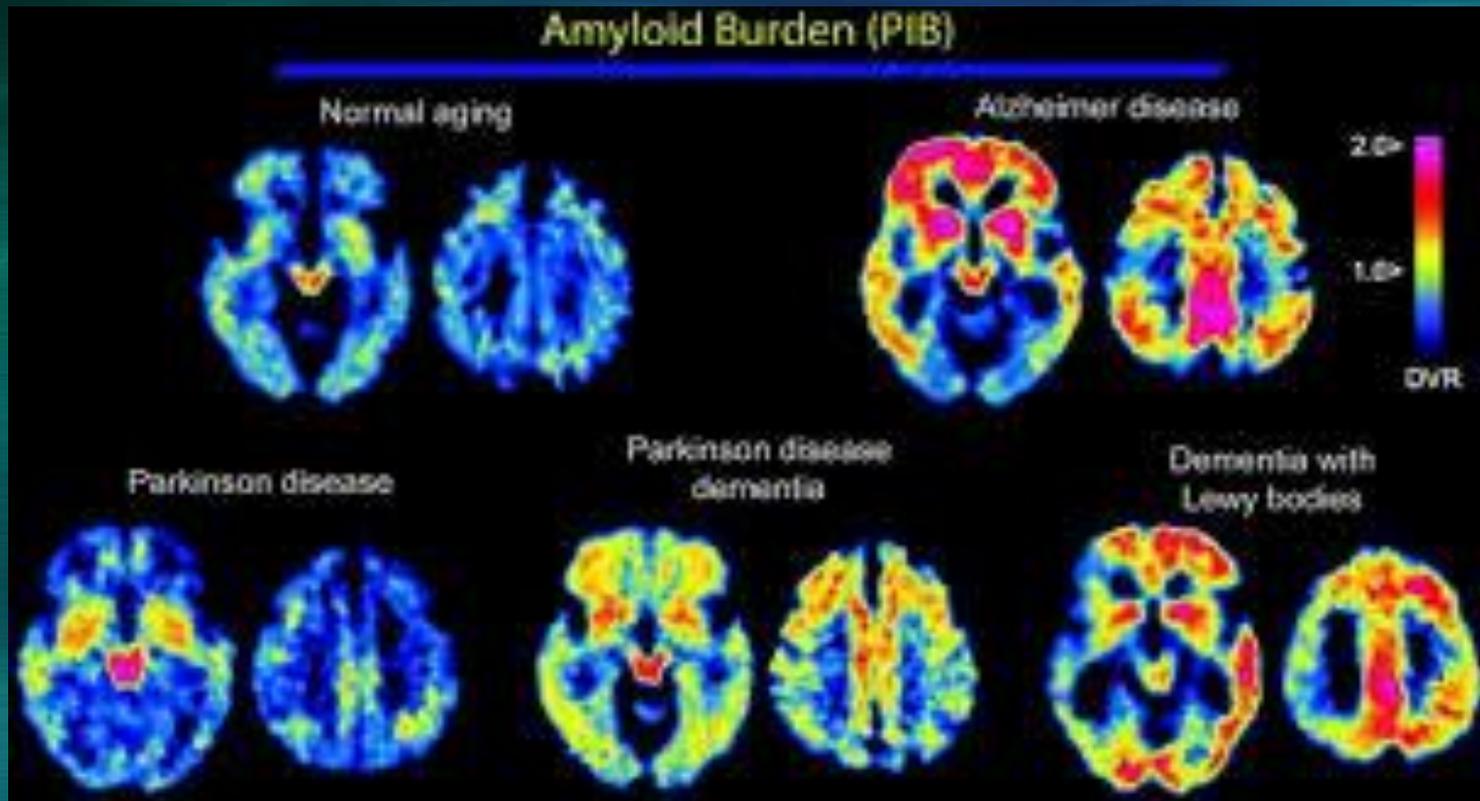
## Lewy Body Dementia: SPECT and PET



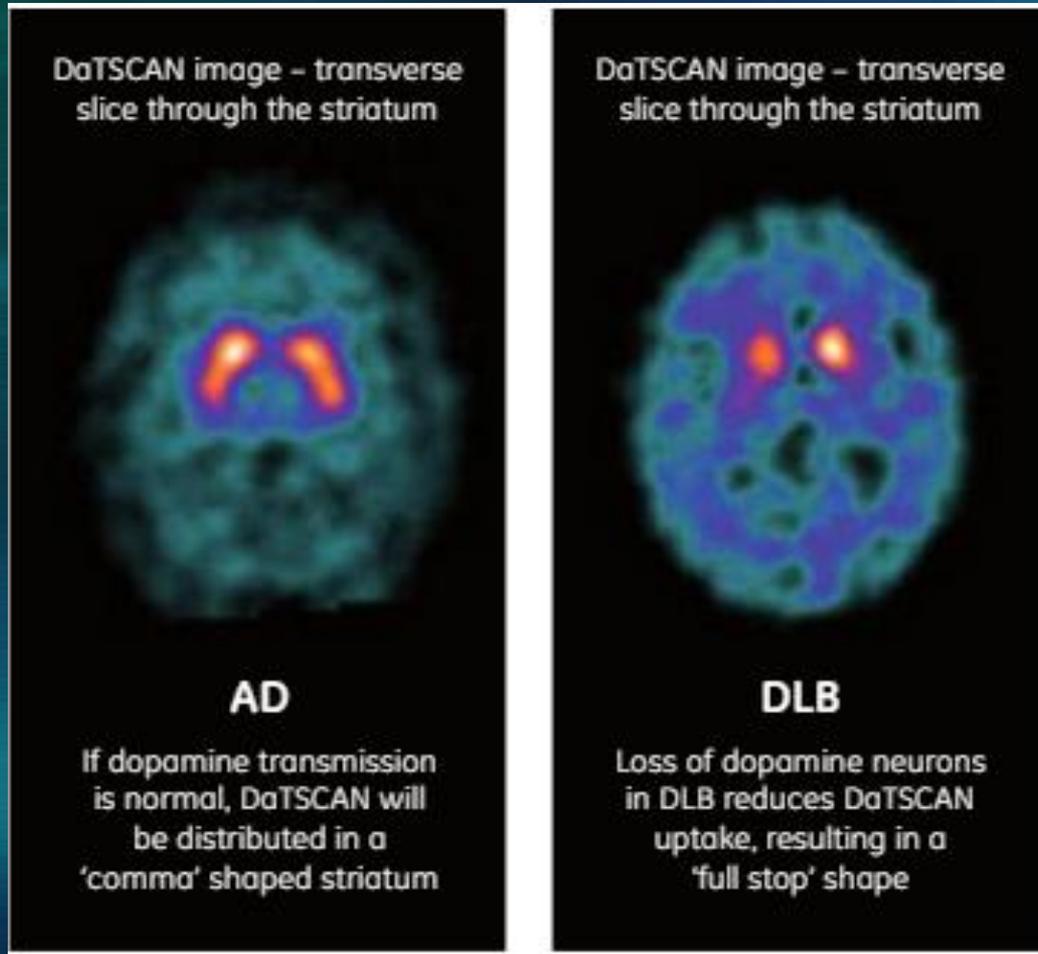
FDG PET demonstrating decreased uptake in the occipital lobes in addition to posterior temporoparietal lobes, bilaterally [arrows]

Silverman et al., Semin Nucl Med 38:251-261, 2008

# Understanding and Living with Lewy Body Dementia



# Understanding and Living with Lewy Body Dementia



# Understanding and Living with Lewy Body Dementia

**Table 1**

Lewy body composite risk score

Please rate the following physical findings being present or absent for the past 6 mo and symptoms as being present or absent for at least 3 times over the past 6 mo.		
Does the patient...	Yes	No
Have slowness in initiating and maintaining movement or have frequent hesitations or pauses during movement?		
Have rigidity (with or without cogwheeling) on passive range of motion in any of the 4 extremities?		
Have a loss of postural stability (balance) with or without frequent falls?		
Have a tremor at rest in any of the 4 extremities or head?		
Have excessive daytime sleepiness and/or seem drowsy and lethargic when awake?		
Have episodes of illogical thinking or incoherent, random thoughts?		
Have frequent staring spells or periods of blank looks?		
Have visual hallucinations (see things not really there)?		
Appear to act out his/her dreams (kick, punch, thrash, shout or scream)?		
Have orthostatic hypotension or other signs of autonomic insufficiency?		
Total score		

Copyright 2013 *The Lewy Body Composite Risk Score* James E. Galvin, MD, MPH.

# Understanding and Living with Lewy Body Dementia

Symptoms can be broken down into different categories

Cognitive

Neuropsychiatric

Motor

Sleep

Autonomic



# Understanding and Living with Lewy Body Dementia

Cognitive symptoms, deficits in:

- executive function (planning, organizing)

- speed of thinking

- spatial orientation

- visual identification

- attention and concentration

# Understanding and Living with Lewy Body Dementia

Cognitive symptoms:

related to deficits in acetylcholine and dopamine

Worsened by medications that block these  
chemicals

acetylcholine- antihistamines  
(Benadryl), bladder medications  
(Oxybutynin), muscle relaxants  
(Cyclobenzaprine), tricyclic  
antidepressants (Amitriptyline)

Dopamine- antipsychotics (Haldol),  
antiemetics (metoclopramide), melatonin

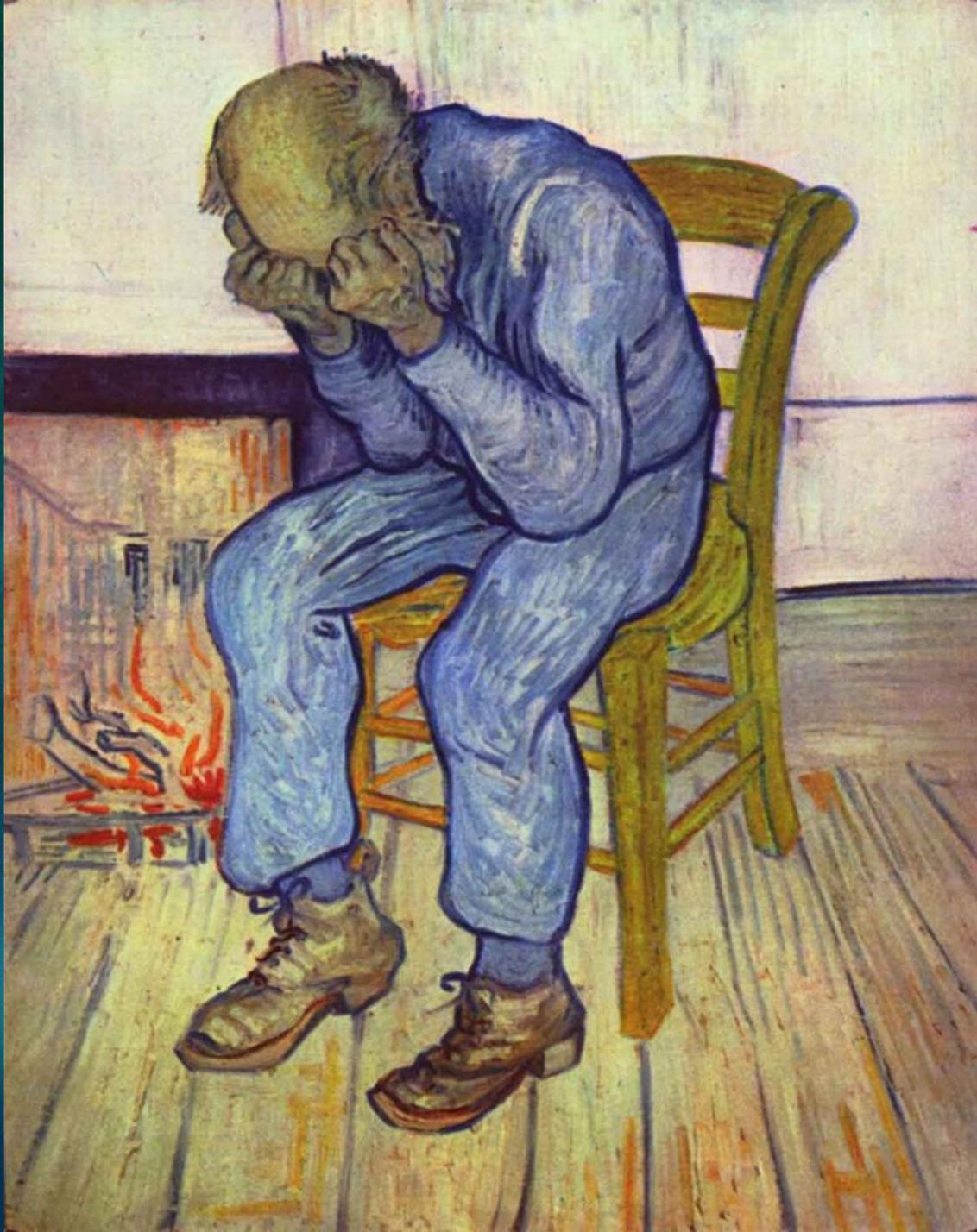
# Understanding and Living with Lewy Body Dementia

Medications that can improve cognition:

cholinesterase inhibitors (donepezil,  
rivastigmine, galantamine)

Sinemet (carbidopa-levodopa)

Memantine



# Understanding and Living with Lewy Body Dementia

Neuropsychiatric symptoms:

hallucinations

illusions (misidentification)

delusions

Capgras syndrome (misidentification of spouse, primary care giver or home)

Depression

Anxiety

Agitation/Aggressive behaviors

# Understanding and Living with Lewy Body Dementia

## Neuropsychiatric symptoms

associated with decrease in acetylcholine and serotonin (5HT3) and increase in dopamine and epinephrine

Worsened by medications that effect these neurotransmitters

- anticholinergics (see previous list)

- 5HT3 blockers- antiemetics such as ondansetron

- DA agonists- Parkinson's medications

- Epinephrine agonists- stimulants (

# Understanding and Living with Lewy Body Dementia

Treatment of neuropsychiatric symptoms

Cholinesterase inhibitors

Antidepressants (SSRI, NSRI, mirtazapine, bupropion)

Atypical Antipsychotics (\*\*\*)black box warning) most often used is quetiapine, probably most effective is clozapine (but higher risk of mortality due to neutropenia and myocarditis)

Pimavanserin (Nuplazid)

Anxiolytics- Avoid use of benzodiazapines (ex: lorazepam, alprazolam except for RBD)

# Understanding and Living with Lewy Body Dementia

Pimvanserin

Approved 4/2016 for Parkinson's disease with psychosis

Acts as an 5HT<sub>2A</sub> inverse agonist (rather than direct agonist of 5HT<sub>2A</sub> and D<sub>2</sub> receptors as atypical antipsychotics do)

Most common side effects: nausea, peripheral edema and confusion

Estimated annual cost: \$23,400 (\$1950 per month)



# Understanding and Living with Lewy Body Dementia

## Motor/Movement symptoms (Parkinsonism)

tremor

bradykinesia (slowing)

rigidity

myoclonus (limb jerking)

shuffling gait

stooped posture

fine motor skills disrupted

masked facies

drooling/swallowing difficulties

hypophonia (soft voice)

# Understanding and Living with Lewy Body Dementia

Associated with decrease in dopamine

Worsened by medications that block dopamine  
(see previous slide on cognition)

Improved by medications that increase dopamine-  
Parkinson's medications (sinemet, Mirapex,  
Requip, Neupro patch)

# Understanding and Living with Lewy Body Dementia

For speech and swallow symptoms (drooling, difficulty chewing, pocketing food, coughing on liquids/foods, food sticking in the throat, “forgetting to swallow”)

Speech amplifier (Spokeman)

Speech therapy

“Chin tuck”



# Understanding and Living with Lewy Body Dementia

## Sleep symptoms

REM sleep behavior disorder (video)

Daytime somnolence

Insomnia

Obstructive Sleep Apnea

Central Sleep Apnea

Restless legs syndrome

Periodic Limb Movements

# Understanding and Living with Lewy Body Dementia

Different symptoms associated with different neurotransmitter issues and treated differently

RBD- clonazepam-increase in GABA(can cause daytime confusion)

Daytime Somnolence- Provigil, Ritalin – increase in dopamine, epinephrine and histamine

Insomnia- trazadone – increase in serotonin



# Understanding and Living with Lewy Body Dementia

## Autonomic dysfunction

orthostatic hypotension (drop in blood pressure when changing position)

impotence

urinary Incontinence

constipation

# Understanding and Living with Lewy Body Dementia

Treatments vary

Orthostatic hypotension- salt, water, compression stockings, midodrine (can be made worse by Parkinson's meds and BP meds)

Impotence- PDE5 inhibitor such as Viagra

Urinary Incontinence- muscarinic antagonist Sanctura (but can make cognition worse)

Constipation- water, seneke, miralax



**FALL RISK**

# Understanding and Living with Lewy Body Dementia

## Special Issue: Falls

gait changes

rigidity

move too slow/too fast

deconditioning

autonomic dysfunction

flexibility and balance

change in vision/interpretation

lack of proprioception

deficit in attention

deficit in integration/planning

# Understanding and Living with Lewy Body Dementia

Treatment for one symptom may worsen another so it is important to use individual symptoms effecting quality of life to guide individualized treatment plan

# Understanding and Living with Lewy Body Dementia

*On The Other Side of  
Suffering is Joy*



# Understanding and Living with Lewy Body Dementia

ACCEPTANCE

EMPATHY

COMMUNICATION SKILLS

UNDERSTANDING NEEDS

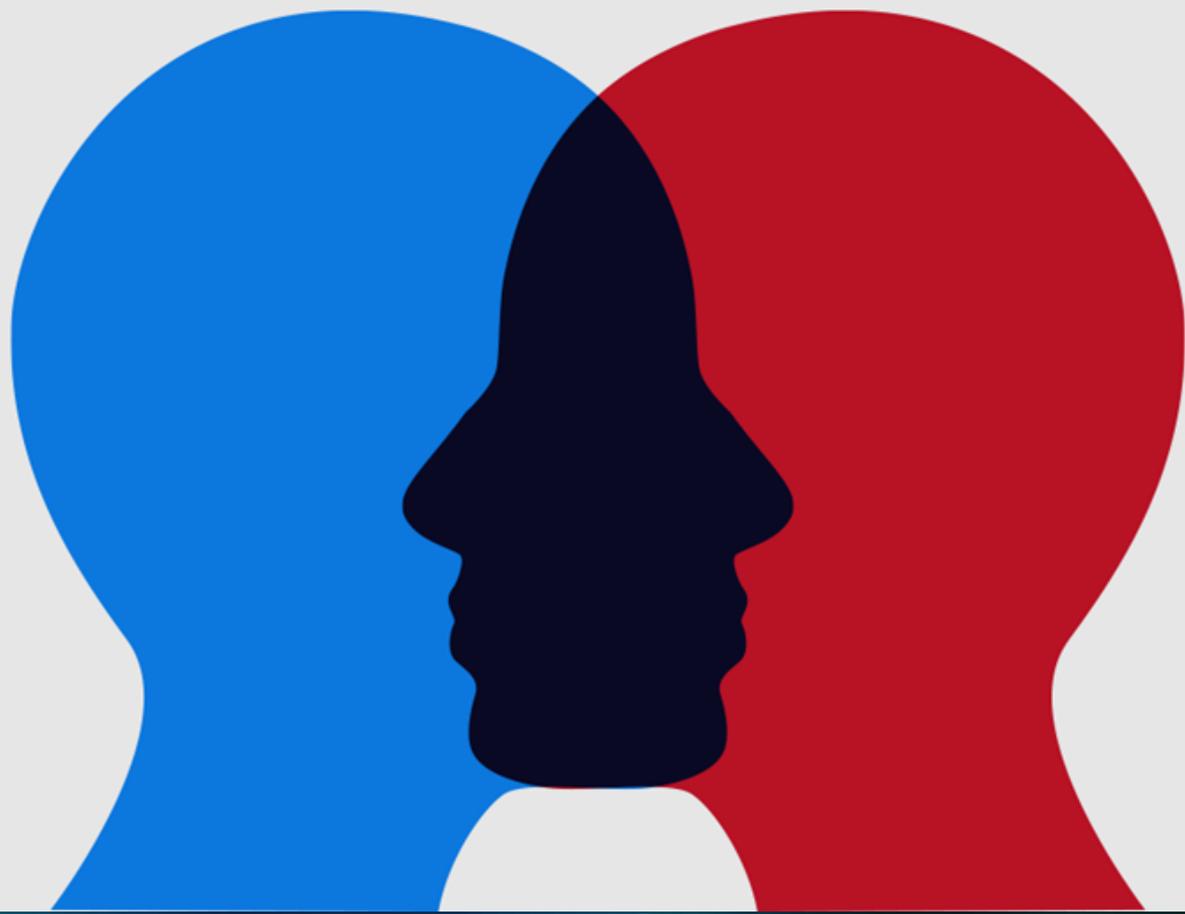


# Understanding and Living with Lewy Body Dementia

## ACCEPTANCE

Not the same as “giving up”

The disease/behaviors are ALWAYS  
changing, we must change with them



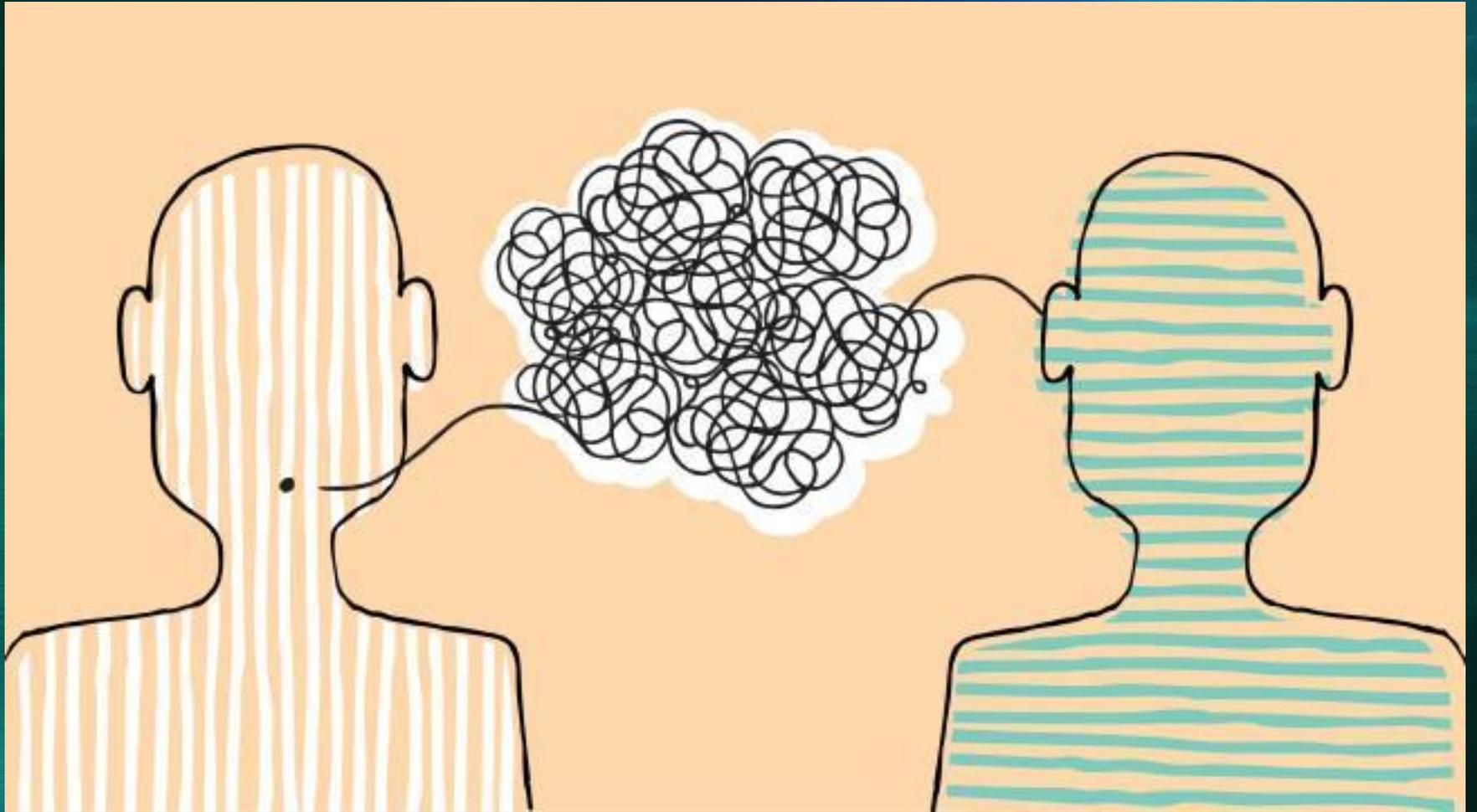
# Understanding and Living with Lewy Body Dementia

## EMPATHY

Behaviors are biomedical and a reasonable reaction to the person's experience

See through their eyes: begin to see solutions

Modify tasks and demands



# Understanding and Living with Lewy Body Dementia

## COMMUNICATION SKILLS

Slow down

Clear and concise

One step requests

Avoid drawn out explanations

Don't try to convince them of something

Keep voice volume moderate- tone of voice changes with volume

Uninterrupted time to process and respond (don't talk for them!) but ok to help them get "unstuck"

Environment free of distractions

Look directly at the person when you talk to them

Watch your tone and body language

# mentia Understanding and Living with Lewy Body Dementia

- Get attention, approach slowly
- Face directly
- Maintain eye contact
- Smile
- Appear relaxed
- Orient (repeat key words)
- paraphrase
- give time to comprehend
- ask “yes/no” questions
- provide two options at a time
- one question/instruction at a time

# Understanding and Living with Lewy Body Dementia

continue same topic for as long as possible

prepare/cue for a new topic

short/simple/direct sentences

\*\*\*Repeat nouns rather than pronouns

hand signals, pantomimes, pictures

facial expressions

begin conversations with pleasant/normal topics

ask easy questions

give the person clues as to how to answer

Don't correct but can repeat what they say using correct word

Ask them to "talk around" or describe something

ignore unimportant errors

ask to speak louder if they are getting too soft

Dementia does not  
rob someone of their  
dignity, it's our  
reaction to them that  
does.

**Teepa Snow**

[AlzheimersCaregiverMinute.com](http://AlzheimersCaregiverMinute.com)



# Understanding and Living with Lewy Body Dementia

## UNDERSTANDING NEEDS

Need to feel respected

Need to feel sense of control

Need to feel useful and worthy

Need to give and receive love

# Understanding and Living with Lewy Body Dementia

**MOST EMOTIONAL DISTRESS  
OCCURS WHEN A BASIC  
EMOTIONAL NEED IS  
THREATENED**

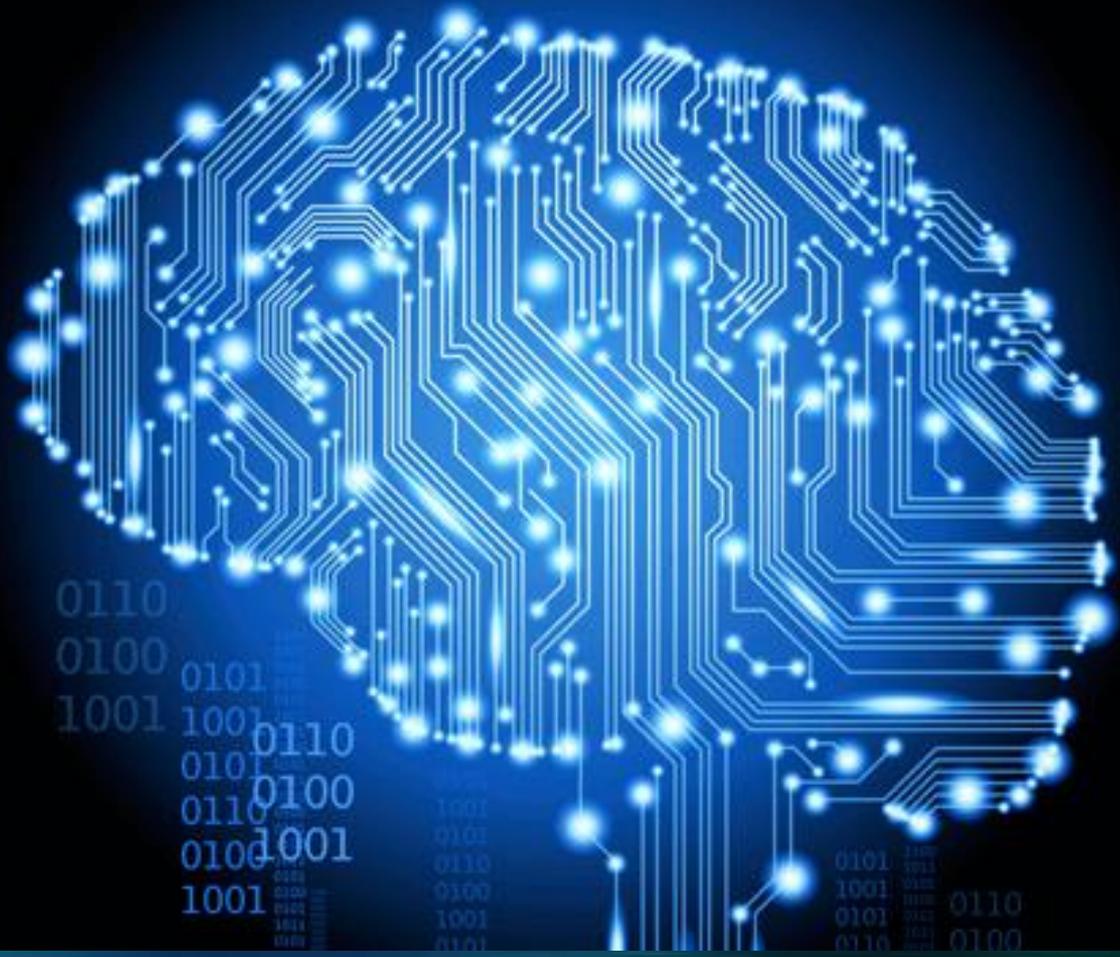


# Understanding and Living with Lewy Body Dementia

SEE STRENGTHS, NOT WEAKNESSES

REMEMBER, YOU ARE A TEAM, YOU  
NEED EACH OTHER TO "WIN"

IF YOU DON'T LAUGH, YOU CRY



# Understanding and Living with Lewy Body Dementia

## THE FUTURE

Genetics- very complicated, research into genes that put one at risk. One gene known (alpha SNCA gene) only a few dozen people in the world

Little effect of APOE. Some increased risk with a first degree relative with DLB, AD or PD



Aging researchers

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# Understanding and Living with Lewy Body Dementia

## THE FUTURE

Sleep Research- Almost everyone who develops RBD will go on to develop DLB or PD , how to use that information to identify people decades before they develop the disease

Imaging- use of MRI, PET , PIB and DaT scans to identify earlier



# Understanding and Living with Lewy Body Dementia

## THE FUTURE

### Therapeutics-

RVT101- 5HT6 antagonist in phase 2 trials for cognition (Recruiting)

Nelotanserin- similar to Pimavanserin, phase 2 trials in DLB or PDD with psychosis (Recruiting)

# Understanding and Living with Lewy Body Dementia

## THE FUTURE

Nuvigil- sleep, apathy and quality of life studies, phase 3 trials (completed- no results available)

Donepezil- clinical trial (already being used, but only approved in Japan)-post marketing (Recruiting)

Nilotinib- decrease alpha synuclein in CSF (completed-no results available)

# Understanding and Living with Lewy Body Dementia

## THE FUTURE

Immunotherapy- Alpha synuclein antibodies,  
phase 1 trials

vaccine- D001A and PA03A

passive- B11B054 and PRX002

Deep Brain Stimulation- currently recruiting  
(London)

*Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.*

LEO BUSCAGLIA



# Understanding and Living with Lewy Body Dementia

Resources:

The Lewy Body Dementia Association

<https://www.lbda.org>

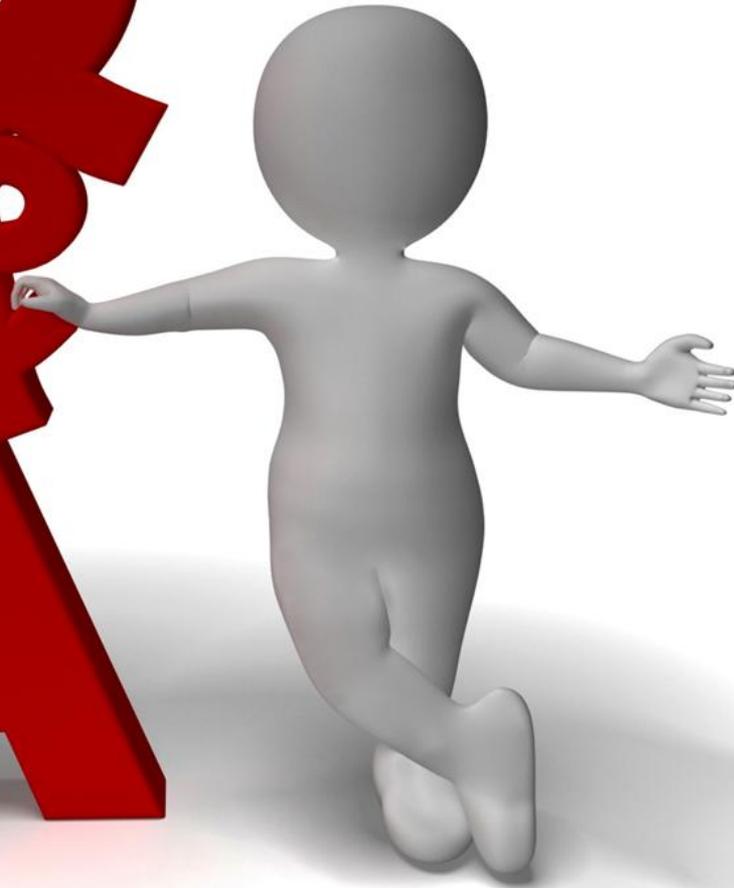
The Alzheimer's Association [www.alz.org](http://www.alz.org)

Living with a thief named Lewy Body Dementia

blog [www.thieflewybodydementia.com](http://www.thieflewybodydementia.com)

Clinical Trials <https://clinicaltrials.gov>

Q  
&  
A



THANK YOU !

