

# *Palliative Care and the Lewy Body Dementias: Educating the Next Generation of Nurses*



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Susan & Charles Berghoff Foundation



Robin Shepherd

**Presented by:**



# AGENDA

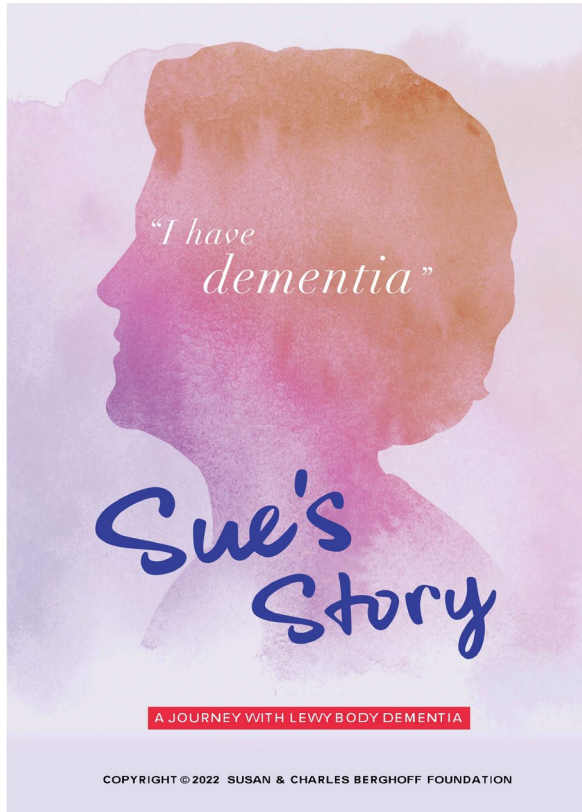
- 1:30**      **Introduction & mindfulness exercise**
- 1:40**      **Film**
- 2:05**      **Presentation by Dr. Jocelyn Jiao**
- 2:40**      **Presentation by Chuck Berghoff**
- 3:00**      **Q&A**
- 3:20**      **Closing remarks**



# LEARNING OBJECTIVES

1. Define 3 symptoms associated with LBD
2. Describe 3 ways palliative care benefits LBD patients and their families
3. Understand how to apply one element from this workshop in an education program

# Sue's Story: A Journey with Lewy Body Dementia



- Adopted by **Kaiser Permanente** and other health systems for Continuing Medical Education
- Adopted by **SJSU** and other universities for Nursing and Allied Health curriculum
- Featured by **AARP** and other organizations for community health education
- Viewed by thousands of people with little or no prior knowledge of Lewy body dementia

# ROADMAP



How do we describe dementia?

What are Lewy Body dementias (LBD)?

What are the challenges of living with LBD?

How do we describe palliative care?

What are the benefits of palliative care for people living with LBD and their families?



# WHAT IS DEMENTIA?



**Normal cognition Mild cognitive impairment Dementia**

A syndrome of cognitive impairment severe enough to interfere with basic activities of daily living (ADLs). Dementia is progressive.

# DISEASES THAT LEAD TO DEMENTIA



- Alzheimer's disease
- Lewy body disease
- Frontotemporal degeneration
- Mixed-etiology dementia
- Vascular disease

\* Some conditions mimic dementia symptoms (UTI, B-12 deficiency, delirium, thyroid problem)

Alzheimer's Disease  
and Related Dementias  
or "ADRDs"

SOURCE: NAT'L INSTITUTES OF HEALTH

# LEWY BODY DEMENTIAS

LBD is the 2<sup>nd</sup> most common type of neurodegenerative dementia after Alzheimer's, but it's not as well known or understood.

SOURCE: MAYO CLINIC





# Lewy Body Disease Lewy Body Dementias



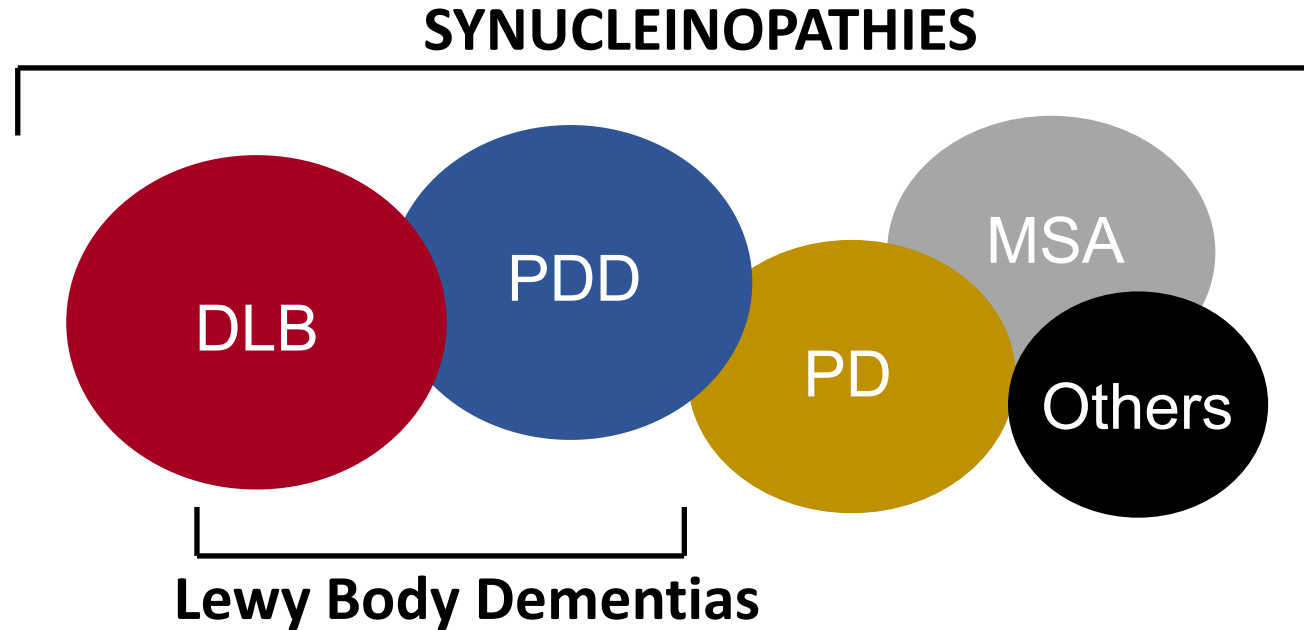
**Disease:** The **alpha-synuclein** protein forms clumps or “Lewy bodies” that impair brain function and cause brain cells to die.

**Diagnoses:**

- **Dementia with Lewy bodies (DLB)**
- **Parkinson’s disease dementia (PDD)**

SOURCE: NAT’L INSTITUTES OF  
NEUROLOGICAL DISORDERS AND STROKE

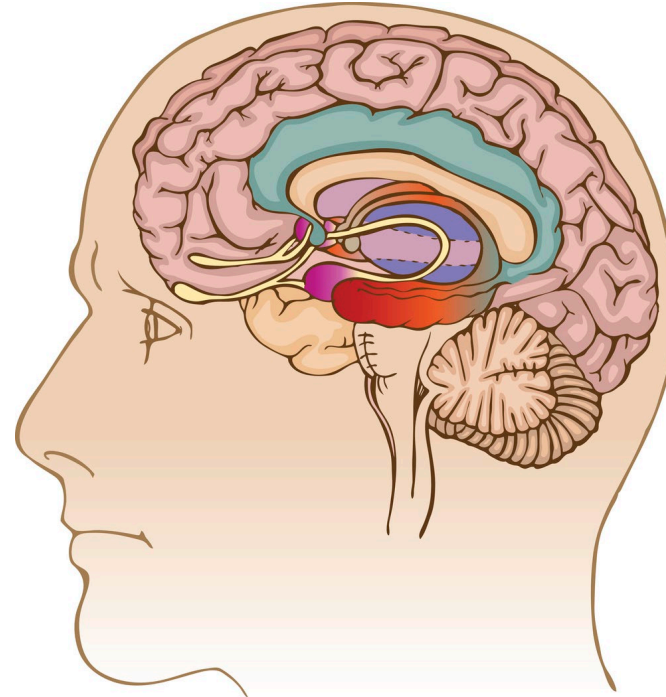
# Lewy Body Disease - Biology



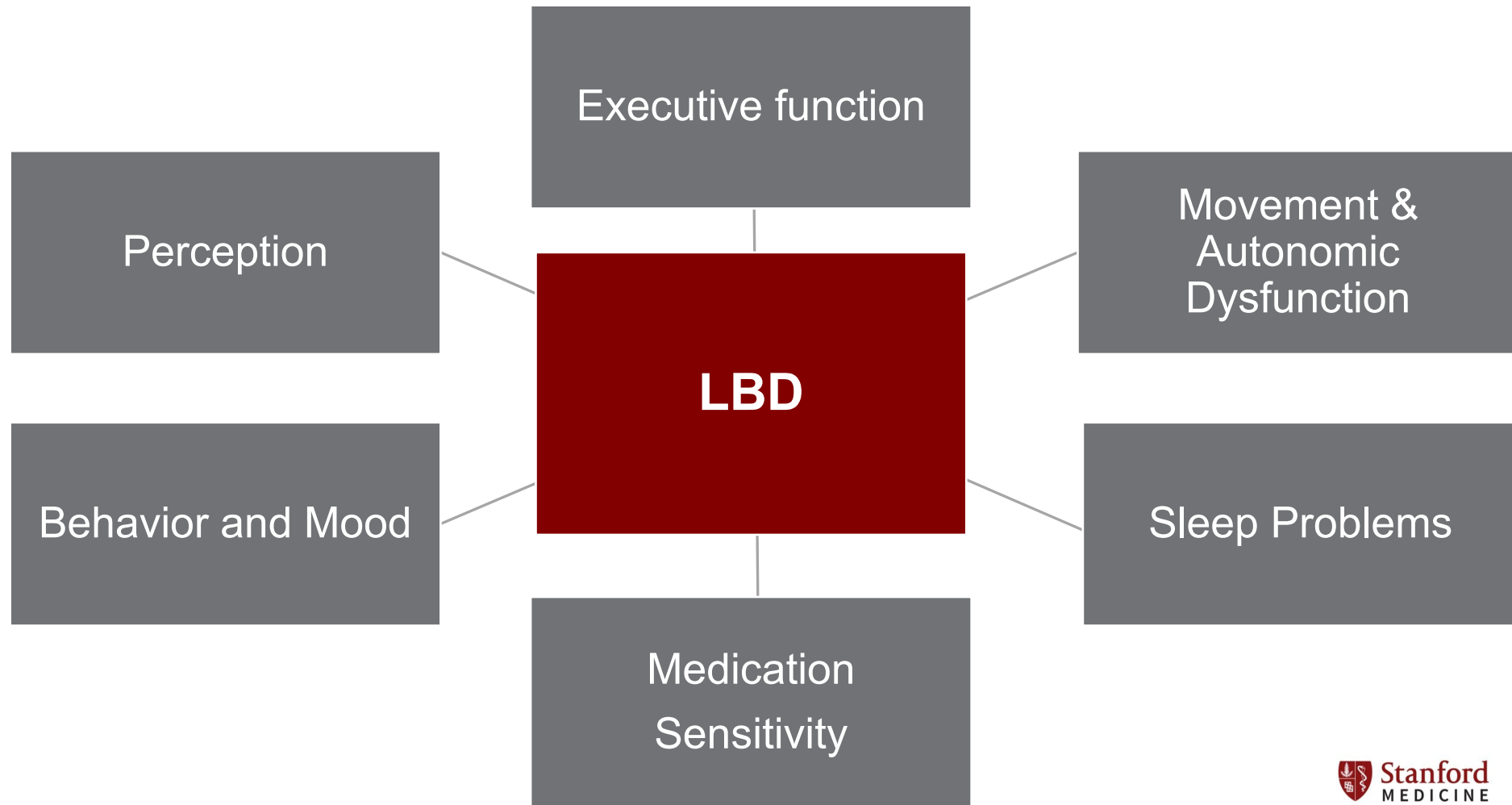
**Terminology:** DLB-Dementia with Lewy bodies; PDD-Parkinson's disease dementia;  
PD-Parkinson's disease; MSA-Multiple system atrophy

# Brain Regions Impacted by LBD

- Cerebral cortex
- Limbic cortex
- Hippocampus
- Midbrain/substantia nigra
- Brain stem
- Olfactory Pathways



# LBD is a Complex Challenge



# LBD – Diagnostic Criteria

## CORE SYMPTOMS

- Dementia with decline in “executive” brain function
- Fluctuating cognition
- Visual hallucinations
- Parkinsonism
- REM sleep disorder
- Visual/spatial deficits

## SUPPORTIVE SYMPTOMS

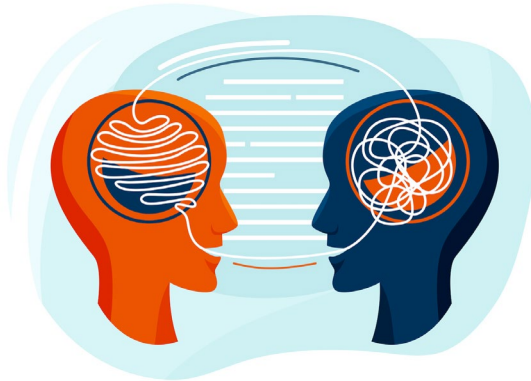
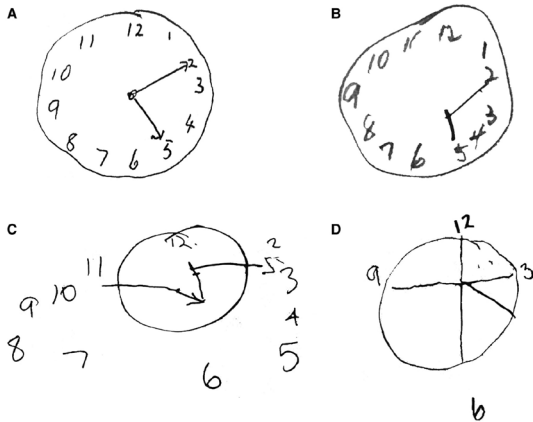
- Behavior and mood changes
- Problems with language
- Autonomic dysfunction
- Sensory loss (smell, etc)
- Hypersensitivity to certain medications
- Sundowning



# LBD and COGNITIVE DECLINE



- Executive function (planning, decision making, problem solving)
- Fluctuations in attention/alertness, periods of confusion
- Visuospatial deficits
- Language (speed of thought, communication)



# LBD and HALLUCINATIONS



- Seeing things that are not there
- In some cases, hearing or smelling things that are not there
- May be benign or upsetting
- May be persistent, vivid, recurring



*Masquerades*, Peter Doig

# LBD and DISRUPTED SLEEP



*Sleeping man Painting, Pawel Kosior*

- Excessive daytime sleepiness
- REM sleep behavior disorder
- Obstructive sleep apnea
- Restless legs syndrome
- Nocturia
- Sundowning

# LBD and MOVEMENT PROBLEMS

- Tremor
- Rigidity
- Bradykinesia
- Postural instability



# LBD and BEHAVIOR / MOOD CHANGES



Young Man Tired of his Hometown, Tayrn Day

- Low mood or depression
- Anxiety
- Apathy
- Fatigue
- Agitation
- Delusions, paranoia
- Social isolation



# LBD and AUTONOMIC DYSFUNCTION

- Blood pressure
- Heart rate
- Body temperature
- Dizziness and fainting
- Digestion
- Bladder and bowel function
- Sweating



# CHALLENGES FOR FAMILIES LIVING WITH LBD



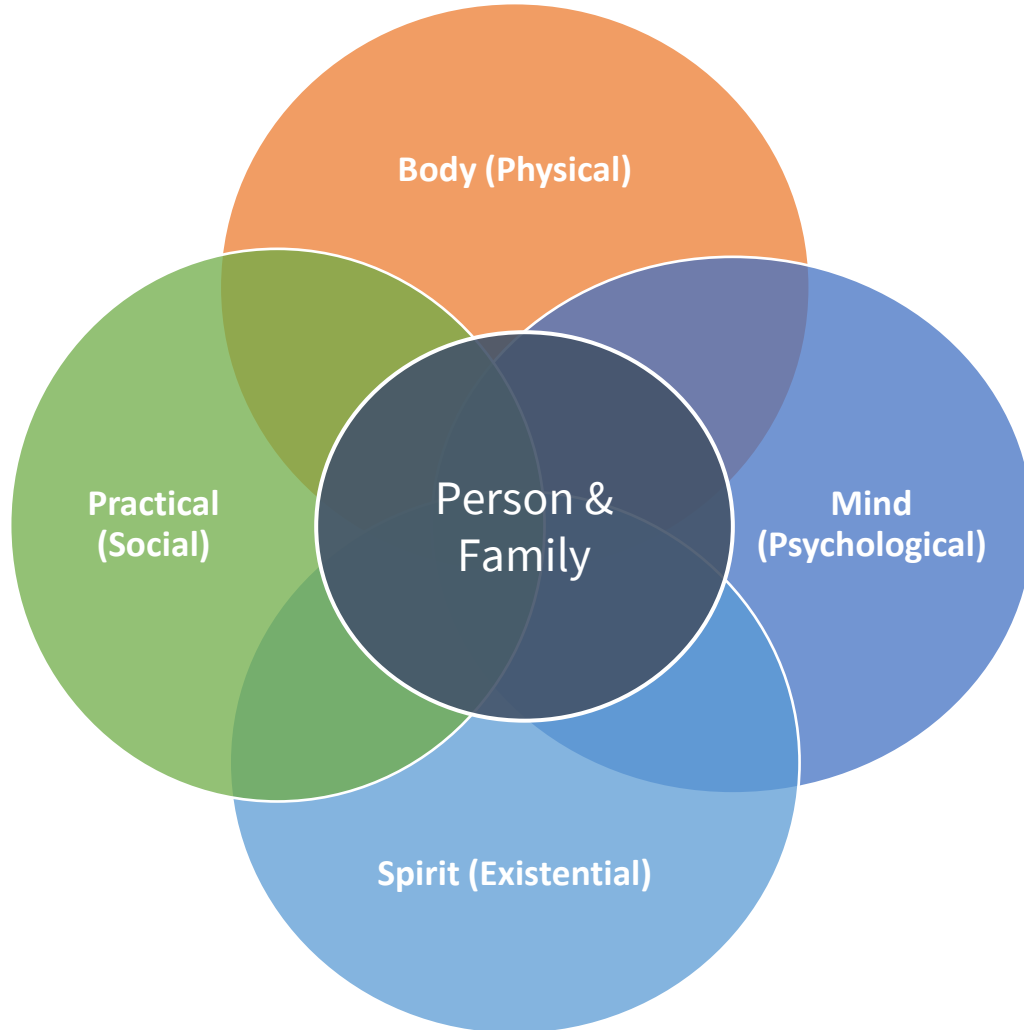
- Unfamiliar with public health services
- Unfamiliar with medical community, lack of care team in place
- Uncertain about diagnosis, prognosis, medication management
- Unsure how to plan for dementia care (health, legal and insurance matters)
- Difficulty with change and transitions

# QUALITY of LIFE on the JOURNEY with LBD



A sense of dignity, purpose, belonging and joy  
for people living with LBD and their families.

# THE ROLE OF PALLIATIVE CARE



A holistic approach to care focused on *the person* beyond the disease.

Appropriate at any age and any stage of cognitive decline and dementia, alongside any medical treatment.

**It's about Quality of Life.**

# THE PALLIATIVE CARE TEAM



## Doctors & Nurses

- Prescribe medication
- Help with medical decisions
- Coordinate with other doctors



## Social Workers

- Emotional Support
- Caregiver support
- Medical equipment
- Financial concerns

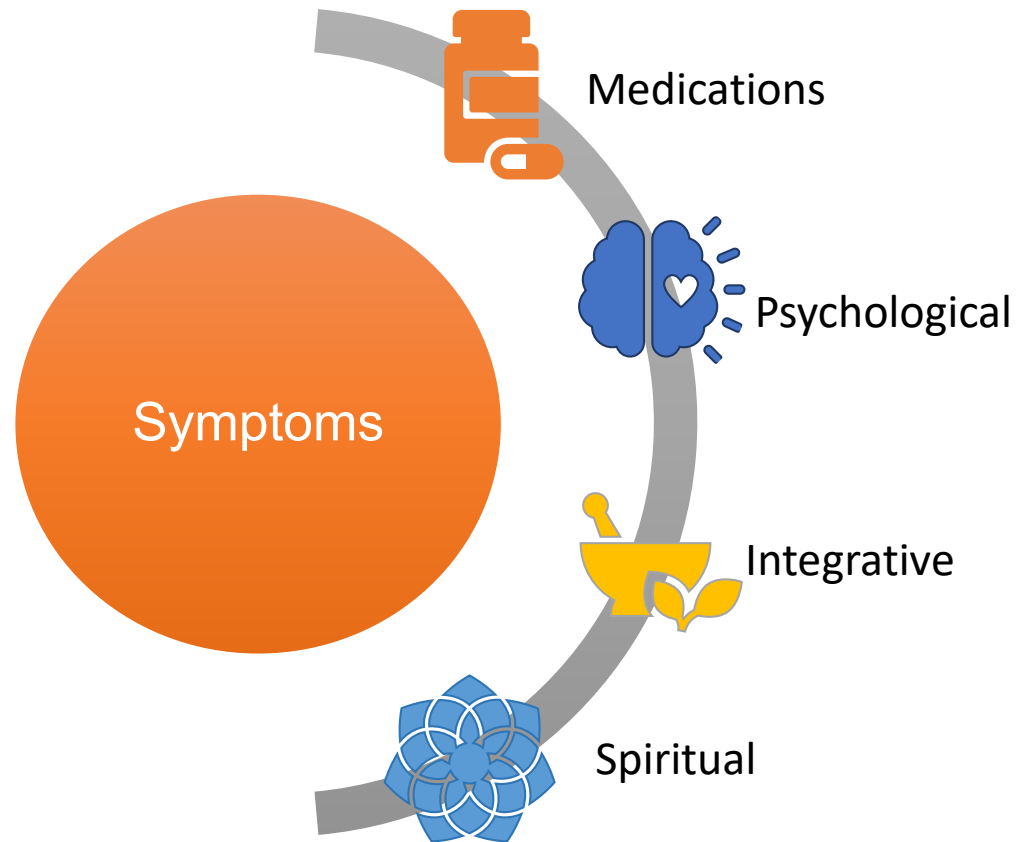


## Chaplain

- Spiritual support
- Relief from existential distress
- Prayers and blessings



# RELIEF FROM SYMPTOMS OF LBD



# HELP with MEDICAL DECISIONS and COPING

Advance Health Care Planning

Completing Advance Directives and  
POLST forms

Weighing treatment options

Adopting caregiver coping strategies  
and resources



# MEDICATION MANAGEMENT

Currently, there are no disease-modifying treatments for LBD, but certain meds can help ease symptoms.



- Memory medications – Donepezil, Namenda
- Anti-psychotics – Seroquel, Nuplazid, Clozaril
- Agitation – Depakote
- Anti-depressant or anxiety meds
- Orthostatic hypotension – Florinef, Midodrine, Northera
- Constipation, bowel regimen

\* Patients may be hyper-sensitive to medications. It's important to remove any that are unnecessary and change dosages gradually.

# PALLIATIVE CARE HAS MANY BENEFITS

## *From Diagnosis to Hospice and End of Life*



- Improved Quality of Life at all stages of dementia
- Symptom and stress management
- Sense of social and spiritual wellbeing
- Satisfaction with care
- Fewer hospitalizations
- Fewer hospital days
- Referrals to resources
- Less burden on caregivers

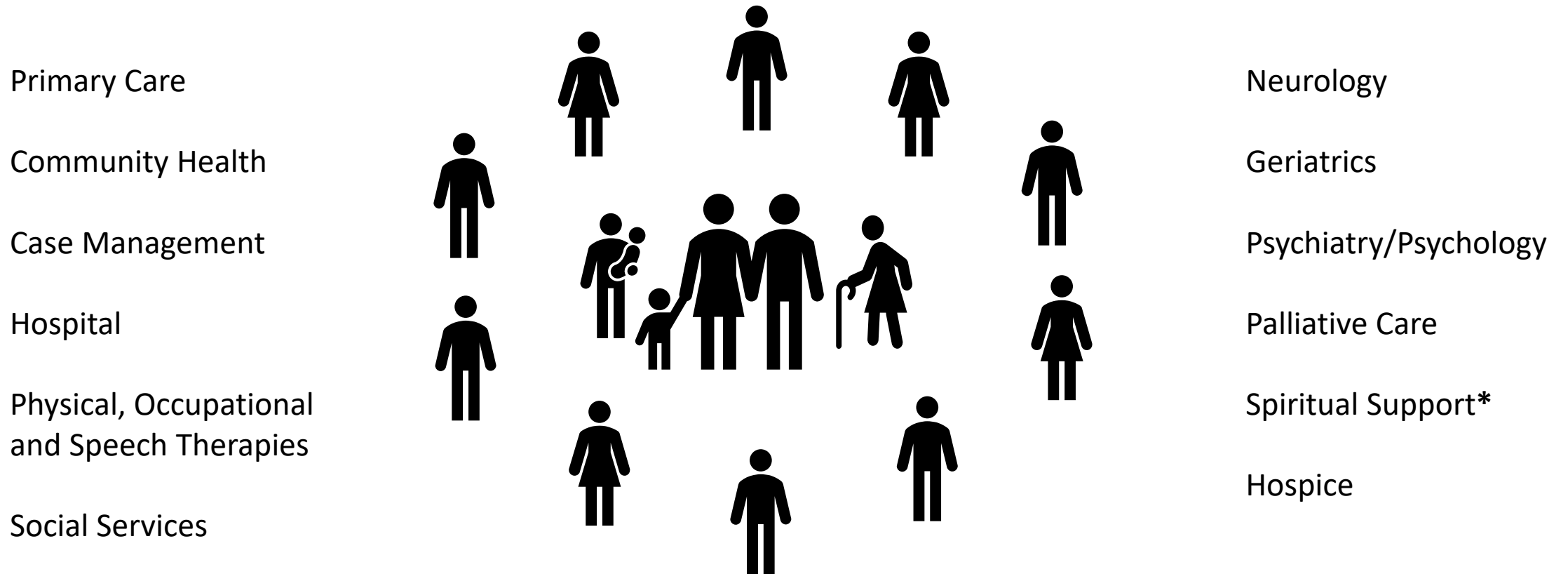
# EMERGENCE OF NEURO-PALLIATIVE CARE



- Meeting the public health challenge of our aging population
- Increasing awareness of palliative care and hospice services
- Increasing advance care plan support and guidance to people and families living with dementia
- Encouraging earlier conversations surrounding values, hopes, worries, and goals, when people are able to have them independently

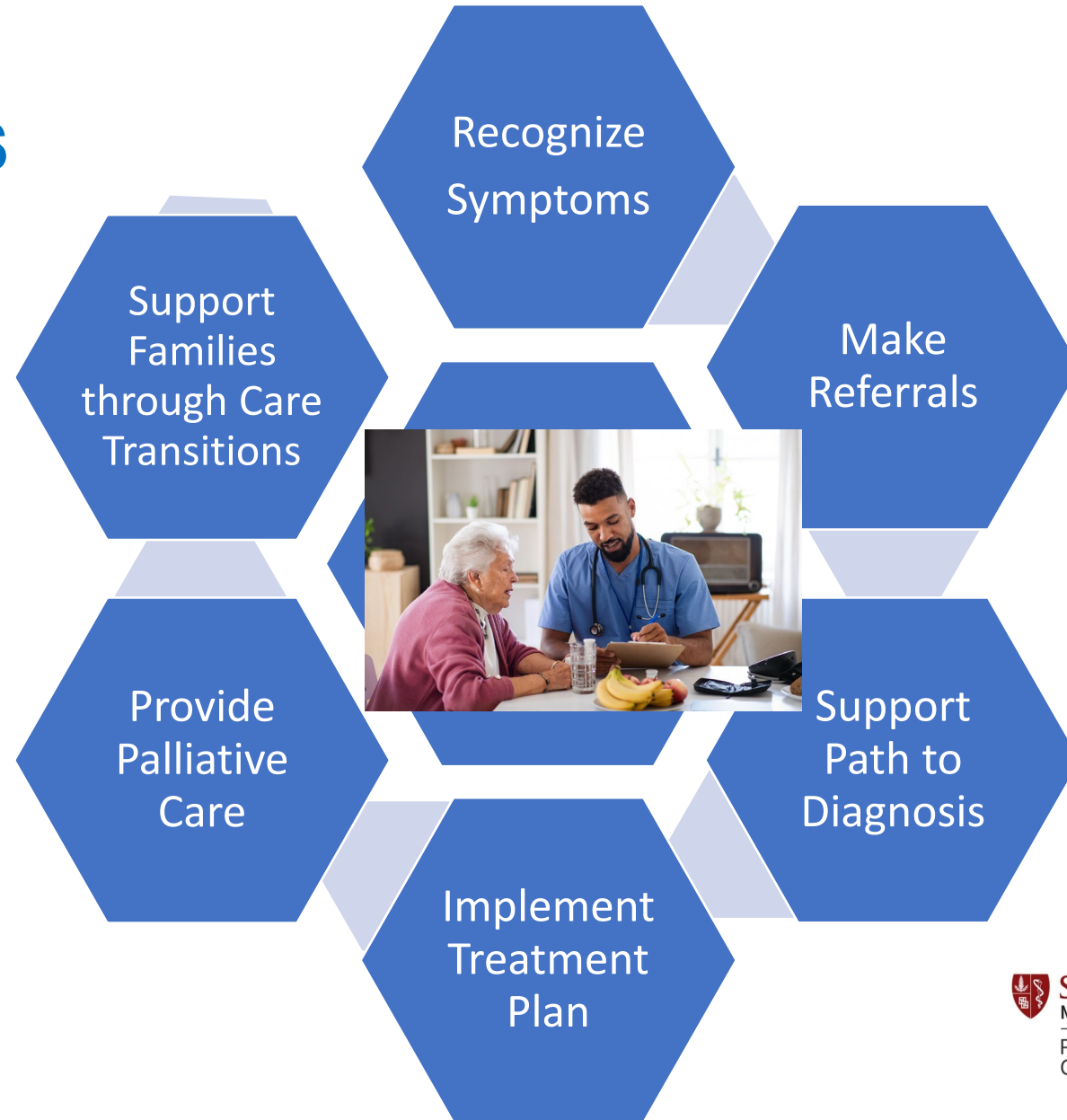


# DEMENTIA CARE TEAM: IT TAKES A VILLAGE



\*A dementia diagnosis is an existential challenge.

# NURSES' ROLES ON THE PATIENT'S JOURNEY WITH DEMENTIA



# NURSES IN ACUTE CARE SETTINGS



When an LBD patient has a **health emergency**, **NURSES** are vital to coordination of care

- Assess patient's condition - "baseline"
- Communicate with patient + family
- Review and verify medications list
- Assess hydration, continence, bowel function
- Connect patient + family with palliative care
- Determine if Advance Care documents exist
- Verify if patient has glasses, hearing aids
- Monitor and manage sleep cycle

# NURSES IN HOMECARE SETTINGS

## Coping Strategies for Family Caregivers



- Daily routine
- Organized activities
- Dementia-friendly communication
- Medication management
- Safe home environment
- Advance Care Planning
- Caregiver support (support groups, respite care)

# PALLIATIVE CARE SUPPORTS QUALITY of LIFE on the JOURNEY with LBD



A sense of dignity, purpose, belonging and joy  
for people living with LBD and their families.

# RESOURCES

## PALLIATIVE CARE

Stanford Website: <https://med.stanford.edu/palliative-care>

PalliativeDoctors.org: <https://palliativedoctors.org/>

National Hospice and Palliative Care Org: <https://www.caringinfo.org/>

Find a palliative care program: <https://getpalliativecare.org/>

## DEMENTIA and LBD

[National Institutes of Health](#)

[National Institute of Neurological Disorders & Stroke](#)

[Michael J Fox Foundation](#)

[Lewy Body Dementia Association](#)

[Susan and Charles Berghoff Foundation](#)

[LBD: Hidden in Plain Sight \(Santa Clara County Medical Assoc.\)](#)



**SCAN QR CODE  
to access these  
resources online**

This presentation is for educational purposes and does not constitute medical advice.  
If you have health concerns, always consult your doctor.





# *Thanks for your participation*



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