



## DEMENTIA CARE SERIES

Michigan Department of Health and Human Services

CARING SHEETS: THOUGHTS & SUGGESTIONS FOR CARING

# Caring Sheet #12: Dementia with Lewy Bodies:

A Summary of Information and Intervention Suggestions with an Emphasis on Cognition

By Shelly E. Weaverdyck, PhD

## Introduction

This caring sheet focuses on Dementia with Lewy Bodies, with an emphasis on cognition.

Caring sheets #11 and #13 summarize information and intervention suggestions regarding Alzheimer's Disease (caring sheet #11) and Frontotemporal Dementia (caring sheet #13). All three outline the brain changes in each type of dementia, the impact these changes have on cognition and behavior, and implications for effective intervention.

The three caring sheets (#11, #12, and #13) are written as companion pieces in outline form with virtually each line of one caring sheet corresponding with each line of the other two. The three can be laid out side by side, and compared almost line by line.

Other caring sheets describe the cognitive and behavioral changes and specific interventions for these dementias in more detail. Caring Sheet #2 in particular describes the characteristics of dementia, and the relationship between the brain changes and changes in cognition.

Dementia is a decline in a person's cognition. This decline occurs because of changes in the brain.

If the cognitive decline is caused by treatable disorders such as a urinary tract infection, vitamin deficiency, reactions to medications, or depression, it is likely **temporary** and **treatable** (e.g., delirium).

In other cases the brain changes and resulting cognitive decline are **irreversible** and **progressive** (i.e., increasingly severe). They are caused by disorders such as Alzheimer's Disease, vascular disorders (e.g., ministrokes), Creutzfeldt-Jakob Disease, Dementia with Lewy Bodies, or Frontotemporal disorders. There are over 80 different disorders that cause this type of progressive dementia. Dementia with Lewy Bodies is one of these disorders.



## **DEMENTIA WITH LEWY BODIES (DLB)**

AD refers to Alzheimer's Disease

### **CHARACTERISTICS**

Brain Disorder

Most obvious symptoms: impairment in cognition, movement, behavior

Progression: increasing severity of symptoms over time (a progressive dementia)

Onset: age 50-70, usually around 55 or 65

Duration: shorter than AD and shorter life expectancy than AD

Cause unknown

Cure: no cure at this time, but there is treatment to reduce symptoms

Diagnosis verified at autopsy

Very common cause of dementia (20% of all dementia cases in United States;  
second most common)

About 66% of people with DLB also have cognitive symptoms of AD

Course: fluctuating (alternating periods of higher and lower functioning)

with an overall decline over time, spontaneous improvement and decline,  
more rapid course than AD

Increased sensitivity to some medications

Named after F. H. Lewy, a German neurologist who in 1912 found the pathology  
(Lewy Bodies) in the brain stem

Other names: Lewy Body Dementia (LBD), Cortical Lewy Body Disease (CLBD)

### **NEUROPATHOLOGY**

Lewy bodies inside brain cells

Acetylcholine reduction

Dopamine reduction

Neuritic plaques and neurofibrillary tangles (when AD present, as it frequently is)

### **LOCATION OF CORTICAL BRAIN CHANGES**

Cortical refers to the cortex (i.e., the outer layer) of the brain

Changes (pathological abnormalities) occur in the cortex and in internal  
(subcortical) structures of the brain

Changes (pathological abnormalities) occur on both sides of the brain

Cortical brain structures affected:

Parietal lobe

Occipital lobe

Temporal lobe



Subcortical changes disrupt frontal lobe functioning  
Brain stem (subcortical): disrupted consciousness, REM sleep, and sleep behavior)  
Limbic cortex (subcortical): disrupted emotions

### **COGNITIVE CHANGES**

Fluctuations: good periods, then periods of more impairment, then good periods  
Memory less affected than in AD (memory loss more evident in later stages)  
Visuospatial: difficulty recognizing distance between objects and from self  
and difficulty arranging objects in space  
Attention impairment (fluctuates)  
Frontal-subcortical skills impaired  
Logic based on wrong premise (paranoia with a detailed, perhaps plausible rationale)  
Problem solving impaired early in course  
More insight than in AD, often  
Sensitivity to noise, sometimes  
Disinhibition, sometimes  
Inappropriate sexual behaviors, sometimes  
Manipulation and controlling behaviors, sometimes  
May sense or know hallucination isn't true, but is still emotionally engaged

### **EMOTIONAL CHANGES**

Mood shifts: may be rapid  
Unexplained and unpredicted anger or aggression, sometimes  
Depression is common

### **BEHAVIORAL CHANGES**

Hallucinations: particularly visual, emotionally engaging; begin early in course;  
well formed, detailed  
Parkinson symptoms: slowed movements (bradykinesia); balance impairment;  
coordination impairment; rigidity; stooped posture; shuffling walk; some  
people have a tremor  
Falls  
Paranoia  
Delusions  
Syncope  
Transient loss of consciousness (unexplained)  
Good days (weeks) bad days (weeks)



REM Sleep disturbance: act out dreams (can begin years or decades before dementia symptoms appear; sleep gets better as dementia symptoms get worse)

Most persons are not aggressive, but many persons with dementia who are aggressive have DLB. Non family caregivers often report particular fondness for the person between episodes.

### **INTERVENTIONS: Non-medicinal**

Use visuospatial interventions:

- economy of movement (move minimally, gesture minimally, organize so most caregiver movement is out of sight of person)

- watch for person's reaction and adjust caregiver response

- reduce clutter and unnecessary objects

- slow down

- approach from front

Maintain flexible and accurate expectations of person (expect fluctuations)

Address unpredictability of cognition and behaviors

Do difficult tasks (e.g., bathing) when person is in higher functioning period

Don't argue

Ask carefully (maybe indirectly) about hallucinations

Counsel to find way of tactfully communicating when hallucination isn't true

Counsel person using insight that may be intact until later stages

Reduce noise

Walk to keep legs from going numb and to reduce rigidity

Prevent falls

Soften environment to reduce risk of injury from falls

Monitor nighttime sleeping behavior

Monitor for mood shifts and unexpected aggression

Constant 1:1 to prevent unpredictable aggression

Treat depression

Remember what is lovable about this person

Support family/caregivers (guilt, doubt, frustration)

May need to move to long-term care setting earlier than in AD (family fatigue, family not accurate in perception, family guilt)

Address uncertainty and guilt of caregiver

Educate/remind caregiver course is unpredictable

Educate/remind caregiver DLB can look like it's not dementia, though it really is



## DEMENTIA CARE SERIES

Michigan Department of Health and Human Services

THOUGHTS & SUGGESTIONS FOR CARING

Caring Sheet # 12

Dementia with Lewy Bodies: A Summary

S. Weaverdyck

Page 5 of 6

Tell families/caregivers:

Description of the course of DLB

Remember it is dementia even when person appears normal or unlike a person with AD (e.g., memory for details)

Fluctuations

Expectations can be too high (or too low some days)

Unpredictable behavior and cognition

Easy to feel guilty

### MEDICAL TREATMENTS

Cure unknown

Reduce loss of dopamine (Parkinson medications)

Reduce loss of acetylcholine (AD medications)

Anti-psychotic medications (neuroleptics) for hallucinations and delusions may cause severe rigidity or death (neuroleptics lower dopamine levels)

Unusually sensitive response to sedatives (extreme responses)

Medications that treat behaviors and hallucinations may make the Parkinsonian symptoms worse; medications that treat the Parkinsonian symptoms may make the behaviors and hallucinations worse. Dosages must constantly be monitored and adjusted.

### COMMENTS

In 1996 consensus criteria for clinical and pathologic diagnosis created and have since been updated.

Kosak detected Lewy Bodies in cortex at autopsy in 1984 with new stain (dye)

Lewy bodies are pink abnormalities that darken over time, inside the cell

Often misdiagnosed as: Dementia with psychosis, with agitation, with hallucinations, or similar behaviors;  
or, early in the course, as a mental illness

### RESOURCES

<http://www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm>

(National Institute of Neurological Disorders and Stroke NINDS)

<http://www.lewybodydementia.org> (Lewy Body Dementia Association, Inc.)

<http://www.alzheimers.org> (Alzheimer's Disease Education and Referral Center ADEAR)

<http://www.alz.org> (Alzheimer's Association)

<http://www.med.umich.edu/madrc/> (Michigan Alzheimer's Disease Research Center MADRC)



This caring sheet focuses on Dementia with Lewy Bodies (DLB). More details about the brain changes and resulting cognitive changes in dementia are in caring sheet #2.

Though these changes in behavior and cognition result from brain damage, they are often mistakenly viewed as intentional or manipulative.

In DLB two of the neuropathological changes to the brain are acetylcholine reduction and dopamine reduction. These refer to the reduction in neurotransmitters, the neurochemicals that are transferred from one nerve cell to another as a method of communication between nerve cells. This intercellular communication is essential to the brain's maintenance and functioning. There are many different kinds of neurotransmitters. Two that are particularly reduced in amount in DLB are acetylcholine and dopamine.

## **Other Dementias**

See caring sheet #11 for more information about Alzheimer's Disease (AD) and caring sheet #13 for more information about Frontotemporal Dementia (FTD). AD is the most common cause of dementia. At the end of caring sheet #11, there is a brief description of vascular dementia, another common cause of dementia.

© Copyright 2005 by S. Weaverdyck (Page 6 and Header Revised 2018).

Citation: Weaverdyck, S. (2005). #12 – Dementia with Lewy Bodies: A Summary of Information and Intervention Suggestions with an Emphasis on Cognition. *Dementia Care Series Caring Sheets: Thoughts & Suggestions for Caring*. Lansing, Michigan: Michigan Department of Health and Human Services.

Edited and produced by Eastern Michigan University (EMU) Alzheimer's Education and Research Program for the Michigan Department of Health and Human Services (MDHHS), with gratitude to the Huron Woods Residential Dementia Unit at St. Joseph Mercy Hospital, Ann Arbor, Michigan.

The author, Shelly Weaverdyck was Director of the EMU Alzheimer's Education and Research Program.

Editor: Shelly Weaverdyck, PhD, Former Director EMU Alzheimer's Education and Research Program; Email: sweaverd@umich.edu

All Caring Sheets are available online at the following websites: [http://www.michigan.gov/mdhhs/0,5885,7-339-71550\\_2941\\_4868\\_38495\\_38498---,00.html](http://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_38495_38498---,00.html) (Michigan Department of Health and Human Services MDHHS), at <http://www.lcc.edu/mhap> (Mental Health and Aging Project (MHAP) of Michigan at Lansing Community College in Lansing, Michigan), and at <https://www.improvingmipractices.org/populations/older-adults> (Improving MI Practices website by MDHHS)

The Caring Sheets were originally produced as part of the in-kind funding for the Michigan Alzheimer's Demonstration Project. Funded by the Public Health Service, Health Resources and Services Administration (1992-1998) and the Administration on Aging (1998-2001) 55% federal funding and 45% in-kind match. Federal Community Mental Health Block Grant funding supported revisions to Caring Sheets (2002-2018).