International Dementia with Lewy Bodies Conference

Fort Lauderdale, Florida

December 3-4, 2015

Patient and Care Partner Guide
Our dedicated planning committee has spent the past year thoughtfully working to create an experience that we hope you find enriching. Our aim is to share research, best practices and practical interventions for the care, treatment and preservation of quality living for persons impacted by Lewy body dementia.

On behalf of Mayo Clinic and the Lewy Body Dementia Association, we welcome each of you. We look forward to the upcoming days of connecting with one another in this beautiful tranquil space by the ocean.

_Angela Lunde and Angela Taylor_

**Patient and Care Partner Track Planning Committee**

Ashley Bayston, The Lewy Body Society, UK

Brad Boeve, Mayo Clinic, USA

Maka Boeve, Rochester, USA

Alexander Dreier, Massachusetts, USA

Olivia Dreier, Massachusetts, USA

Tanis Ferman, Mayo Clinic, USA

Angela Lunde, Mayo Clinic, USA

Diana Myles, California, USA

Francine Parfitt, Mayo Clinic, USA

Paul Primakoff, California, USA

Deborah Richman, Alzheimer’s Association, USA

Lisa Snyder, California, USA

Angela Taylor, Lewy Body Dementia Association, USA

Joy Walker, Lewy Body Dementia Association, USA
General Information

Venue

The Patient and Care Partner Track is located in Oceans Ballroom, Salons I & III. Break refreshments and lunches are located in Oceans Ballroom, Salons II & IV. The Poster Session is in Caribbean Ballroom in the main hotel.

Registration

The registration fee includes tuition, continental breakfasts, break refreshments, reception, and lunches for paid course attendees. No guests for meals, please.

Once you have picked up your packet from registration, you are ‘checked in’ for the duration of the conference. There is no need to check in every morning.

WiFi

Complimentary wireless internet access is available in the meeting space. The password is: DEMENTIA

Cell Phones

Please silence your mobile device.

Restrooms

Restrooms are located in the foyer of the Oceans Ballroom. Follow the signs.

Relaxation Spaces

Need a break? Oceans Ballroom Salons II & IV are available as a quiet space throughout the day. The only exception is 1:30 – 3:00 p.m. Wednesday when they are being used for breakout sessions.
**Lost and Found**

The conference registration desks will serve as lost and found for the duration of the conference. At the conclusion of the conference, any found items will be turned over to the hotel. Call (954) 525-4000 for information regarding lost items.

**Have a Question?**

Ask anyone at the conference registration desks. Look for ‘STAFF’ on their name badges.
Patient and Care Partner Track Location

Ocean Ballroom

Salon I & III – General Session

Salon II & IV – Break, lunch, breakout rooms
Poster Session – Caribbean Ballroom, First Floor Main Building

Scientist and Health Care Provider Track – Grand Ballroom, Third Floor Main Building
<table>
<thead>
<tr>
<th>Schedule at a Glance:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Monday November 30</strong></td>
</tr>
<tr>
<td>Registration and Welcome Reception</td>
</tr>
<tr>
<td>6:00 p.m. -7:30 p.m.</td>
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<tr>
<td>Welcome reception and pre-registration</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Tuesday, December 1</strong></th>
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<tbody>
<tr>
<td>Pre-Conference: Scientific DLB Review and Update</td>
</tr>
<tr>
<td>7:00 a.m. -7:30 a.m.</td>
</tr>
<tr>
<td>Registration</td>
</tr>
<tr>
<td>7:30 a.m.- 4:45 a.m.</td>
</tr>
<tr>
<td>DLB Scientific Review &amp; Update</td>
</tr>
<tr>
<td>5:30 p.m. 6:45 p.m.</td>
</tr>
<tr>
<td>The Day Decoded</td>
</tr>
<tr>
<td>A special Q &amp; A for patients and care partners who attended any of the Tuesday Scientific Sessions.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Wednesday December 2</strong></th>
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<tbody>
<tr>
<td>Day 1: Patient and Care Partner Track</td>
</tr>
<tr>
<td>8:00 a.m.-8:50 a.m.</td>
</tr>
<tr>
<td>Registration and Check-in</td>
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<tr>
<td>8:50 a.m.</td>
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<tr>
<td>Welcome</td>
</tr>
<tr>
<td>9:20 a.m-10:20 a.m.</td>
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<tr>
<td>Session 1: The Science</td>
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<tr>
<td>10:35 a.m-12:15 p.m.</td>
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<tr>
<td>Session 2: Diagnosis and Management</td>
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<tr>
<td>12:15 p.m-1:30 p.m.</td>
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<tr>
<td>Lunch</td>
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<tr>
<td>1:30 p.m.- 3:30 p.m.</td>
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<tr>
<td>Session 3: The Struggles and the Strategies</td>
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<tr>
<td>3:30 p.m.- 4:30 p.m.</td>
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<tr>
<td>Relax</td>
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<tr>
<td>4:30 p.m.- 5:00 p.m.</td>
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<tr>
<td>Research Posters Guided Tour</td>
</tr>
<tr>
<td>5:00 p.m.-6:30 p.m.</td>
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<tr>
<td>Wine and Cheese Reception with the Scientists</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Thursday December 3</strong></th>
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<tbody>
<tr>
<td>Day 2: Patient and Care Partner Track</td>
</tr>
<tr>
<td>7:30 a.m.-9:00 a.m.</td>
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<tr>
<td>Registration and Check-in</td>
</tr>
<tr>
<td>7:45 a.m.-8:45 a.m.</td>
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<tr>
<td>(optional) Critical Conversations</td>
</tr>
<tr>
<td>9:00 a.m.</td>
</tr>
<tr>
<td>Welcome</td>
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<tr>
<td>9:20 a.m-10:10 a.m.</td>
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<tr>
<td>Session 4: The Experience</td>
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<tr>
<td>10:25 a.m-11:35 a.m.</td>
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<tr>
<td>Session 5: The Research</td>
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<tr>
<td>11:35 a.m.- 12:35 a.m.</td>
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<tr>
<td>Lunch</td>
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<tr>
<td>12:35 p.m.-2:45 p.m.</td>
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<tr>
<td>Session 6: The Therapies</td>
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<tr>
<td>3:00 p.m.- 4:20 p.m.</td>
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<tr>
<td>Session 7: The Hope</td>
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<tr>
<td>4:20 p.m.</td>
</tr>
<tr>
<td>Adjourn</td>
</tr>
</tbody>
</table>
Pre-Conference Schedule:

Tuesday, December 1 – Pre-conference Scientific Track: DLB Review and Update
(optional day for Patient and Care Partner track participants)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event/Title</th>
<th>Speaker/Participants</th>
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</thead>
<tbody>
<tr>
<td>7:00 -7:30 a.m.</td>
<td>Registration</td>
<td></td>
</tr>
<tr>
<td>7:30 -7:45 a.m.</td>
<td>Conference overview</td>
<td>Organizers</td>
</tr>
<tr>
<td>7:45- 8:00 a.m.</td>
<td>A caregiver's perspective of DLB</td>
<td>Angela Taylor LBDA</td>
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</tbody>
</table>

**Session 1: DLB Update - Clinical**

Session Co-Chairs: Brad Boeve, Mayo Clinic Rochester; Jim Galvin, Florida Atlantic University

<table>
<thead>
<tr>
<th>Time</th>
<th>Event/Title</th>
<th>Speaker/Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 – 8:20 a.m.</td>
<td>DLB history, differential diagnosis and diagnostic features</td>
<td>Ian McKeith Newcastle University</td>
</tr>
<tr>
<td>8:20 – 8:40 a.m.</td>
<td>Key clinical, epidemiologic, neuropsychological, and imaging features of DLB</td>
<td>Brad Boeve Mayo Clinic Rochester</td>
</tr>
<tr>
<td>8:40 – 9:00 a.m.</td>
<td>DLB: Tools for the clinician</td>
<td>Jim Galvin Florida Atlantic University</td>
</tr>
<tr>
<td>9:00 – 9:30 a.m.</td>
<td>Discussion</td>
<td>Panel and audience</td>
</tr>
<tr>
<td>9:30 – 10:00 a.m.</td>
<td><em>Break</em></td>
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</table>

**Session 2: DLB Update – Imaging/Biomarkers**

Session Co-Chairs: John O’Brien, Cambridge University; John-Paul Taylor, Newcastle University

<table>
<thead>
<tr>
<th>Time</th>
<th>Event/Title</th>
<th>Speaker/Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 – 10:20 a.m.</td>
<td>Cross-sectional and longitudinal structural imaging studies in DLB</td>
<td>John O’Brien Cambridge University</td>
</tr>
<tr>
<td>10:20 – 10:40 a.m.</td>
<td>Functional imaging changes in DLB</td>
<td>Nicolas Bohnen University of Michigan</td>
</tr>
<tr>
<td>10:40 – 11:00 a.m.</td>
<td>Electrophysiologic correlates of DLB</td>
<td>John-Paul Taylor Newcastle University</td>
</tr>
<tr>
<td>11:00 – 11:30 a.m.</td>
<td>Discussion</td>
<td>Panel and audience</td>
</tr>
<tr>
<td>11:30 a.m. – 1:00 p.m.</td>
<td><em>Lunch</em></td>
<td></td>
</tr>
</tbody>
</table>
### Session 3: DLB Update – Neuropathology/Genetics/Basic Science

Session Co-Chairs:  
Dennis Dickson, Mayo Clinic Florida; Brit Mollenhauer, Paracelsus-Elena Klinik

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:00 – 1:20 p.m.</td>
<td>Historical perspective of DLB and Lewy body disease</td>
<td>Kenji Kosaka, Yokohama Univ.</td>
</tr>
<tr>
<td>1:20 – 1:40 p.m.</td>
<td>Neuropathologic perspectives of Lewy body disease</td>
<td>Dennis Dickson, Mayo Clinic Florida</td>
</tr>
<tr>
<td>1:40 – 2:00 p.m.</td>
<td>Genetic perspectives of DLB</td>
<td>Jose Bras, University College London</td>
</tr>
<tr>
<td>2:00 – 2:20 p.m.</td>
<td>Molecular biology and animal models of Lewy body disease</td>
<td>Virginia Lee, University of Pennsylvania</td>
</tr>
<tr>
<td>2:20 – 2:45 p.m.</td>
<td>Discussion</td>
<td>Panel and audience</td>
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<tr>
<td>2:45 – 3:15 p.m.</td>
<td>Break</td>
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</table>

### Session 4: DLB Update – Therapeutics

Session Co-Chairs:  
Ian McKeith, Newcastle University; Doug Galasko, UCSD

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speaker</th>
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</thead>
<tbody>
<tr>
<td>3:15-3:35 p.m.</td>
<td>Cholinesterase inhibitors and memantine</td>
<td>Zuzana Walker, University College London</td>
</tr>
<tr>
<td>3:35 – 3:55 p.m.</td>
<td>Antipsychotics</td>
<td>Clive Ballard, King's College London</td>
</tr>
<tr>
<td>3:55 – 4:15 p.m.</td>
<td>Antiparkinsonism agents</td>
<td>David Burn, Newcastle University</td>
</tr>
<tr>
<td>4:15 – 4:45 p.m.</td>
<td>Discussion</td>
<td>Panel and audience</td>
</tr>
<tr>
<td>4:45-5:30 p.m.</td>
<td>Relax</td>
<td></td>
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</tbody>
</table>
| 5:30-6:45 p.m. | The Day Decoded  
A special Q & A for patients and care partners who registered for and attended any of the Scientific Track Sessions. Dinner provided. | Tanis Ferman, PhD, Mayo Clinic Florida  
Gregory Jicha, MD, PhD, Univ. of Kentucky |
## Day One

### Wednesday, December 2

**Patient and Care Partner Track**

<table>
<thead>
<tr>
<th>Time</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>8:00-8:50 a.m.</td>
<td>Breakfast, Registration, Check-in</td>
</tr>
<tr>
<td>8:50 a.m.</td>
<td>Welcome</td>
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<tr>
<td></td>
<td>Paul Primakoff</td>
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<td></td>
<td>Living with DLB</td>
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<td></td>
<td>Angela Taylor</td>
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<tr>
<td></td>
<td>Lewy Body Dementia Association (LBDA)</td>
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<td></td>
<td>Angela Lunde</td>
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<td></td>
<td>Mayo Clinic</td>
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</tbody>
</table>

### Session 1: THE SCIENCE

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:20-10:20 a.m.</td>
<td>Setting the Stage: A DLB Primer</td>
<td>Erin Golden, MD</td>
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<td></td>
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<td>Mayo Clinic</td>
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<td></td>
<td>DLB Clinical Distinctions</td>
<td>Gregory Jicha, MD, PhD</td>
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<td></td>
<td></td>
<td>Univ. of Kentucky</td>
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<tr>
<td></td>
<td>DLB Neurological Causes</td>
<td>Jennifer Molano, MD</td>
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<td></td>
<td></td>
<td>Univ. of Cincinnati</td>
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<tr>
<td>10:20</td>
<td><strong>BREAK</strong></td>
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</table>

### Session 2: DIAGNOSIS & MANAGEMENT

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:35 a.m.-12:15 p.m.</td>
<td>Making the Diagnosis</td>
<td>Jonathan Graff-Radford, MD</td>
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<td></td>
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<td>Mayo Clinic</td>
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<td></td>
<td>Symptom Management</td>
<td>Gregory Jicha, MD, PhD</td>
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<tr>
<td></td>
<td></td>
<td>Univ. of Kentucky</td>
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<tr>
<td></td>
<td>The Patient and the Family</td>
<td>James Galvin, MD, MPH</td>
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<td></td>
<td></td>
<td>Florida Atlantic University</td>
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<tr>
<td>11:37</td>
<td><strong>BREAK</strong></td>
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<tr>
<td></td>
<td>Q&amp;A Sessions 1 &amp; 2</td>
<td>James Galvin</td>
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<td>Erin Golden</td>
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<td>Jonathan Graff-Radford</td>
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<td>Gregory Jicha</td>
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<td></td>
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<td>Jennifer Molano</td>
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<tr>
<td>12:15-1:30 p.m.</td>
<td><strong>LUNCH</strong></td>
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</tbody>
</table>
## Session 3: THE STRUGGLES AND THE STRATEGIES

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Participants</th>
</tr>
</thead>
</table>
| 1:30-2:55 p.m. | Separate gatherings for education, support and peer to peer discussion.  
• Persons living with Lewy body dementia  
• Care Partners | Ashley Bayston  
The Lewy Body Society, UK  
Debbie Richman  
Alzheimer's Association and Related Dementias |
| 2:55       | **BREAK**                                     |                                                                              |
| 3:10-3:30 p.m. | Reflections                                   |                                                                              |
| 3:30- 4:30 p.m. | **BREAK,**  
Relax, Mingle                              |                                                                              |
| 4:30-5:00 p.m. | Research Posters Guided Tour                  |                                                                              |
| 5:00-6:30 p.m. | Wine and Cheese Reception with the Scientists |                                                                              |

## CONNECTING

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
</table>
| 3:30- 4:30 p.m. | **BREAK,**  
Relax, Mingle                              |
| 4:30-5:00 p.m. | Research Posters Guided Tour                  |
| 5:00-6:30 p.m. | Wine and Cheese Reception with the Scientists |
# Day Two

## Thursday, December 3

### Patient and Care Partner Track

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speakers</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30-9:00 a.m.</td>
<td>Registration, Check-in</td>
<td></td>
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<tr>
<td>7:45-8:45 a.m.</td>
<td>Critical Conversations over Breakfast</td>
<td>Beth-Anne Sieber, PhD. NIH</td>
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<td>Creighton Phelps, PhD. NIH/NIA</td>
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<tr>
<td>9:00-9:25 a.m.</td>
<td>Morning Welcome</td>
<td>Diana Myles Care Partner</td>
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<td></td>
<td>Ian McKeith, MD, F Med Sci Newcastle University, UK</td>
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<td>Angela Lunde Mayo Clinic</td>
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## Session 4: THE EXPERIENCE

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speakers</th>
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</thead>
<tbody>
<tr>
<td>9:20-10:10 a.m.</td>
<td>Personal Stories, Meaningful Insights</td>
<td>Paul Smith Care Partner</td>
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<tr>
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<td>Alexander Dreier Living with DLB</td>
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<td></td>
<td></td>
<td>Olivia Dreier Care Partner</td>
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<tr>
<td>10:10</td>
<td><strong>BREAK</strong></td>
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## Session 5: THE RESEARCH

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speakers</th>
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</thead>
<tbody>
<tr>
<td>10:25-11:35 a.m.</td>
<td>Steps Forward in Research</td>
<td>Brad Boeve, MD Mayo Clinic</td>
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<tr>
<td></td>
<td>Featured Poster Presentations</td>
<td>Claire Bamford Newcastle University, UK</td>
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<tr>
<td></td>
<td>• Principles for managing Lewy body dementia:</td>
<td>Michael Inskip University of Sydney</td>
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<td>patient and carer perspectives from the</td>
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<td>DIAMOND-Lewy study</td>
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<td></td>
<td>• The effect of exercise on individuals with</td>
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<td></td>
<td>Dementia with Lewy Bodies: A systematic</td>
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<tr>
<td></td>
<td>review</td>
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<tr>
<td>Time</td>
<td>Session Title</td>
<td>Presenter(s)</td>
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<td>-----------------------------------------------------------------------------</td>
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<tr>
<td>11:35 -12:35 PM</td>
<td><strong>LUNCH</strong></td>
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<tr>
<td>12:35-2:45 p.m.</td>
<td><strong>Session 6: THE THERAPIES</strong></td>
<td></td>
</tr>
<tr>
<td>Evidence Based Therapies for Family Caregivers</td>
<td>Steven Zarit, PhD&lt;br&gt;Penn State University &amp; Jonkoping University, Sweden</td>
<td></td>
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<tr>
<td>Team Based Care</td>
<td>James Galvin, MD, MPH&lt;br&gt;Florida Atlantic University</td>
<td></td>
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<tr>
<td>Healthy Actions to Benefit Independence and Thinking</td>
<td>Julie Fields, PhD&lt;br&gt;Mayo Clinic</td>
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<tr>
<td><strong>BREAK</strong></td>
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<tr>
<td>Cultural Arts as an Intervention in Dementia Care</td>
<td>Kate DeMedeiros, PhD&lt;br&gt;University of Miami</td>
<td></td>
</tr>
<tr>
<td>Q &amp; A Session 6</td>
<td>Steven Zarit, &lt;br&gt;James Galvin, &lt;br&gt;Julie Fields, &lt;br&gt;Kate DeMedeiros</td>
<td></td>
</tr>
<tr>
<td>2:45</td>
<td><strong>BREAK</strong></td>
<td></td>
</tr>
<tr>
<td>3:00-4:20 p.m.</td>
<td><strong>Session 7: THE HOPE</strong></td>
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<tr>
<td>A Mindful Journey</td>
<td>Marguerite Manteau-Rao, LCSW&lt;br&gt;Presence Care Project</td>
<td></td>
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<tr>
<td>A Call to Action</td>
<td>Angela Taylor</td>
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<tr>
<td>Closing Remarks</td>
<td>Paul Primakoff</td>
<td></td>
</tr>
<tr>
<td>4:20 p.m.</td>
<td>Adjourn</td>
<td></td>
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</tbody>
</table>
Speakers and Facilitators
Speakers and Facilitators

Ashley Bayston
The Lewy Body Society, UK

Ashley Bayston founded the Lewy Body Society with Prof Ian McKeith in 2006 after learning that there was no UK – or European - charity dedicated exclusively to Lewy body dementia. The Society’s mission is to support research and raise awareness. Ashley is a retired English human rights barrister whose work has changed legislation in the UK and Australia. After hanging up her wig in 2010 she moved to the Netherlands but continues to be deeply involved in the Lewy Body Society as Chair of the trustees, press officer, editor, liaison between the charity’s trustees and Specialist Advisory Committee and official Tweeter.

Brad Boeve, MD
Mayo Clinic

Dr. Boeve is Chair of the Department of Behavioral Neurology at Mayo Clinic Rochester. His clinical and research interests include normal aging, neurodegenerative disorders that cause cognitive impairment/dementia, neurogenetics, prion disorders, autoimmune encephalopathies, and the neurologically-based sleep disorders. Specific disorders of interest include mild cognitive impairment, frontotemporal dementia, Lewy body dementia, REM sleep behavior disorder, narcolepsy, and restless legs syndrome/periodic limb movement disorder. He serves as Medical Advisor for the Lewy Body Dementia Association
Kate de Medeiros, PhD, is Associate Professor of Gerontology at Miami University. Broadly defined, her work centers on understanding the experiences of later life for people of all cognitive abilities. Studies include arts-based interventions with people with dementia, the meaning of friendship in the context of dementia, and narrative approaches to later life. Her work has been funded by the Alzheimer’s Association and the National Institutes of Health.

Alexander Dreier, M.Ed, grew up in Washington DC. A former organic farmer and psychotherapist, he has over the years also devoted much of his time to performing improvisational comedy and comic, autobiographical monologues. He and his wife, Olivia, have been married for 39 years, and have two sons and two grandchildren. Alexander had to abandon his pursuit of a Harvard doctorate in Counseling Psychology when he developed severe fatigue in 1990. His symptoms finally led to a diagnosis of Lewy Body Disease in 2012 after many years of misdiagnosis and mystery as to what was wrong. He recently published a book of poems based, in part, on his experience with Lewy Body, and made possible by the invaluable assistance of Olivia.
Olivia Dreier

Olivia Stokes Dreier is Executive Director of the Karuna Center for Peacebuilding, a non-profit in Amherst, MA that works in war-torn countries to foster reconciliation across ethnic, religious, or political divides. In her early twenties, Olivia worked for two years with the Gandhian movement in rural India. After returning to the U.S., she worked as a psychotherapist for the next 20 years. She has a B.A. in psychology from Yale University and graduate degrees in clinical social work and public administration from Smith College and Harvard University’s Kennedy School of Government respectively. While she travels frequently for her work, she is deeply committed to supporting Alexander as he manages life with Lewy Body Disease and is also an adoring grandmother.

Tanis Ferman, PhD
Mayo Clinic

Dr. Ferman is an Associate Professor in the Department of Psychiatry and Psychology at Mayo Clinic Florida. She is a Clinical Neuropsychologist and an active researcher. She was the Principal Investigator of an NIH/NIA grant studying Dementia with Lewy Bodies (DLB) for over 10 years, and continues to serve as a co-investigator in the Mayo Alzheimer Disease Research Center and the Mangurian Foundation for Lewy body research. Her research focuses on improving diagnostic accuracy, identifying the cognitive profile of DLB, assessing the contribution of sleep disturbance and understanding how the neuropathology of DLB relates to clinical presentation and disease trajectory.
I am Associate Professor of Psychology and a Neuropsychologist in the Division of Neurocognitive Disorders. I have participated in clinical research related to neurodegenerative disease for the past 20 years, focusing on cognitive, mood, and quality of life as well as outcomes of surgical and behavioral interventions. I have received funding to examine the impact of a multicomponent behavioral intervention (HABIT Healthy Action to Benefit Independence & Thinking®) on neurobehavioral functioning in individuals with mild cognitive impairment and their caregivers. Through my first-hand involvement with patients and their caregivers, I have become aware of the need to understand the disease processes involved in order to find the most effective prevention and treatment strategies.

Dr. James E. Galvin is Professor and Associate Dean for Clinical Research at the Charles E. Schmidt College of Medicine, Florida Atlantic University and is the Director of the Institute for Healthy Aging and Lifespan Studies. He has authored 165 scientific publications and 22 book chapters covering basic, clinical and translational science in the area of neurodegenerative disorders, dementia and cognitive aging, is the editor of three textbooks on dementia, and directed 37 clinical trials investigating new therapeutics. His research has been funded by the NIH Centers for Disease Control, Michael J Fox Foundation, American Federation for Aging Research, Alzheimer’s Association, and Association for Frontotemporal Degeneration.
Erin Golden, MD  
Mayo Clinic

Erin Golden completed her Neurology residency at Mayo Clinic and is now in a Behavioral Neurology fellowship.

Jonathan Graff-Radford, MD  
Mayo Clinic

Jonathan Graff-Radford is an Assistant Professor of Neurology at the Mayo Clinic in Rochester. He received his medical degree from the University of Florida. He completed his neurology residency and behavioral neurology fellowship at Mayo Clinic in Rochester, MN. He evaluates and treats patients with neurodegenerative diseases including Dementia with Lewy Bodies. He currently has a Junior Investigator award from the National Alzheimer's Coordinating Center to investigate pathologic predictors of survival in Dementia with Lewy Bodies.
Dr. Jicha is a Professor in the Department of Neurology and Sanders-Brown Center on Aging at the University of Kentucky, serving as an Associate Center Director and leader of the Clinical Core of the NIA-funded Alzheimer’s Disease Center. Dr. Jicha holds the McCowan Endowed Chair in Alzheimer’s Research at UK. He serves on the Clinical Task Force and Steering Committee for the NIA Alzheimer’s Disease Center Program. He is also an active researcher investigating aspects of DLB that are designed to move diagnosis and care forward. His work includes elucidation of early preclinical features of DLB, studies of aging effects on DLB, male gender prevalence in DLB, neuropsychological profiles in DLB, and symptomatic treatment of DLB.

Angela Lunde, MA
Mayo Clinic

Angela Lunde is part of the Education and Outreach Core at the Mayo Clinic Alzheimer’s Disease Research Center and she is the Cognitive Health and Wellness Director at Mayo Clinic Charter House. She is a collaborator in Behavioral Neurology Family Seminars for those impacted by Frontotemporal dementia, Lewy body dementia, Corticobasal degeneration, and Primary progressive aphasia. She is involved in training professionals about methods and best practices in dementia and person-directed care. She currently writes the Alzheimer’s expert blog and newsletter is a contributing writer and editor for the Mayo Clinic Guide to Alzheimer’s and Related Dementia’s. She was named Associate in the Department of Neurology in 2012.
Marguerite Manteau-Rao, LCSW

Marguerite Manteau-Rao is a geriatric social worker, and Founder of the Mindfulness-Based Dementia Care (MBDC) program, first at University of California San Francisco Osher Center for Integrative Medicine, and now with Presence Care Project. She served as co-investigator with University of California San Francisco Institute for Health and Aging, for a caregiver research grant from the California Department of Public Health. Marguerite is a Huffington Post contributor, and the author of ‘Caring for a Loved One With Dementia’, to be released in February 2016 by New Harbinger Publications. She is also the Co-Founder of Neurocern, a dementia population health software company that aims to empower patients, families and health organizations.

Ian McKeith, MD, F Med Sci
Newcastle University, UK

Professor of Old Age Psychiatry
Clinical Director, Institute for Ageing and Health
University of Newcastle upon Tyne
Dr. Jennifer Rose V. Molano is an Associate Professor of Neurology and Rehabilitation Medicine at the University of Cincinnati. She completed medical school and neurology residency training in her home state at West Virginia University. She further received training in behavioral neurology at the Mayo Clinic in Rochester, Minnesota and sleep medicine at Vanderbilt University in Nashville, Tennessee. She is actively involved in the American Academy of Neurology, including participation on the editorial advisory board for Neurology Now, an education publication for patients and caregivers living with neurological disorders. She is very interested in the evolving interface between sleep and cognition, including sleep issues in Lewy body disease.

Diana Myles  
Care Partner

My husband, Paul Primakoff, and I met as postdoctoral fellows in 1977. Our first faculty job was at the University of Connecticut Medical School. In 1994 we moved to UC Davis, where we continued our research on fertilization and teaching of undergraduates and medical students. We have both retired. We have two children, twins (boy and girl) who are married and live outside California, so we find ourselves traveling to see them. In the last couple of years that has meant trips to Washington DC, Sicily, Ethiopia, New England and Chicago. Since Paul’s diagnosis. I have tried to keep our life as normal as possible. In late February we are looking forward to the arrival of our first grandchildren, one from each couple. The due dates are only a couple days apart!
Ms. Parfitt earned her M.S.H. degree from the University of North Florida, Jacksonville, Florida, and advanced certificates in aging and adult studies. Before joining Mayo Clinic, Ms. Parfitt was instrumental in implementing a comprehensive community based program for Alzheimer’s disease patients and families through a Robert Wood Johnson Foundation grant. Since joining Mayo Clinic, Ms. Parfitt has held several positions in the Department of Neurology focusing on clinical research in Alzheimer’s disease, related dementia and the normal aging process. In 1997 she was honored with the prestigious appointment as associate in research. Ms. Parfitt currently serves as the administrator for the Memory Disorder Clinic and Operations Manager – Research at Mayo Clinic where she oversees several projects including clinical trials, longitudinal studies and educational programming. Ms. Parfitt is an avid sports fan and enjoys traveling and spending time with her family.

Christel Patnaude joined Mayo Clinic Alzheimer’s Disease Research in 2000. She has worked extensively with the aging population performing neuropsychological testing. Most recently she joined a team of dementia education coaches at Mayo Clinic. She graduated from St. Mary’s University of MN earning her Master’s degree in counseling and psychological services in 2006. She is a Mayo Clinic Certified Wellness Coach. Christel’s professional interests include dementia education, healthy aging, and caregiver wellness. She currently facilitates group supportive sessions, wellness education, and brain fitness in the HABIT Program (Healthy Action to Benefit Independence & Thinking).
Paul Primakoff
Living with DLB

I grew up in Kirkwood, a small town near St. Louis, Missouri. I then lived in various places, finally settling in Northern California for the past 20 years. I worked there as a Professor at the University of California, Davis doing medical research and teaching. I retired in 2009. In retirement I spend my time reading, traveling, singing, working (volunteer) in the University Arboretum/Garden and hanging out with family and friends. In 2010 I was diagnosed as having LBD. This chronic illness has been the most difficult situation I have had to deal with in my life. But I do not feel alone in the struggle because of the support of my doctors, family and friends.

Deborah E. Richman, BS, ACC
Alzheimer’s Association® Minnesota-North Dakota

Deborah received her Bachelor of Science Degree from the University of Wisconsin-Oshkosh and is a certified consultant with the National Certification Council of Activity Professionals. Her career in senior services is focused in the areas of program development and education/training. She is also co-chair of the Meeting of the Minds Dementia Conference annually in collaboration with Mayo Clinic. She provides consultation and training for professional staff in the areas of communication and memory loss, dementia related behaviors and therapeutic program development.
She has presented at the national, state and local level for a variety of professional health related organizations and community groups.
Paul Smith
Former Caregiver

I live in Illinois right by the Mississippi River in a place known as the Quad Cities. I am married with 3 grown kids and 3 small grandchildren. I have worked in sales for most of my adult life and have traveled all over the US. My main hobby is gardening. I would describe myself as introverted with the ability to be an extrovert as needed. I have volunteered with the LBDA for several years mainly as a caregivers group coordinator. I was the main caregiver for my father for roughly 6 years and started the group to find emotional support with others in the same situation. Dad's suffering ended 2 years ago. My recovery therapy is to make something positive come out of a very difficult experience.

Angela Taylor
Lewy Body Dementia Association

Angela Taylor is the Director of Programs with the Lewy Body Dementia Association (LBDA). She served on LBDA’s Board of Directors for 4 years after her father was diagnosed with LBD and then joined LBDA’s staff in 2008. Ms. Taylor currently oversees all aspects of LBDA’s mission delivery, including programs and resources for LBD families, educational initiatives, advocacy and research efforts. She has just been appointed to the Advisory Council on Alzheimer’s Research, Care and Services which provides input on the National Alzheimer’s Plan.
Steven H. Zarit, Ph.D. is Distinguished Professor of Human Development and Family Studies at the Pennsylvania State University. He also holds the position of Adjunct Professor at the Institute of Gerontology, Jönköping University, Jönköping, Sweden. Dr. Zarit has conducted pioneering research on caregiver burden and stress. His recent research has examined the role of adult day service programs in lowering stress and improving health for caregivers of people with dementia. He also studies family relationships across the life span and functioning and mental health in very old age. He is the recipient of numerous awards including including the Distinguished Mentorship Award from the Behavioral and Social Sciences Section of the Gerontological Association of America and the M. Powell Lawton Awards from both the American Psychological Association and the Gerontological Society of America.
In this talk, the basics of DLB will be discussed in a general overview. We will briefly review the history of how DLB was discovered. We will define dementia and describe the different clinical manifestations of Lewy body disease, including DLB. Finally, we will address the prevalence of DLB and the demographics of those who have DLB.

Important key messages from this presentation are:

- Lewy body dementia is the second most common dementia, after Alzheimer’s dementia.
- Dementia is cognitive impairment that affects daily functioning.
- In Lewy body dementia, dementia begins within one year of parkinsonism, as opposed to Parkinson’s disease dementia in which dementia begins at least one year after parkinsonism.
How common is Lewy body dementia?

- Prevalence in the population: 0.36% (0-21.9%)
  - 1 in 270 people
- Prevalence in those with dementia: 7.5% (2.2-24.7%)
  - 1 in 13 people with dementia
- Incidence: 3.8% of new dementia diagnoses annually (3.2-4.5%)
  - OR 3.5 per 1000,000 person-years

Lewy body dementia is the second most common dementia, after Alzheimer’s dementia.

What is dementia?

- Problem in at least two areas of cognition severe enough to AFFECT daily functioning
  - Memory
  - Communication and language
  - Attention
  - Reasoning and judgment
  - Visual perception

Spectrum of Lewy body disease

- Lewy body disease refers to the build-up of proteins called Lewy bodies in the brain
- Lewy body disease causes three main syndromes:
  - Lewy body dementia
  - Parkinson’s disease
  - Parkinson’s disease dementia
What is the difference between Lewy body dementia (LBD) and Parkinson’s disease dementia (PDD)?

- Both LBD and PDD are associated with **parkinsonism**.
- Parkinsonism (2 out of 4)
  - Slowness of movement
  - Rigid muscles
  - Resting tremor
  - Balance trouble

What is the difference between Lewy body dementia (LBD) and Parkinson’s disease dementia (PDD)?

- **Lewy body dementia**
  - Onset of dementia within one year of parkinsonism

- **Parkinson’s disease dementia**
  - Onset of dementia more than one year after parkinsonism
Important things I want to remember:

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• _______________________________________________________________
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• _______________________________________________________________
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• _______________________________________________________________
  _______________________________________________________________

Questions I want to ask:

1. _______________________________________________________________
   _______________________________________________________________

2. _______________________________________________________________
   _______________________________________________________________
This presentation focuses on an overview of the clinical diagnostic for DLB with special emphasis on associated symptoms that are diagnostic clues for disease. Recognized confounds for DLB diagnosis including discussion of common comorbid pathology and diagnostic dilemmas that must be addressed are focused on. The full spectrum of clinical pathology is DBLB is discussed, setting the landscape for further discussions of symptomatic treatment approaches are included.

Important key messages from this presentation are:

- DLB can affect every aspect of neurologic function from cognitive, behavioral, psychiatric to motor and non-motor symptoms including sleep disorders and autonomic dysfunction.
- Clinical presentations can be quite varied and include both core as well as affiliated clinical symptoms, marking DLB as a person-specific disease in presentation.
- Caveats and diagnostic conundrums are presented that drive home the difficulty in clinical diagnostic accuracy and further work involving the most promising biomarkers for underlying molecular disease are discussed.
Clinical Diagnostic Criteria for DLB include:

- Dementia
- At least 2 of 3 core features:
  - Fluctuating attention and concentration
  - Recent, well-formed, visual hallucinations
  - Spontaneous parkinsonism
- Suggestive clinical features
  - Rapid eye movement (REM) sleep behavior disorder
  - Severe neuroleptic sensitivity
  - Low dopamine transporter uptake in basal ganglia demonstrated by SPECT or PET imaging

Cognitive Changes

- May or may not include memory
- Often memory affected by attentional problems
- Different from STM loss in AD
- Attentional deficits
  - "In one ear and out the other"
  - Distraction-"spacing out"
- Visuospatial dysfunction
  - "Getting lost"
  - "Can't find the ketchup"
  - "Where's the curb"- depth perception

Fluctuations?

- Drowsiness and lethargy all the time or several times a day, despite getting enough sleep the night before
- Daytime sleep for two or more hours before 7 p.m.
- Times when patient's flow of ideas seem disorganized, incoherent or not logical
- Staring into space for long periods of time.
**Hallucinations?**

- Psychotic features can include delusions, paranoia, visual and auditory hallucinations.
- These can present before any cognitive decline or parkinsonism is seen.
- Visual hallucinations are stereotypic:
  - Well-formed visions of animals or people, especially small people or children.
  - Bonnet's syndrome?

**Confusion with other forms of dementia?**

- Many of these signs & symptoms can occur in other forms of dementia.
  - Early appearance of these increases suspicion.
  - Prominence of these increases suspicion.
  - DLB may be present in 50% AD cases.
  - LBV of AD.
  - Biological testing is still in its infancy, but several tests are available.
  - They may not be paid for by insurance however.

**An accurate diagnosis is really important!**

- Prognosis?
- Planning?
- Treatment considerations?
- And, this will only become more important as we begin to develop specific disease-modifying therapy for the different forms of degenerative dementia.
- What works for AD or FTD may not work for DLB, and vice versa...
DLB Clinical Distinctions

Important things I want to remember:

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- ________________________________
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- ________________________________
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- ________________________________
  ________________________________

Questions I want to ask:

1. ________________________________
   ________________________________
2. ________________________________
   ________________________________
This talk will review the role of alpha-synuclein in LBD, as well as the neurotransmitter systems and nervous system structures involved in LBD. The association between dysfunction in these systems and symptoms of LDB will also be discussed.

Important key messages from this presentation are:

- The main pathological feature seen in Lewy body disease is the presence of Lewy bodies in the nerve cells.
- Lewy bodies are associated with abnormal processing of the protein, alpha-synuclein.
- Cognitive, psychiatric, motor, sleep, and autonomic symptoms associated with LBD are due to dysfunction in the multiple neurotransmitter systems and the presence of Lewy bodies throughout the nervous system.
- Lewy bodies may disrupt these neurotransmitter systems and nervous system structures in an ascending fashion throughout the body, which subsequently may correspond with some of the symptom progression seen in LBD.
**Dementia With Lewy Bodies**

**Motor Issues:** Parkinsonism due to reduced dopamine
- Tremor
- Dyskinesia
- Rigidity
- Shuffling gait
- Stooped posture
- Difficulty with fine motor skills
- Masked facies

**Sleep Issues:**
- irresistible sleepiness, insomnia, and fragmented sleep related to changes in the brainstem
- REM sleep behavior disorder: acting out dreams related to changes in the dorsal pons
- Reduced DA and 5-HT also affects sleep

**Autonomic Issues:**
- Many autonomic changes related to changes in the aging SNS and peripheral nervous system
- Heart
- Stomach and intestines
- Bladder
- Symptoms may include:
  - Cardiac arrhythmias
  - Constipation
  - Urinary incontinence
DLB Neurological Causes

Important things I want to remember:

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  ______________________________________________________________________
  ______________________________________________________________________

Questions I want to ask:

1. _________________________________________________________________
   __________________________________________________________________

2. _________________________________________________________________
   __________________________________________________________________
Session 2: THE DIAGNOSIS

Making the Diagnosis
Jonathan Graff-Radford, MD

The presentation will Outline and describe the process a family would go through in obtaining an accurate diagnosis of LBD.

Important key messages from this presentation are:

- The history is the most important component of the dementia diagnosis
- Key elements of the history include identifying presenting symptom, mode of onset, duration of symptoms, and rate of progression
- Cluster of symptoms suggestive of Dementia with Lewy Bodies
- Neurologic examination will focus on mental status exam, parkinsonism (2 of 4) but also include tests of strength, reflexes, coordination, sensation, gait and look for tremor, rigidity, bradykinesia, postural instability, micrographia, masked face, shuffling gait
- Neuropsychological examination: Cognitive battery assessing multiple cognitive domains including memory, language, attention, executive, and visuospatial
Dementia With Lewy Bodies
Clinical Evaluation: History

Cognitive symptoms
• Visual spatial problems
• Memory problems
• Fluctuations
  • Frequent episodes of
drowsiness, long periods of
staring into space, long naps
during the day or disorganized
speech

Motor
• Tremor
• Slowness of movement
• Gait problems/Falls
• Monotone voice
• Less facial expression

Neuropsychiatric
• Hallucinations
  • Animals or people. Some people may
experience sound (auditory), smell
(olfactory) or touch (tactile)
hallucinations
• Delusions
• Anxiety
• Depression
Dementia With Lewy Bodies
Clinical Evaluation: History

Sleep
- REM sleep behavior disorder
- History of snoring

Dementia With Lewy Bodies
Clinical Evaluation: History

Autonomic
- Dizziness upon standing (orthostasis)
- Bowel/bladder dysfunction
- Erectile dysfunction
- Impaired sweating

Dementia With Lewy Bodies
Clinical Evaluation: Examination

Neurologic examination
- Strength, reflexes, coordination, sensation, gait
- Focus on mental status exam, parkinsonism
- Parkinsonism (2 of 4)
  - Tremor, rigidity, bradykinesia, postural instability
  - Micrographia, masked face, shuffling gait
Making the Diagnosis

Important things I want to remember:

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•

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Questions I want to ask:

1.

2.
This presentation focuses on the rationale, empiric use of pharmacologic therapy for the treatment of DLB associated symptoms. Pharmacological targets include cognitive decline, behavioral and mood-related symptoms such as depression and anxiety, psychotic symptoms such as hallucinations, delusions, motor symptoms of parkinsonism, and autonomic symptoms including orthostatic hypotension and syncope. Emphasis is placed on doctor patient relationships and the need to establish a therapeutic partnership for medication management.

Important key messages from this presentation are:

- A rationale strategy for medication management focused on identification of primary symptoms is established, including frequent reassessment of issues that may change pharmacologic management priorities in line with symptomatic changes that are part of the disease process.
- Your physician cannot manage these medications without developing a partnership with you, given the fluctuations in symptoms that are part of the DLB process.
- Continuous reassessment of medication management is necessary to optimize function throughout the disease course.
- Future pharmacologic therapies will address disease modification in an effort to slow, stop, or cure the underlying disease process in DLB.
If we can’t treat the disease yet, at least let us treat the symptoms!

- Can we do this?
  - Issues to consider:
    - Clinical heterogeneity
    - Pathological heterogeneity
- Of course we can!
  - The issues may appear in different order, may or may not come, but they can be categorized and there are treatments that can help!

Symptoms to treat...

- Cognitive impairment
- Behavioral symptoms: Depression, anxiety, irritability, restlessness, agitation, aggression, compulsions, euphoria, excitability, impulsivity...
- Psychotic symptoms: Hallucinations, delusions, paranoia...
- Motor symptoms: Parkinsonism
- Autonomic symptoms: Orthostatic hypotension, GI dysmotility, impotence...
- Sleep disorders: Excessive daytime hypersomnia, RBD/DEB...

Caveats...

- Parkinson’s medicines lower BP and worsen orthostatic hypotension
- Parkinson’s medicines can also worsen hallucinations, delusions, and paranoia
- Antipsychotics can worsen Parkinsonism and cognition
- Antipsychotics can also increase risk for heart attack, stroke, pneumonia, and death
  - FDA Black Box warning
**Classes of medications to consider?**

- Alzheimer’s approved medications
  - Cholinesterase inhibitors and memantine
- Antidepressants
  - SSRIs, SNRIs, SRIs, MAOIs
- Mood stabilizers
  - Antiepileptics and lithium
- Sedatives
  - Benzodiazepines and histaminergics
- Antipsychotics
  - Atypical and typical agents
- Stimulants
  - Ritalin, adderall, strattera, modafinil
- Antihypertensives
  - Clonidine and β-blockers

**Give each medication a “good college try”**

- Up’s and down’s in daily function are common and may not reflect medication effects
- Make sure you reach an effective dose before discounting a medication benefit
- Stay on the medication for 4-6 weeks to truly know if it is helping or not
- Don’t ever jump from medicine to medicine, or you will never know what might help
- It’s OK to start and stop medicines to test the effect in a metered fashion

**Empiric Approach to Treatment**

1. Assess symptoms in hierarchical fashion and target real symptoms
2. Cognitive issues identified as major problem
3. Behavioral issues identified as major problem
4. Psychiatric issues identified as major problem
5. Mood issues identified as major problem
6. Sleep issues
7. Nutritional issues
8. Attention issues
9. Depression
10. Anxiety
11. Medications: antidepressants, mood stabilizers, antipsychotic, anticonvulsant, anti-epileptic, anti-seizure, histamine receptor antagonist, β-blockers, atypical antipsychotic, anticonvulsant
12. Evaluation
13. Every 3 months
Symptom Management

Important things I want to remember:

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- ________________________________________________________________
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- ________________________________________________________________
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- ________________________________________________________________
  ________________________________________________________________

Questions I want to ask:

1. ________________________________________________________________
  ________________________________________________________________

2. ________________________________________________________________
  ________________________________________________________________
Lewy body dementia is the second most common cause of dementia after Alzheimer’s disease. Because Lewy Body Dementia shares features with the more widely recognized diseases of Alzheimer’s disease and Parkinson’s disease it is frequently under-recognized and misdiagnosed. This delay in diagnosis affects both patients and families. We present here the results of two large surveys of Lewy Body Dementia Caregivers to address the challenges, burdens, and frustrations obtaining a diagnosis and caring for the patient.

Important key messages from this presentation are:

- DLB caregivers face a number of challenges: social, medical, functional and financial. DLB caregivers feel isolated and often have to respond to crises, but are not currently receiving adequate support.
- DLB caregiving has both negative and positive aspects. While caregivers experience burden and grief as the disease progresses, they are also able to enhance their social support and improve their psychological well-being.
- Programs that assist caregivers develop coping skills and enhance their social support should improve caregiver-centered outcomes.
- Community resources such as the Lewy Body Dementia Association may serve this end, while also providing practical information and support for caregivers.
Introduction

- LBD is the second most common cause of dementia after AD, affecting approximately 1.3 million Americans.
- Because LBD shares clinical features with more widely recognized diseases such as Alzheimer’s disease, Parkinson’s disease and psychiatric disease, it is more likely to be under-recognized and initially misdiagnosed.
- These problems impact the LBD caregivers’ subjective burden and the patient’s quality of life, and may present different challenges compared with caregivers of patients with AD or PD.
- Two web-based surveys were conducted in conjunction with the Lewy Body Dementia Association.

Caregiver Experience With Diagnosis

- Patients saw 3.3 ± 1.5 physicians before a DLB diagnosis was made.
- 68% reported >3 doctors were consulted, 15% saw >5 different physicians.
- The mean number of office visits needed was 3.7 ± 1.9.
- 33% required >6 office visits.
- 19% patients diagnosed within 1st month and 51% were diagnosed within 1st year.
- 31% took more than 2 years from the start of symptoms to establish a DLB diagnosis.
- Neurologists diagnosed most cases (62%), while primary care providers diagnosed 6%.

First Diagnoses

- The initial diagnosis was a disorder other than DLB in 78% of cases.
- The most common first diagnoses were PD (39%) or AD (26%).
- Other dementing illnesses were given as the first diagnosis: FTD (4%), vascular dementia (5%), MCI (6%) or some unspecified dementia (12%).
- Primary psychiatric diagnoses were first diagnosed in 24% cases: major depression (19%), bipolar disorder (9%), or schizophrenia (2%).
Caregiver Burden

• DLB caregivers reported medium-high levels (mean 37.6 ± 8.8, range 11-55) of burden
• 56% reported moderate burden and 38% reported severe burden on 7 out of 11 items
• No difference in total burden or frequency of individual items by symptom presentation
• Spouse caregivers reported greater burden (mean 35.2 ± 7.7) than non-spouse caregivers (mean 33.6 ± 8.2, p=0.008)
• After correction for multiple comparisons, burden was most strongly associated with patient disturbances in mood (r=0.328, p<0.001) and sleep (r=-0.233, p<0.001)

Summary

• With our large samples of DLB caregivers, we are able to take a unique look at prominent DLB stressors and their relationship to caregiver burden, well-being, grief and quality of life
• DLB caregivers are often frustrated by their experiences with physicians
• Obtaining a DLB diagnosis often required multiple visits to multiple physicians, causing significant delay in initiation of therapy
• DLB caregivers face a number of challenges: social, medical, functional and financial. DLB caregivers feel isolated and often have to respond to crises, but are not currently receiving adequate support
The Patient and the Family

Important things I want to remember:

• _______________________________________________________________

• _______________________________________________________________

• _______________________________________________________________

• _______________________________________________________________

Questions I want to ask:

3. _______________________________________________________________

4. _______________________________________________________________
This session will provide the opportunity for persons living with Lewy body dementia to share their experience and engage in a discussion around topics that are important to them. During this session participants may also work to identity key messages that they would like family members, medical professionals and the general public to know about living with this disease and the best ways to impact the quality of their life.
THE STRUGGLES AND THE STRATEGIES

For Persons living with DLB

Important things I want to remember:

• _______________________________________________________________
• _______________________________________________________________
• _______________________________________________________________
• _______________________________________________________________

Questions I want to ask:

1. _____________________________________________________________
2. _____________________________________________________________
THE STRUGGLES AND THE STRATEGIES

NOTES
Session 3: THE STRUGGLES AND THE STRATEGIES

For Care Partners and those who simply care
Facilitators Angela Lunde, Christel Patnaude & Ashley Bayston

This session will provide the opportunity for small group discussions around identified topics selected by care partners. The second half of the session will offer a framework aimed at mitigating common struggles experienced within families impacted by DLB.

Important key messages from this presentation are:

• Make Room for Acceptance
• Employ Empathy
• Practice Good Communication Skills
• Understand Universal Needs
• Fine-tune Good Communication
The ways in which we (spouses, sons, daughters, care partners) interact and communicate can set the tone...

Ease and Calm
or Tension and Stress?

Inviting More Ease

- Make Room for Acceptance
- Employ Empathy
- Practice Good Communication Skills
- Understand Universal Needs
- Fine-tune Good Communication Skills

Make Room for Acceptance

- Accept that a diagnosis, with all its implications, will have a profound impact on your marriage, relationship, or friendship.
- Accept that trouble with multitasking, attention and confusion is real even though it will fluctuate.
- Accept that persons with LBD really can ‘get it’ one minute and not the next.
- Accept that you will not be perfect and you will get angry.
When we try to understand the world from the perspective of a person with Lewy Body Dementia, we can see solutions rather than problems.

Inviting More Ease
Universal Emotional Needs

- Need to feel respected
- Need to feel a sense of control
- Need to feel useful and worthy
- Need to give and receive love

Fine-Tuning Communication

- Respond to repeated questions as if it were the first time. Requires acceptance.
- Speak using positive language. Offers respect, control, self-worth.
- Avoid correcting or criticizing. Offers respect, control, self-worth.
- Validating the emotion eases negative tension more than anything else. Offers respect, control, self-worth.
- Allow the person with LBD complete their daily routine at their own pace. Offers respect, control, self-worth.
- Employ Empathy.
THE STRUGGLES AND THE STRATEGIES
For Care Partners and those who simply care

Important things I want to remember:

•

Questions I want to ask:

1.

2.
THE STRUGGLES AND THE STRATEGIES

NOTES
The National Institutes of Health (NIH) is the largest funder of biomedical research in the world. Two of its 27 institutes play a pivotal role in advancing the scientific understanding of Lewy body dementias (LBD). This session provides an important opportunity to a) learn more about the role of NIH in LBD research, b) what types of research are being funded and c) to serve as a patient advocate by sharing your own examples of the impact of LBD in your life.

Important things I want to remember:

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CRITICAL CONVERSATIONS

Questions I want to ask:

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Session 4: THE EXPERIENCE

*Paul Smith*
*Alexander Drier*
*Olivia Drier*

It is not what happens to us that determines the quality of our lives but how we choose to respond to what comes our way that does. In this session hear from 3 individuals impacted by Lewy body dementia in very different ways. Their stories offer opportunities for learning, reflection and community.
The Experience

Important things I want to remember:

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Questions I want to ask:

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Dr. Boeve will provide an overview of the types of research being conducted as well as highlight research being shared at the conference.
Research Update on DLB

Outline

- Clinical/Neuropsychology
- Imaging
- Genetics/Biofluid
- Neuropathology/Basic Science
- Therapeutics

Clinical/Neuropsychology

Diagnostic Criteria
- REM sleep behavior disorder (RBD)
- Specific details of parkinsonism
- Specific details of fluctuations

Neuropsychology
- Attention/concentration, executive functions, memory, visuospatial functioning, language

Non-cognitive features

Prodromal DLB

Imaging/Biomarkers

- MRI and MR spectroscopy (MRS)
- DaTscan/ioflupane SPECT
- Glucose PET (FDG-PET)
- Amyloid PET
- Tau PET
- MIBG
- Electroencephalogram (EEG)
- Polysomnogram (PSG)
Genetic/Biofluid

Genetic
  DLB/PD related genes
  AD related genes
  FTD related genes
  Other

Cerebrospinal fluid (CSF) proteins

Blood/plasma proteins

Neuropathology/Basic Science

Neuropathology
  DLB/PD related pathology
  AD and vascular pathology
  Diagnostic criteria update

Animal models

Synucleinopathy pathogenesis
  Targets for therapy

Therapeutics

Symptomatic
  Acetylcholinesterase inhibitors
  Memantine
  Atypical neuroleptics
  Dopaminergic agents
  Wake promoting agents
  Sedatives/hypnotics
  Blood pressure/vascular modulators
  New agents

Disease-modifying
  Agents which affect LBD pathogenesis
Steps Forward

Important things I want to remember:

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Questions I want to ask:

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The aim of the DIAMOND-Lewy programme is to improve the diagnosis and management of LBD through a series of linked work packages. This includes the development, and subsequent assessment, of an evidence-based LBD practical management toolkit for clinicians through a systematic review and Delphi survey. To inform the development of the management toolkit, we also explored the views of patients and carers on the symptoms they found most troubling and their experiences of medical consultations for LBD.

Important things I want to remember:

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Question I want to ask:

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Dementia with Lewy Bodies (DLB) is estimated to be the second most prevalent dementia, affecting 1.3 million Americans. Physical function declines through Parkinsonism and sedentariness exacerbated by the cluster of motor, psychiatric and cognitive symptoms in DLB. Exercise may improve functional outcomes in Parkinson’s disease (PD), as well as Alzheimer’s disease (AD). However, due to the multi-domain DLB symptom cluster, vulnerable individuals are often excluded from exercise studies evaluating physical function in PD or cognitive function in dementia to avoid confounding results. The aim of this review was to evaluate existing literature reporting the effects of exercise or physical activity on physical, cognitive or psychological function in DLB.

Important things I want to remember:

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Question I want to ask:

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There is now considerable evidence of interventions that lower emotional distress and burden among caregivers. In this presentation, I review characteristics interventions that have been found to be effective with family caregivers of persons with dementia, and the implications for helping caregivers of persons with Lewy Body Dementia. Three effective interventions will be highlighted: a group intervention (Savvy Caregiver), a family-oriented treatment (NYU Caregiver Intervention) and Adult Day Services as a form of respite for caregivers.

Important key messages from this presentation are:

- There is now an extensive foundation of evidence about types of interventions that are and are not effective in helping lower burden among family caregivers.
- Effective interventions use multiple strategies for lowering distress, use psychological methods for building new skills for managing daily care problems, and build emotional and practical support.
- Families should be encouraged to use evidence-based interventions and clinicians who want to serve families should consider utilizing these existing models.
- More research is needed to determine if existing interventions work as effectively with caregivers of persons with Lewy Body Dementia compared to other caregivers or if LDB-specific modules and approaches would be need to improve outcomes for caregivers.
Overview

- Treatment of family caregivers is effective in lowering burden and distress
- Types of interventions
- Characteristics of successful interventions
- What approaches do NOT work
- Examples of successful interventions
  - The Early Caregiver group intervention
  - The NNU family-focused caregiver intervention
  - Adult Day Services: Despite issues, health risk for caregivers

Interventions for Family Caregivers Are Effective!

- Accumulating evidence of interventions that work
- No specific studies of interventions with family caregivers of persons with LBD
- In developing interventions, don’t reinvent the wheel!

Types of Intervention Modules in Effective Treatments

- Information about the disease and resources for managing it
- Understanding the patient's behavior and the caregiver role
- Stress reduction strategies: yoga, relaxation, mindfulness
- Behavioral management/Problem solving
- Increase family support and reduce conflict
- Use of respite — adult day services (ADS)
Characteristics of Effective Interventions

- Psychological vs. educational
  - Change model?
- Multi-dimensional vs uni-dimensional
- Flexible, rather than rigidly manualized
- Family focus
- Targeted treatment at appropriate dosage


Daily Stress and Health of Family Caregivers Study (DaSH)

- Stress hormones as a link between daily experiences and health
- Use of adult day services (ADS) for caregivers of persons with dementia leads to better regulation of two critical stress hormones (cortisol & DHEA-S)
- Use of ADS is also associated with lower feelings of anger and lower depressive feelings
- Functional health was stable among caregivers who used more ADS days

Zalt et al., 2014, Gerontologist; Kline et al., 2014, Gerontologist; Zalt et al., 2014, American J of Geriatric Psychiatry; Liu et al., 2014, J of Aging & Health

Significance of the Findings from DaSH

- Improved levels of the stress hormones (cortisol and DHEA-S) lower risk of illness
- Improvements in affect are associated with lower risk of illness
- Reduced risk is dose specific—more days of adult day service use → lower risk
- ADS and other respite services can be extended over the whole course of care
- Respite is more than just compassion or babysitting
Important things I want to remember:

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Questions I want to ask:

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4. ____________________________________________________________________
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Lewy Body dementia affects not only patients but also families. Each patient is estimated to have 2.9 informal (mostly family) caregivers who are estimated to provide millions of hours of unpaid care. An accountable way to improve dementia care and patient- and family-centered outcomes is greatly needed. The Institute of Medicine recommends interprofessional teams to address patients' complex needs – these teams are composed of physicians, nurses, social workers, therapists and other clinicians working together in a collaborative arrangement. Collaborative care models provide a pragmatic strategy to deliver integrated health and medical care to patients and families.

Important key messages from this presentation are:

- Collaborative care models utilizing a transdisciplinary cadre of clinicians maximizing the unique skills and abilities of every team member provide a pragmatic strategy to deliver integrated health and medical care to patients and families.
- Key to these efforts is the need to take into account patient and family needs, social norms and preferences for care in shared decision making, a concept all the more important because of the progressive nature of dementing illnesses.
- Collaborative care approach has improved patient- and family-centered outcomes, satisfaction with care, and met pre-specified quality indicators by incorporating clinicians with different but complementary competencies into the healthcare model.
- Approach is also consistent with health care reform and National Alzheimer Plan Act goals to integrate quality care, health promotion and preventive services, and mitigating the emotional and psychological effects of disease on patients and families.
Introduction

- LBD affects not only patients but also families. Each patient is estimated to have 2-9 informal (mostly family) caregivers who provide millions of hours of care annually.
- An accountable way to improve dementia care and patient- and family-centered outcomes is greatly needed.
- The Institute of Medicine recommends interprofessional teams of physicians, nurses, social workers, therapists to address patients' complex needs.
- Collaborative care models provide a pragmatic strategy to deliver integrated health and medical care to patients and families.

Collaborative Care Models

- Based on Wagner's Chronic Care Model, collaborative care models focus on the need for long-term, systematic approaches to properly manage chronic conditions, rather than prioritizing treatment of acute symptoms.
- The collaborative approach to providing memory care is a model of care that utilizes a transdisciplinary team to allow for the most comprehensive means of providing care to patients and caregivers.
- In a collaborative care model, each member of the care team provides their own clinical, management, and/or administrative strengths which allow the patient and caregiver to receive comprehensive care outside of the simply medical domain.

Empirical Evidence

- Ganz and colleagues
  - Nurse Practitioner participation in care coordination improves quality of care for dementia and increased adherence to recommended care by 20%
- Vickers and colleagues
  - Increased use of social workers increased compliance with dementia guidelines and provided a beneficial improvement in patients' health-related quality of life
- Lee and colleagues
  - Family health teams increased satisfaction with care by patients and families, and nearly all patients were treated with appropriate anti-dementia medications
- Callahan and colleagues
  - Advanced practice nurse led to fewer behavioral problems and fewer depression symptoms
Final Perspectives

- Collaborative care models utilizing a transdisciplinary cadre of clinicians maximizing the unique skills and abilities of every team member provide a pragmatic strategy to deliver integrated health and medical care to patients and families.
- Key to these efforts is the need to take into account patient and family needs.
- Collaborative care approach has improved patient- and family-centered outcomes.
- Approach is consistent with health care reform and National Alzheimer Plan Act goals.
Team Based Care

Important things I want to remember:

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- Questions I want to ask:

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This presentation will introduce and describe a multicomponent behavioral intervention designed for individuals with mild cognitive impairment and their caregivers. Benefits to be gained from participation in the HABIT program will be enumerated, such as acquiring tools for increased independence, self-efficacy, and quality of life as well as supportive strategies for coping and self-care.

Important key messages from this presentation are:

- Mild cognitive impairment (MCI) impacts functional abilities in patients and increases dependence on caregivers, which increases emotional distress.
- Pharmacologic treatment has shown limited efficacy in delaying the progression of MCI. Effects of non-pharmacological therapeutic interventions have been shown to be at least as good as medication, and can be more readily individualized.
- Compensatory mechanisms implemented before dementia presents may prolong the window of stability in mild memory decline.
- Participation in a multicomponent program that includes memory compensation training, support groups, brain fitness activities, physical exercise (e.g., yoga), and wellness education appears to improve self-efficacy and improvement in quality of life in individuals with MCI and decreased burden, depression and anxiety in their caregivers, at least in the short-term.
- Individuals with Lewy body disease experience a different set of cognitive and physical symptoms than those with other neurodegenerative diseases, and thus the intervention may need to be tailored to achieve optimal benefit.
Multicomponent Programs

- Non-pharmacological therapies
  - Delayed institutionalization of persons with Alzheimer’s disease and related dementias
  - Effects on cognition, ADLs, behavior, and mood similar to medication
  - No side effects
  - More readily individualized

HABIT Program Philosophy

Persons with mild cognitive impairment (MCI) have an opportunity to incorporate new “habits” into their lives. These habits, when supported by a partner, can help compensate for certain memory deficits and promote optimal wellness for mind and body.
Program Benefits

• Tools for increased independence, self-efficacy, and quality of life
• Enhanced knowledge, skills, and resources
• Supportive strategies for coping and self-care
• Establishment of supportive relationships and networks for future support

Program Benefits

• Understanding techniques for managing communication and relationship changes
• Better management of psychiatric symptoms (e.g., depression, anxiety)
• Improved physical conditioning, balance, and/or flexibility
• Understanding of technologies available to support independence

HABIT Research

• Compared to no intervention
  • HABIT MCI: greater sense of self-efficacy and improvement in QOL
  • HABIT caregivers: greater decrease in burden, less depression and anxiety, and a trend towards improved QOL
• LBD presents with different symptoms and may require a uniquely tailored program
Healthy Actions to Benefit Independence and Thinking

Important things I want to remember:

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This presentation will provide an overview of arts-based interventions for people with dementia and the corresponding research. It will also argue that current methods and research designs, which are focused on long-term measurable outcomes, do not adequately capture the experiences of those with cognitive challenges and people who care for them. Finally, it will offer recommendations on arts-based programs available to group programs and to home caregivers.

Important key messages from this presentation are:

- There are many creative possibilities for people with dementia or other forms of cognitive decline.
- Although the scientific literature has not found a clear relationship between arts-participation and improved outcomes, it doesn’t mean that the arts are not important.
- A person’s individual preferences must play a part in selecting an appropriate arts intervention.
- Future research better aimed at defining “success” and capturing outcomes of arts-based interventions is needed.
**Arts Defined**

- Art therapy – artist/therapist driven with a clear therapeutic goal in mind
- Cultural arts – “the practice of creating perceptible forms expressive of human feeling” (Langer, 1966, p. 6); artist driven
  - Can be active or passive

**Arts Defined**

- Participatory arts – programs where the person is an active participant (co-creator) versus passive (e.g., observer, listener)
  - E.g., singing, dancing, storytelling

**What does the scientific literature say?**

- No conclusive evidence of benefits
- Psycho-social interventions that are tailored to recipient tend to have better outcomes
- Designs not well suited to capture what occurs during participatory arts programs.
**What do the participatory arts offer?**

- Imagination
- The chance to be heard and validated
- Innovation
- Creation of moments not based in memory, moments of joy
- Joint meaning making

**Where to go from here?**

- Resources for home and community caregivers
- Types of programs
The Arts as a Cultural Therapy for Dementia

Important things I want to remember:

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Mindfulness, the practice of being fully aware of the present moment, on purpose, and without judgment, can help lessen stress and bring greater ease for both care partners throughout the LBD journey.

Important key messages from this presentation are:

- Mindfulness practice can help relieve the stress for both the person with LBD and family member in caregiving role. Both care partners can practice mindfulness together.
- Mindfulness can help both care partners hold their grief.
- Mindfulness practice can help ease the interactions between both care partners.
- Key solo mindfulness practices include: mindful check in, awareness of breath, Stop – Take a breath – Observe – Proceed (STOP), mindfulness of feeling state, self-compassion, mindful walking, mindfulness of sounds, book end practice.
- Mindful care practices include: ‘sitting with’, ‘walking with’, patience with repetitions, lending executive function, being with changes, sensory awareness, aikido communication, preparing to meet.
A Mindful Journey

Important things I want to remember:

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Each person has an important role to play to make the world a better place for others touched by LBD. This session offers attendees a roadmap to follow after leaving the conference. Find out who needs to hear your story and ways you can share it. Learn how to take action in your community. Discover the “expertise” you have to offer and why it’s extremely valuable in the fight against LBD.

Important key messages from this presentation are:

- Each person touched by LBD has an important story to tell. By sharing a bit of your personal LBD journey, you can educate your friends and co-workers. Use it to raise awareness of LBD among healthcare providers, hospitals and businesses that serve older adults.
- By attending this conference, you are very well-prepared to help others in the LBD community. Join LBDA as a volunteer and receive the training you need to launch a support group in your community. You can also volunteer as a “Lewy Buddy” to lend a listening ear and support to others by phone or email.
- Each October, with the help of volunteers across the country, we celebrate LBD Awareness Month. LBDA has resources to help you organize a 5K walk/race, host a Little Black Dress event, give a presentation on LBD, and more. Contact your local television and radio station to share information about your event and personal story. These compelling human interest stories raise a great deal of LBD awareness.
- Use your voice to lobby for change! Help LBDA send a message to Washington, DC that it’s not always Alzheimer’s disease and that more research funding is urgently needed!
- You can help advance research by participating in studies as a person diagnosed with LBD or as a healthy participant. Studies in Alzheimer’s disease and Parkinson’s disease may also reveal important information about LBD, if you can’t find an LBD study near you. Visit www.clinicaltrials.gov to find studies that you may qualify for.
Important things I want to remember:

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Closing Remarks:
<table>
<thead>
<tr>
<th>Early differentiating symptoms</th>
<th>LBD</th>
<th>Alzheimer's</th>
<th>Parkinson's</th>
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<tbody>
<tr>
<td>Decline in thinking abilities that interfere with everyday life</td>
<td>Always</td>
<td>Possible</td>
<td>Possible</td>
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<tr>
<td>Significant memory loss</td>
<td>Always</td>
<td>Possible</td>
<td>Possible</td>
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<tr>
<td>Planning or problem-solving abilities</td>
<td>Likely</td>
<td>Possible</td>
<td>Possible</td>
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<tr>
<td>Difficulty with sense of direction or spatial relationships between objects</td>
<td>Likely</td>
<td>Possible</td>
<td>Possible</td>
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<tr>
<td>Language problems</td>
<td>Possible</td>
<td>Unlikely</td>
<td>Unlikely</td>
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<tr>
<td>Fluctuating cognitive abilities: attention or alertness</td>
<td>Possible</td>
<td>Unlikely</td>
<td>Unlikely</td>
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<tr>
<td>Changes in mood</td>
<td>Possible</td>
<td>Unlikely</td>
<td>Unlikely</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>Likely</td>
<td>Unlikely</td>
<td>Unlikely</td>
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<tr>
<td>Severe sensitivity to medications used to treat hallucinations</td>
<td>Possible</td>
<td>Possible</td>
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<tr>
<td>Changes in walking or movement, such as slower, smaller steps, problems using hands, tremors</td>
<td>Possible</td>
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<tr>
<td>Balance problems and/or falls</td>
<td>Possible</td>
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<tr>
<td>Rapid eye movement (REM) sleep behavior disorder</td>
<td>Possible</td>
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Resources

Lewy Body Dementia

- Visual hallucinations and/or sensitivity to neuroleptics
- Cognitive dysfunction (may look like Alzheimer’s)
- Motor dysfunction (may look like Parkinson’s)
- Fluctuating levels of attention (May mimic delirium)
- Acting out dreams (REM Sleep Behavior Disorder) and/or other sleep disturbances
- Autonomic dysfunction
Resources

LBD Caregiver Link  Toll-free # – 800.539.9767

Mayo Clinic Dementia With Lewy Bodies
http://www.mayoclinic.org/lewy-body-dementia/

Lewy Body Dementia Association
http://www.lbda.org/

Alzheimer’s Association
www.alz.org

NINDS Dementia With Lewy Bodies Information Page

National Parkinson Foundation, Inc.
http://www.parkinson.org

Michael J. Fox Foundation
http://www.michaeljfox.org/

(I also have 3 PDF documents that we need to print and insert here)

- Medication glossary
- Comprehensive lbd symptom checklist
- Caregiver burden in lbd
Comprehensive Lewy Body Dementia Symptom Checklist

Instructions
Add a check mark next to any new or concerning LBD symptoms. Write your comments or questions for the doctor in the comment field. Bring this form with you to your next appointment or send it to the doctor in advance.

<table>
<thead>
<tr>
<th>Cognitive Symptoms</th>
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<tbody>
<tr>
<td>Forgetfulness</td>
</tr>
<tr>
<td>Trouble with problem solving or analytical thinking</td>
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<tr>
<td>Difficulty planning or keeping track of sequences (poor multi-tasking)</td>
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<tr>
<td>Fluctuating levels of concentration and attention</td>
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<tr>
<td>Disorganized speech and conversation</td>
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<tr>
<td>Unexplained episodes of confusion</td>
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<tr>
<td>Difficulty with sense of direction or spatial relationships between objects</td>
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<table>
<thead>
<tr>
<th>Parkinson's-like Symptoms</th>
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<tbody>
<tr>
<td>Rigidity or stiffness</td>
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<tr>
<td>Shuffling walk</td>
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<tr>
<td>Balance problems or repeated falls</td>
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<tr>
<td>Tremor</td>
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<tr>
<td>Slowness of movement</td>
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<tr>
<td>Weak voice</td>
</tr>
<tr>
<td>Change in handwriting</td>
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<tr>
<td>Decrease or change in facial expression</td>
</tr>
<tr>
<td>Drooling</td>
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<tr>
<td>Loss of or decreased ability to smell</td>
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<tr>
<td>Change in posture</td>
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<table>
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<tr>
<th>Behavior and Mood Changes</th>
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<tbody>
<tr>
<td>Hallucinations - Seeing or hearing things that are not really present</td>
</tr>
<tr>
<td>Other hallucinations (touch, smell)</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Apathy (loss of interest and drive)</td>
</tr>
<tr>
<td>Delusions (false beliefs)</td>
</tr>
<tr>
<td>Anxiety</td>
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</tbody>
</table>
**Sleep Concerns**
- Acting out dreams during sleep (sometimes violently), falling out of bed
- Excessive daytime sleepiness
- Insomnia
- Restless leg syndrome

**Autonomic System Dysfunction**
- Dizziness, lightheadedness or fainting – or changes in blood pressure
- Sensitivity to heat and cold
- Sexual dysfunction
- Urinary incontinence
- Constipation
- Unexplained blackouts or transient loss of consciousness

**Reactions to Recent Medication Changes**
- Significant improvement
- Minimal improvement
- No change
- Increased parkinsonism (stiffness, rigidity, etc.)
- Increased confusion
- Increased hallucinations
- Increased sleepiness
- Increased dizziness or fainting

**Comments/Other Concerns**

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The information set forth in this material is intended for general informational use only. It is not intended to be medical, legal or financial advice or to take the place of competent medical, legal or financial professionals who are familiar with a particular person’s situation. Each individual is advised to make an independent judgment regarding the content and use of this information.

For more information on Lewy body dementia please visit [www.lbda.org](http://www.lbda.org) or call the LBD Caregiver Link 800-539-9767.
Lewy body dementias (LBD) are a set of related brain disorders affecting approximately 1.3 million Americans. These disabling diseases affect not only the individual diagnosed with the illness, but also caregivers, families, and friends. Caregiver Burden in Lewy Body Dementias provides a quantitative overview of LBD’s impact on caregivers as assessed by a survey. This report includes:

- Background information on LBD,
- A description of the survey,
- Selected survey findings,
- Discussion of survey results, and
- Key points for action.

Caregiver Burden in Lewy Body Dementias seeks to accomplish several goals. First, it allows the families and friends of people with LBD to compare their experiences in caring for loved ones with LBD. Second, it provides other interested lay readers, policymakers, and researchers with an overview of LBD and the effect it has on families. Finally, it serves as a blueprint for action to overcome some of the challenges encountered by LBD caregivers.

WHAT IS LEWY BODY DEMENTIA?

Although not familiar to many, LBD affects an estimated 1.3 million individuals and their families in the United States. LBD is an ‘umbrella term’ for two related diagnoses, “Parkinson’s disease dementia” and “dementia with Lewy bodies”. The earliest symptoms of these two diseases differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms. (See Fig. 1)

200 Years of Research Connect LBD to Parkinson’s. In 1817, Dr. James Parkinson first reported on the “shaking palsy” that “spared the intellect.” In 1912, Dr. Friederich Lewy reported microscopic protein accumulations in the brainstems of autopsied people with Parkinson’s. In time, it also became widely acknowledged that a large proportion of individuals with Parkinson’s disease also developed cognitive impairment that progressed to dementia. In 1961, the protein deposits (now called Lewy bodies) were also linked to progressive dementia that did not start with Parkinson’s disease, and, by 1990, researchers across the world were using different names to describe a single disease that had motor, cognitive, and psychiatric symptoms. In 1996, an international consortium established a single set of diagnostic criteria for the disease now known as ‘dementia with Lewy bodies’.
In 2007, researchers and clinical experts in both dementia and movement disorders established a new consensus that Parkinson’s disease with dementia and dementia with Lewy bodies probably share the same underlying disease mechanism. This new consensus established four important priorities for the future:

1) Continued communication between experts who specialize in Parkinson’s disease with dementia and dementia with Lewy bodies;

2) Research studies to validate diagnostic criteria;

3) The development of tests using blood, urine, or brain imaging to diagnose LBD, instead of relying only on symptom reporting by the person with LBD and their caregiver; and

4) Accelerated efforts to find more effective treatments for these diseases.
LBD is Under-Diagnosed. Because LBD symptoms can closely resemble more widely recognized diseases like Alzheimer’s disease and Parkinson’s disease, it is under-diagnosed. Many physicians and other medical professionals are not familiar with the symptoms and management of LBD.

LBD’s primary symptom is a progressive dementia that features memory and language impairment and visuo-spatial and executive function impairment. Additional symptoms occur in varying combinations, including fluctuating cognitive abilities, visual hallucinations, parkinsonism, rapid eye movement (REM) sleep behavior disorder and severe sensitivity to neuroleptics (medications used to treat hallucinations).
LBD CAREGIVER BURDEN SURVEY

The Lewy Body Dementia Association (LBDA) conducted an Internet-based survey of family caregivers in order to better understand the impact of caring for a relative with LBD. It was designed to examine a wide range of experiences, including early symptoms, the process and problems of obtaining a diagnosis, on-going care of the person with LBD, and stress on the family. The survey was the first of its kind to highlight the plight of LBD families, and the response was enthusiastic. Between December 2007 and April 2008, when the survey was posted on the LBDA website, 962 people with a relative with LBD completed the survey.

Respondents to the survey included both people who were currently providing care for someone with LBD and also people whose relative with LBD had already died. The results presented in this report include all respondents for those questions concerning characteristics, symptom onset, diagnosis, and physician satisfaction. However, for the analysis of questions involving current levels of disability and current emotional or behavioral problems of the person with LBD, caregiver burden, and resources being used, the results include data for only those people who were still caring for someone with LBD.

RESULTS OF THE SURVEY

Characteristics of Respondents and Persons with LBD

Most survey respondents (88 percent) were women: 44 percent were daughters of the person with LBD, and 35 percent were wives. Smaller numbers of husbands, sons and other relatives completed the survey.

- 64 percent of respondents indicated that they were the person who had primary responsibility for care of the person with LBD.
- 46 percent of respondents lived in the same household as the person with LBD.
- 62 percent indicated they saw the person with LBD daily.
Respondents provided information about the person with LBD.

- 62 percent of their relatives with LBD were men.
- 68 percent of persons with LBD were married, and 24 percent were widowed.
- 66 percent of persons with LBD lived in ordinary housing, and 33 percent lived in some type of special housing (nursing home, assisted living).

**Disease Onset, Diagnosis and Treatment Experiences**

**Symptoms at Disease Onset.** The most frequent early symptoms of LBD reported by family members were:

- Memory problems (67 percent)
- Shuffling or other walking problems (47 percent)
- Lapses or fluctuations in attention or alertness (43 percent)
- Hallucinations (43 percent)
- Driving difficulties (42 percent)
- Hand tremors (38 percent)
- Depression (37 percent)

**Obtaining a Diagnosis.** Respondents reported that it usually took some time to obtain a diagnosis of LBD:

- Respondents indicated that their relative saw an average of 3 physicians before receiving a diagnosis of LBD, and 15 percent said their relative had gone to 5 or more physicians.
- 27 percent of respondents were able to obtain a diagnosis of LBD within 3 months after symptoms were first evident. Another 23 percent obtained a diagnosis within the first year of noticing symptoms. The remaining 50 percent took longer than one year to obtain a diagnosis, with almost 20 percent of the sample reporting that it took longer than 3 years before their relative was diagnosed with LBD.

Neurologists made the diagnosis of LBD in 62 percent of cases, while psychiatrists made 9 percent of the diagnoses and neuropsychologists made 8 percent.
Initial Diagnosis Often Changed. In 78 percent of cases, respondents reported that LBD was not the initial diagnosis, but rather:

- Alzheimer’s disease, another dementia, or mild cognitive impairment (54 percent)
- Parkinson’s or other movement disorder (39 percent\(^1\))
- Mood or psychiatric disorder (24 percent)

Discussion.

In contrast to Alzheimer’s disease, significantly more LBD caregivers are women\(^2\) and are more often the spouse of the affected person\(^3\). This may reflect that fact that LBD is slightly more common in men than women, as compared to Alzheimer’s disease, which is more common in women.

Caregivers experienced significant barriers in obtaining a diagnosis for their loved ones. Most saw multiple physicians over more than a year before their relative was diagnosed with LBD and more than three-quarters of persons with LBD were given a different diagnosis at first. Given the evidence that early, aggressive treatment with cholinesterase inhibitors may be even more beneficial to persons with LBD than persons with Alzheimer’s disease, these barriers are especially significant. Early diagnosis also provides physicians an opportunity to minimize exposure to medications that may aggravate symptoms, such as traditional neuroleptics (medications used to treat hallucinations). It is estimated that almost 60 percent of persons with LBD may experience severe, potentially irreversible reactions to neuroleptics, which suggests traditional neuroleptics (i.e. haloperidol, fluphenazine or thioridazine) should be avoided. In rare cases, a life threatening condition called neuroleptic malignant syndrome (NMS) may also occur. This reinforces the need for an accurate diagnosis.

In addition to its role in good medical care, early diagnosis allows families and caregivers the time to plan for the expected decline. Preventive steps to improve safety in the home environment should be taken, given the tendency for recurrent falls and rapid fluctuations in attention. Families also will have time to develop a better understanding of their role in patient care, including assistance with daily activities and provision of social and cognitive stimulation.

A delayed LBD diagnosis may be due to multiple factors, such as:

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\(^1\) No effort was made to identify how many Parkinson’s diagnoses were made within 1 year of the LBD diagnosis. A significant portion of these diagnoses may be long standing Parkinson’s disease diagnoses.

\(^2\) 2009 Alzheimer’s Disease Facts and Figures reported that about 60 percent of family and other unpaid caregivers of people with Alzheimer’s and other dementias are women.

\(^3\) 2009 Alzheimer’s Disease Facts and Figures reported that spouses represent only about 6 percent of family caregivers of people with Alzheimer’s and other dementias.
• Limited awareness of LBD among physicians, especially primary care physicians and other general healthcare providers. Despite the complexity of LBD diagnostic criteria, the four most common causes of dementia - Alzheimer’s disease, LBD, stroke, and frontotemporal dementia - should become core knowledge for all general physicians.

• Mild symptoms may not be observed by a physician during a short office visit and may go unreported by the person with LBD or the caregiver. LBD symptoms such as REM sleep behavior disorder or visual hallucinations are often not reported to physicians by the person with LBD and/or the caregiver, as they may seem unrelated to declining cognition. Caregiver observations are valuable to the LBD diagnostic process and the creation of caregiver questionnaires may lead to earlier LBD diagnosis.

• There are no widely-accessible biomarkers for LBD.

Physician Satisfaction. In a series of 11 questions, respondents rated their satisfaction with physicians in both diagnosing their loved ones’ condition and providing ongoing treatment. (Diagnosis and treatment are often provided by different physicians.)

70 percent of respondents indicated that finding a physician who was knowledgeable in diagnosing LBD was somewhat or very difficult, and 77 percent indicated problems finding a physician knowledgeable in treating LBD. A majority of people rated the diagnosing physicians as adequate or excellent on most items, but there were some areas where a sizable number of respondents found physicians’ performance to be inadequate.

• Physicians providing a diagnosis of LBD were rated highest for their knowledge of LBD, with 54 percent receiving a score of “excellent”.

• 40 percent were scored as “excellent” in answering the family’s questions.

Diagnosing physicians received their lowest ratings for:

• Telling persons with LBD and their families what to expect in the future (42 percent were judged to be inadequate in that area),

• Telling persons with LBD and their families where to find more information about LBD (56 percent were rated inadequate), and

• Giving persons with LBD and their families information about community services (62 percent were scored inadequate).
Over 50 percent of respondents brought the person with LBD to see a different physician for ongoing treatment. 77 percent of those respondents said it was somewhat difficult or very difficult to find a physician who was knowledgeable about treating LBD.

- The level of satisfaction was lower in all categories for those physicians who treated, but did not originally diagnose the individual with LBD.
- Treating physicians were more often family physicians, geriatricians, and internists than neurologists.

**Coordination of Care.** Families reported that their relative with LBD had other medical conditions for which they were receiving treatment.

- Half of respondents said their relative was seeing 2 or more physicians in addition to the physician who was providing care for LBD-related problems.
- 58 percent indicated they had difficulty coordinating the care provided by multiple physicians.

**Discussion.** With most LBD diagnoses being made by neurologists and generally lower level satisfaction reported for primary care physicians providing follow-up treatment, the survey highlights the need for increased continuing medical education in LBD. Due to the nature of their practice primary care physicians face a number of obstacles in diagnosing LBD, because they:

- Need an enormous amount of information to practice effectively in the 21st century. Their practice is typically filled with the more common, easily identifiable problems such as hypertension, high cholesterol, diabetes, etc. Because primary care physicians are so busy with the demands of daily practice, they may not have adequate opportunity to learn about less common disorders. This may lead them to view all dementias as due to Alzheimer’s disease.
- Do not recognize non-tremor parkinsonism. For example, if a primary care physician sees a patient who is slow and stiff, but has no tremor, the physician might see him just as an older patient who is slow and stiff. In reality, he might have parkinsonism. It is important to heighten awareness that parkinsonism has different presentations and the combination of parkinsonism and dementia should raise the suspicion of LBD.
- May not understand the full spectrum of the LBD symptoms and signs. The complex diagnostic criteria may not be practical for most general physicians. (See Table 1.)

Thus, the survey highlights the need for increased continuing medical education on LBD.

LBD is a complex disorder affecting cognition, mood, sleep, movement and behavior, and its symptoms often require a team of collaborating health care providers. In this survey, persons with LBD routinely saw an average of three physicians for ongoing care. For example, it would not be unusual for a person...
to receive treatment for different LBD symptoms from a primary care physician plus specialists in neurology, psychiatry, and urology. Today’s medical system is not set up to deal with the level of coordination needed between different physicians. More than half of the survey’s respondents had difficulty coordinating the care of different physicians. These difficulties often include challenges such as:

- Conflicting medication orders and symptom management priorities of different physicians; i.e. managing orthostatic hypotension or urinary symptoms while maintaining optimum cognition.
- Medications to treat one symptom which exacerbate a symptom managed by a different physician; i.e. treating parkinsonism which may exacerbate hallucinations.

In addition, due to their ages, people with LBD often have other medical conditions as well, further complicating the need for coordination of care.
**TABLE I: COMPARISON OF SYMPTOMS IN DEMENTIA WITH LEWY BODIES AND PARKINSON’S DISEASE DEMENTIA.**

<table>
<thead>
<tr>
<th>Symptom/Area of Deficit</th>
<th>Dementia with Lewy Bodies (DLB)</th>
<th>Parkinson’s Disease Dementia (PDD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dementia</strong></td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>Components of dementia:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Memory impairment</td>
<td>(common but not required)</td>
<td>Core</td>
</tr>
<tr>
<td>2. Language impairment</td>
<td>(common but not required)</td>
<td>Core</td>
</tr>
<tr>
<td>3. Visuo-spatial function impairment</td>
<td>Usually prominent</td>
<td>Core</td>
</tr>
<tr>
<td>4. Executive function impairment</td>
<td>Usually prominent</td>
<td>Core</td>
</tr>
<tr>
<td><strong>Parkinsonism</strong></td>
<td>Core</td>
<td>PD diagnosis required</td>
</tr>
<tr>
<td>(can occur around the same time OR after dementia)</td>
<td></td>
<td>(usually years before dementia)</td>
</tr>
<tr>
<td><strong>Fluctuating Cognition</strong></td>
<td>Core</td>
<td>Core</td>
</tr>
<tr>
<td>1. Reduced attention</td>
<td>Usually prominent</td>
<td>Core</td>
</tr>
<tr>
<td>2. Excessive daytime sleepiness</td>
<td>(common but not required)</td>
<td>Supportive</td>
</tr>
<tr>
<td><strong>Visual hallucinations</strong></td>
<td>Core</td>
<td>Supportive</td>
</tr>
<tr>
<td><strong>Severe neuroleptic sensitivity</strong></td>
<td>Suggestive</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>REM sleep behavior disorder</strong></td>
<td>Suggestive</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>Changes in personality and mood</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Depression</td>
<td>Supportive</td>
<td>Supportive</td>
</tr>
<tr>
<td>2. Anxiety</td>
<td>(common but not required)</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>Delusions</strong></td>
<td>Supportive</td>
<td>Supportive</td>
</tr>
<tr>
<td><strong>Apathy</strong></td>
<td>(common but not required)</td>
<td>Supportive</td>
</tr>
<tr>
<td><strong>Hallucinations in other modalities</strong></td>
<td>Supportive</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>Severe autonomic dysfunction</strong></td>
<td>Supportive</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>Repeated falls and syncope</strong></td>
<td>Supportive</td>
<td>(common but not required)</td>
</tr>
<tr>
<td><strong>Transient, unexplained loss of consciousness</strong></td>
<td>Supportive</td>
<td></td>
</tr>
</tbody>
</table>
### Diagnostic Criteria:

<table>
<thead>
<tr>
<th>Probable DLB:</th>
<th>Probable PDD:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia plus 2 Core</td>
<td>Parkinson’s, Dementia plus 2 Core</td>
</tr>
<tr>
<td>Dementia plus 1 Core &amp; 1 Suggestive</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Possible DLB:</th>
<th>Possible PDD:</th>
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<tr>
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</tr>
<tr>
<td>Dementia plus 1 Suggestive</td>
<td></td>
</tr>
</tbody>
</table>

### Symptoms and Disability

Respondents indicated their relative with LBD had high rates of cognitive and behavioral problems. In addition to dementia,

- Over 60 percent of persons with LBD had delusions or hallucinations.
- About one half of persons with LBD had problems sleeping.
- Falls were a problem in 44 percent.

Respondents to the survey were caring for people with LBD who had moderate to severe levels of disability.

- For complex and intellectually demanding activities, such as shopping and cooking, over 90 percent of persons with LBD were unable to perform the activity.
- Even for essential activities of daily living such as dressing and bathing, over 60 percent of respondents said their relative could not perform those activities unassisted.

**Discussion.** Loss of independence often occurs early in LBD, with the inability to manage one’s own medications and finances. Driving is commonly curtailed early in LBD due to visuospatial problems, hallucinations, or fluctuating cognitive abilities. LBD caregivers provide increasing supervision and vigilance as the person with LBD experiences increasing executive dysfunction (affecting judgment and problem solving skills), changing levels of cognitive abilities from day to day or even hour to hour, early incontinence, hallucinations and an increased risk for falls due to muscle rigidity or syncope (fainting).

Recent studies demonstrate that LBD families need considerable resources and assistance from healthcare professionals and other health-related agencies, possibly even more than families caring for a relative with Alzheimer’s disease.
The Caregiving Experience

Caregiver Burden. Respondents reported medium to high levels of burden brought on by the demands of caring for their relative.

- 38 percent of respondents reported they felt very or extremely burdened on 7 out of the 12 items measuring burden.
- Family members reported the highest burden when describing the impact of providing care on their personal lives, health and emotional well-being.
- One quarter of the sample said they felt that no one understood what they were going through.
- Over 80 percent said they felt somewhat or very isolated because of their involvement in providing care.

Supportive Services Needed. Most respondents indicated that their relative with LBD was not currently receiving paid help to assist with care, and most had not received paid help in the past.

- 38 percent of respondents reported their relative received no assistance from outside services.
- 29 percent indicated their relative had paid care in the home.
- 23 percent of respondents were attending a support group.
- 21 percent reported their relative used an adult day services program.
- Among those respondents whose relative was receiving paid help, a majority was satisfied with the help that they received, but most rated the cost of services as a problem.

Prevalence of Crises. A majority of respondents (64 percent) indicated they dealt with a crisis involving their relative with LBD within the past year. During a crisis, the most frequent place where respondents sought help for their relative with LBD was a hospital emergency room.

Discussion. The high levels of burden reported by LBD caregivers in this survey result not just from the time, effort, and energy it takes to provide care, but also from increased emotional and financial burdens. Disrupted sleep, depression, and decreased health are also common in dementia caregivers. Social isolation can occur as a result of caregiving responsibilities as well as a lack of emotional support from being in a situation not easily understood by others. Financial burden can result from loss of income, increased medical expenses, and the often un-reimbursed costs of in home supportive services, respite care, and long term care. LBD caregivers often face an unexpected lack of experienced clinical guidance from primary care physicians, nurses and other medical professionals who are unfamiliar with Lewy body dementia. However, despite these needs, many of the survey respondents said that their
relative received no assistance from outside services. This may be because many of the survey respondents were spouses who took on the care of the person with LBD themselves.

The caregivers in this survey faced a variety of crisis situations in the care of their relative with LBD. Behavioral problems or a sudden decline in functional ability are two common reasons that people with LBD are seen in the emergency room. The most common behavioral problems reported by caregivers included talking aggressively, shouting, hitting or attempting to hit someone, and having hallucinations and delusions. Inappropriate sexual behavior also was reported. When behavioral problems dramatically increase and require emergency treatment, physical ailments like bronchitis, pneumonia, urinary tract infections, or pain are often the cause. Medications also may cause agitation leading to behavioral problems. Falls and wandering are common in LBD and may necessitate a trip to the hospital, as would health emergencies unrelated to LBD. This frequent need for emergency care highlights the importance of education about LBD for emergency room staff and for close medical management by primary care physicians.

Caregiver Support Needs

Respondents indicated the types of services and assistance that they would like to have for their relative with LBD and themselves.

- 76 percent wanted web based information about LBD and 54 percent an on-line support group.
- 66 percent indicated they would like directories of physicians who were skilled in LBD diagnosis and treatment.
- 62 percent indicated they would like directories of nursing homes skilled in LBD care.
- 61 percent wanted information about new medication trials for treatment of LBD.
- 57 percent also indicated they would like a local support group.

KEY POINTS FOR ACTION

In response to a lack of information on LBD and support resources for LBD families, the Lewy Body Dementia Association was formed in 2003 to provide LBD outreach and education to families, raise LBD awareness in the general public and medical professionals, and to advance LBD research.

This survey has more clearly identified the needs of families affected by LBD and has suggested many possible avenues for future action, such as:
Caregiver Burden in Lewy body dementias: Challenges in Obtaining Diagnosis and Providing Daily Care

- Increase awareness of LBD among physicians, especially general physicians and provide them with tools to differentially diagnose and treat the four most common causes of dementia – Alzheimer’s disease, LBD, stroke, and frontotemporal dementia;
- Create caregiver questionnaires regarding LBD symptoms to aid early diagnosis;
- Support research into LBD biomarkers;
- Develop continuing medical education on LBD to help primary care and other physicians better manage the ongoing care of their patients with LBD;
- Foster better communication among physicians to prevent conflicting medication orders and LBD symptom management priorities;
- Deliver increased web based information about LBD and provide on-line support groups;
- Establish more local LBD support groups;
- Collect information about new medication trials for treatment of LBD;
- Develop directories of physicians who are skilled in LBD diagnosis and treatment; and
- Develop directories of nursing homes skilled in LBD care.

The Lewy Body Dementia Association expresses our gratitude to the hundreds of caregivers who took the time to participate in our survey.

For more information on Lewy body dementias, visit www.lbda.org.

References

To learn more about LBD, visit www.lbda.org

LBD Caregiver Link:
1-800-LEWYSOS
1-800-539-9767
lbda@lbda.org

By supporting the work of LBDA, you too will be

Increasing Knowledge
Sharing Experience
Building Hope

Lewy Body Dementia Association
404-935-6444
www.lbda.org

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Understanding Lewy Body Dementia

Lewy body dementia (LBD) is a brain disorder that impairs thinking, movement, sleep and behavior. It also affects autonomic body functions, such as blood pressure control, temperature regulation, and digestion.

Lewy body dementia is not a rare disease. An estimated 1.3 million individuals and their families are touched by LBD in the United States alone. Because LBD symptoms may closely resemble other more commonly known diseases like Alzheimer’s and Parkinson’s, it is currently widely under-diagnosed. LBD is an umbrella term for two related diagnoses. It refers to both ‘Parkinson’s disease dementia’ and ‘dementia with Lewy bodies.’ The presenting symptoms differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms.

How to Use this Glossary

This glossary provides helpful information to Lewy body dementia (LBD) families about medications used to treat cognitive, motor, mood or behavioral disorders. The glossary is divided up into sections to make it easier to find what you are looking for.

- **Section 1: Medication Sensitivities** should be read first. It provides an important overview about potentially severe sensitivities to medications used to treat hallucinations or other LBD-related behavioral problems.
- The next part, **Section 2: Medications**, alphabetically lists generic drugs (and corresponding brand names) that are used to treat symptoms of LBD, Alzheimer’s disease and Parkinson’s disease. **NOTE:** Some of these individual drugs should be avoided in Lewy body dementia, but are included here for informational purposes only.
- Lastly, **Section 3: Medication Classes and Related Terms**, defines medication types that fall into the same ‘class’ because they have similar chemical structures or mechanism of action. **NOTE:** Some of these classes of drugs should be avoided in Lewy body dementia, but are included here for informational purposes only.

To learn more about treating symptoms of LBD, please visit LBDA’s website:

- **For LBD families:** [http://www.lbda.org/content/treatment-options](http://www.lbda.org/content/treatment-options)
- **For healthcare providers:** [http://www.lbda.org/content/therapeutics](http://www.lbda.org/content/therapeutics)
Section 1: Medication Sensitivities

Some people with LBD are extremely sensitive, or may react negatively, to certain medications used to treat Alzheimer’s or Parkinson’s disease, as well as several over-the-counter medications. There are no definitive indicators as to whether a person with LBD will respond well or poorly to any particular medication. For that reason, treatment can be a delicate balancing act to improve certain LBD symptoms without worsening others.

One of the largest LBD treatment challenges is managing behavioral problems, such as hallucinations, delusions or agitation. Antipsychotics are medications used to treat hallucinations or other serious mental disorders like schizophrenia or bipolar disorder. People with LBD commonly experience severe sensitivity to these medications. Side effects include increased confusion, worsened parkinsonism, extreme sleepiness and low blood pressure that can result in fainting (orthostatic hypotension).

While traditional (or typical) antipsychotic medications, e.g., haloperidol and thioridazine, have been commonly prescribed for individuals with Alzheimer’s for disruptive behavior, these medications can affect the brain of an individual with LBD differently, sometimes causing severe side effects. For this reason, traditional antipsychotic medications like haloperidol which block the brain chemical, dopamine, should be avoided.

Some newer ‘atypical’ antipsychotic medications like risperidone may also be problematic for someone with LBD because they still strongly block dopamine. Some LBD experts prefer quetiapine or clozapine, which work differently from the other antipsychotics. If quetiapine is not tolerated or is not helpful, clozapine should be considered, but requires ongoing blood tests to assure a rare but serious blood condition does not develop.

Therefore, hallucinations, delusions and agitation must be treated very conservatively, using the lowest doses possible under careful observation for side effects. Again, those side effects include increased confusion, worsened parkinsonism, extreme sleepiness and low blood pressure that can result in fainting (orthostatic hypotension). Caregivers should contact the doctor if these side effects continue after a few days.

**WARNING:** In rare cases, a potentially deadly condition called neuroleptic malignant syndrome can occur with the use of any antipsychotic medication. Symptoms of this condition include high fever, muscle rigidity, and muscle tissue breakdown that can lead to kidney failure. Report these symptoms to your doctor immediately or seek emergency medical care.
The U.S. Food and Drug Administration (FDA) requires a black box warning on all antipsychotic medications, due to an increased risk of death in elderly people with any form of dementia. LBD families and doctors should weigh the risk of antipsychotic use against the risks of physical harm and distress that may occur as a result of untreated behavioral problems.

Medications to treat other LBD symptoms, including some over-the-counter medications for insomnia or colds, can cause side effects like confusion, sedation, agitation, or even make existing symptoms, like hallucinations and parkinsonism, worse. Report any concerning reactions to new medications to the prescribing physician promptly.

For more information on treating LBD behavioral problems, visit http://www.lbda.org/content/treatment-behavioral-symptoms-when-consider-antipsychotic-medications-lbd
Section 2: Medications

Medications below are listed alphabetically by generic name, with related brand names in parentheses.

**alprazolam (Xanax):** A medication in the benzodiazepine class, used to treat anxiety and panic disorders. Shorter acting than clonazepam, but can cause sedation, confusion or paradoxical agitation in people with LBD.

**amantadine (Symmetrel):** Used to treat dyskinesia (abnormal involuntary muscle movements) in Parkinson’s disease and other motor disorders. Also used to prevent and treat respiratory infections caused by certain forms of influenza. May worsen cognitive impairment in individuals with LBD and should be avoided.

**amphetamine with dextroamphetamine (Adderall):** Psychostimulant medication whose effects can include improved concentration, decreased sensory overstimulation, decreased irritability and decreased anxiety. It is commonly used to treat ADHD and narcolepsy. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**armodafinil (Nuvigil):** Psychostimulant medication used to treat excessive sleepiness caused by narcolepsy or shift work sleep disorder. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**botulinum toxin:** Used to weaken certain muscles by interfering with the nerve to muscle signal. Administered by injection in or near the salivary gland in the cheek or under the jaw to treat drooling in Parkinson’s disease and LBD. It can be an effective alternative to oral medications with anticholinergic properties, which can exacerbate confusion.

**buspirone (Buspar):** Medication mainly used to treat anxiety disorders. May be helpful in reducing anxiety, obsessions or compulsions in individuals with LBD.

**carbamazepine (Tegretol, Carbatrol):** Anticonvulsive and mood stabilizing medication used primarily to treat epilepsy and bipolar disorder. Also used to treat agitation in individuals with dementia.

**carbidopa (Lodosyn):** Medication used together with levodopa, which treats the motor symptoms of Parkinson’s disease and other parkinsonian disorders, such as tremors, stiffness and slowness of movement. Functions by allowing higher levels of levodopa to enter the brain and also can help reduce levodopa’s side effects.
carbidopa/levodopa (Sinemet): Combination of two medications used to treat motor symptoms of Parkinson’s disease and Lewy body dementia, such as tremors, stiffness and slowness of movement. The addition of carbidopa prevents levodopa from being broken down before it reaches the brain, allowing for a lower dose of levodopa and minimizing any nausea or vomiting.

chloral hydrate: Medication used as a sedative and hypnotic, often as a sleeping aid for insomnia or as a sedative before minor medical treatment. This medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect. Increased nighttime confusion may occur with any sedative when treating insomnia in those with LBD.

citalopram hydrobromide (Celexa): A type of selective serotonin reuptake inhibitor (SSRI) antidepressant medication used in the treatment of depression and associated mood disorders such as panic disorder and anxiety. This medication works by restoring the balance of neurotransmitters in the brain.

clonazepam (Klonopin): Medication mainly used to treat anxiety or epilepsy. Also helpful in managing symptoms of REM sleep behavior disorder, a sleep disorder common in LBD. However, clonazepam and other types of benzodiazepines may potentially aggravate confusion and sleepiness in elderly people with LBD. Low and cautious doses are advised.

clozapine (Clozaril): An atypical antipsychotic medication used mainly to treat schizophrenia. It is helpful in the treatment of psychosis in Parkinson's disease. Requires ongoing blood tests to assure a rare but serious blood condition does not develop. Monitoring for low blood pressure is recommended.

diazepam (Valium): Benzodiazepine drug used to treat anxiety, muscle spasms and seizures. May produce sedation, confusion or paradoxical agitation in people with LBD and should be avoided. See clonazepam.

dimenhydrinate (Dramamine): Over-the-counter antihistamine used to treat motion sickness and nausea. May produce confusion and hallucinations in people with LBD and should be avoided.

diphenhydramine (Benadryl, Nytol, Unisom): Over-the-counter antihistamine mainly used as an antihistamine and also for its sedative properties. It is sometimes used to counter the motor-related side effects of some antipsychotic drugs. May produce confusion and hallucinations in people with LBD and should be avoided.
**donepezil (Aricept):** Acetylcholinesterase inhibitor mainly used to treat mild to moderate dementia in Alzheimer's disease. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms of LBD.

**entacapone (Comtan):** A COMT inhibitor used in combination with carbidopa/levodopa to prolong the action of carbidopa/levodopa and treat motor symptoms in Parkinson’s disease.

**fludrocortisone acetate (Florinef):** Medication used to treat orthostatic hypotension or low blood pressure, a common LBD symptom of dysfunction in the autonomic nervous system.

**fluoxetine (Prozac):** SSRI antidepressant used to treat mood disorders such as depression, panic attacks and other anxiety disorders. This medication works by restoring the balance of neurotransmitters in the brain. Due to known interactions with other drugs and slowed metabolism in older adults, this SSRI antidepressant is not often used in elderly adults.

**fluphenazine (Modecate):** Potent traditional (typical) antipsychotic drug mainly used to treat schizophrenia and bipolar disorder. May also be used to treat psychotic symptoms such as delusions and hallucinations in other conditions. **WARNING:** Fluphenazine and all traditional (typical) antipsychotic drugs are known to have severe side effects in individuals with LBD, and should be avoided.

**galantamine (Razadyne):** Acetylcholinesterase inhibitor mainly used to treat mild to moderate dementia caused by Alzheimer's disease. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms.

**glycopyrrolate (Robinul):** Anticholinergic medication which reduces stomach acid and saliva. May also reduce sweating as a side effect. Low and cautious doses are advised due to cognitive and behavioral side effects of confusion and hallucinations.

**haloperidol (Haldol):** Traditional (typical) antipsychotic medication that interferes with the effects of neurotransmitters in the brain. It primarily functions by blocking receptors on neurons for the neurotransmitter dopamine. **WARNING:** Haloperidol and all traditional (typical) antipsychotic drugs are known to have severe side effects in individuals with LBD, and should be avoided.
levodopa (Dopar, Larodopa): Medication used to treat the symptoms of Parkinson's disease such as tremors. It acts on the brain by increasing levels of the neurotransmitter dopamine in the brain. See carbidopa/levodopa.

lorazepam (Ativan): Benzodiazepine drug mainly used to treat anxiety and to counter the effects of nausea in chemotherapy. May cause paradoxical agitation in people with LBD. Low and cautious doses are advised.

melatonin: Naturally occurring hormone responsible for regulating various biological functions such as sleep/wake cycle. It can be available over-the-counter in the form of a supplement, used to treat disorders such as insomnia. May be helpful in managing REM sleep behavior disorder or insomnia in individuals with LBD.

memantine hydrochloride (Namenda): Medication mainly used for Alzheimer's disease that may protect nerve cells from excessive stimulation by glutamate. Memantine may help with cognition, functional ability and behavioral symptoms in people with LBD.

methylphenidate (Ritalin): Drug commonly used to treat attention deficit hyperactivity disorder (ADHD) that acts as a stimulant of the central nervous system. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

midodrine (Proamantine): Medication which can be used to treat orthostatic hypertension or low blood pressure, a symptom of autonomic nervous system dysfunction in LBD.

modafinil (Provigil): Stimulant-like medication used to treat excessive daytime sleepiness or problems with breathing while asleep. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

olanzapine (Zyprexa): Atypical antipsychotic drug used to treat schizophrenia and bipolar disorder. It has not been shown to be safe or effective in treating hallucinations in Parkinson's disease, and causes worsened motor function. Olanzapine has a higher incidence of serious side effects in individuals with LBD, such as severe neuroleptic sensitivity reactions, parkinsonism, solemnence and orthostatic hypotension, and should be avoided if possible.

oxybutynin (Ditropan): Anticholinergic medication commonly used to treat bladder control problems. Medications in this class can increase sedation and confusion in a person with LBD.
quetiapine (Seroquel): Atypical antipsychotic drug mainly used to treat schizophrenia and bipolar disorder. Some LBD experts prefer quetiapine to other medications in its class to treat behavioral symptoms of LBD since it does not require blood count monitoring. Monitor for low blood pressure.

paroxetine (Paxil): SSRI antidepressant used to treat mood disorders such as depression, panic attacks and other anxiety disorders.

pramipexole (Mirapex): Dopamine agonist drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

rasagiline (Azilect): An MAO inhibitor (type B) used to treat the motor symptoms of Parkinson’s disease.

risperidone (Risperdal): Atypical antipsychotic drug used mainly to treat schizophrenia. Risperidone has a higher incidence of serious side effects in individuals with LBD, such as severe neuroleptic sensitivity reactions, parkinsonism, sleepiness and orthostatic hypotension, and should be avoided if possible.

rivastigmine (Exelon): An acetylcholinesterase inhibitor used to treat dementia. It is also the first treatment for dementia available in a transdermal patch. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms of LBD.

rotigotine (Neupro patch): Dopamine agonist drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

ropinirole (Requip): Dopamine agonist drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

selegiline (Eldepryl): An MAO inhibitor (type B) used to treat the motor symptoms of Parkinson’s disease.

sertraline (Zoloft): SSRI antidepressant used to treat mood disorders such as depression, panic attacks and other anxiety disorders.
thioridazine (Mellaril): *Traditional (typical) antipsychotic* medication used to treat schizophrenia and symptoms such as hallucinations and delusions. **WARNING:** Thioridazine and all *traditional (typical) antipsychotic* drugs are known to have severe side effects in individuals with LBD, and should be avoided.

tolcapone (Tasmar): A *COMT inhibitor* used in combination with *carbidopa/levodopa* to treat motor symptoms in Parkinson’s disease; this medication requires monitoring of liver function.

trazadone (Desyrel): Serotonin modulator drug used to treat depression. May also be helpful in managing insomnia, but this medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect.

valproic acid (Depakote): Used alone or with other medications to treat seizures. Also used to treat mania in bipolar disorder. May be helpful in LBD to reduce behavioral symptoms.

zolpidem (Ambien): Sedative-hypnotic medication used to treat insomnia. This medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect.
Section 3: Medication Classes and Related Terms

**acetylcholine**: Key chemical in neurons (brain cells) that acts as a neurotransmitter, which carries information between two brain cells. It is involved in several functions including cognition, emotion, sensation and arousal. Some of the memory and cognitive symptoms of Alzheimer’s disease and Lewy body dementias are commonly attributed to a loss of acetylcholine-producing neurons.

**acetylcholinesterase inhibitor (AChEI)**: Medication that increases the level of acetylcholine in the brain by inhibiting the function of substances which break down acetylcholine. These drugs can decrease some cognitive symptoms of dementia. They may also be used for treatment of agitation and hallucinations. Side effects may include slowed heart rate, lightheadedness, fainting, mild increase in tremor or parkinsonism. Also called cholinesterase inhibitor or anticholinesterase.

**anticholinergic**: A medication that reduces the effect of acetylcholine in the brain. They are often used to reduce cramps and spasms in smooth muscles such as the stomach, intestines, or bladder, and also tremors in the limbs and body. Some allergy medicines (e.g., diphenhydramine) also have high anticholinergic activity. Drugs in this class may worsen cognitive impairment, confusion, and hallucinations in individuals with LBD and should be avoided if possible.

**anticholinesterase**: See acetylcholinesterase inhibitor.

**antidepressants**: Medication or substance used to treat depression. The most common classes of antidepressant drugs include tricyclics, SSRIs, and SNRIs. Tricyclic antidepressants can worsen hallucinations and sedation, especially in elderly and cognitively impaired individuals. Other symptoms include cardiac rhythm disturbances and dry mouth.

**antipsychotic drug**: Medication which can treat hallucinations, delusions and agitations. Traditional (or typical) antipsychotic medications are also known as neuroleptic drugs. Individuals with LBD can have severe neuroleptic sensitivity to antipsychotic drugs, with possible worsening of symptoms and increased mortality rate. See atypical antipsychotic drug and traditional (typical) antipsychotic drug.

**anxiolytic**: Medication used to treat the symptoms of anxiety.
atypical antipsychotic drug: Newer generation of antipsychotic drugs differing from traditional (typical) antipsychotic drugs in their pharmacological action. Drugs in this class carry a black box warning from the U.S. Food and Drug Administration, indicating that for older adults with dementia, the medication carries an increased risk of serious or even life-threatening adverse effects. Despite this risk, due to the presence of visual hallucinations in LBD, there may be a need to prescribe this type of medication. Physicians should discuss the risks and benefits of these types of medications, so that individuals with LBD and caregivers can consider issues of quality of life against the risks associated with these medications.

benzodiazepine: Drugs that enhance a neurotransmitter involved in motor control. These drugs have various properties, such as anti-anxiety, hypnotic, muscle relaxant, anti-convulsant, or amnesiac. May produce sedation and confusion in people with LBD and should be avoided.

black box warning: The strongest warning issued by the U.S. Food and Drug Administration, required to be included on prescription package inserts when medical studies indicate a prescription drug carries a significant risk of serious or even life-threatening adverse effects. It is so named for the black border that surrounds the text of the warning.

cholinesterase: Enzyme responsible for breaking down the neurotransmitter acetylcholine.

cholinesterase inhibitor: See acetylcholinesterase inhibitor.

COMT inhibitors: Medication which inhibits the action of the enzyme Catechol-O-methyl transferase (COMT). COMT is responsible for degrading the neurotransmitters dopamine, epinephrine, and norepinephrine.

depressant: Medication or substance reducing the activity of the central nervous system, resulting in calmness, slowed breathing, reduction in anxiety, muscle relaxation, and sleepiness. Examples of depressants include benzodiazepines, alcohol, anesthetics, and anticonvulsants. Also known as a sedative or sedative-hypnotic.

dopamine: One of the primary neurotransmitters in the brain, it is involved in several functions including movement, cognition, motivation, and pleasure. The motor symptoms of Parkinson’s disease and Lewy body dementias are commonly attributed, at least in part, to a loss of dopamine-producing neurons.

dopamine agonist: Medication which mimics the action of the neurotransmitter dopamine, activating dopamine receptors. They are often used to treat Parkinson’s disease. As this class of drugs has side effects, especially drug-induced psychosis, it should be avoided if possible in LBD.
glutamate: Main excitatory neurotransmitter in the brain.

MAO inhibitor: Class of drugs used to treat motor symptoms or depression in Parkinson's disease by inhibiting the breakdown of dopamine. MAO inhibitors may worsen cognition and should be avoided if possible in LBD.

mood stabilizer: Medication typically used to treat symptoms such as mania and agitation in bipolar disorder.

neuroleptic: Term referring to the effects of antipsychotic drugs on a person, especially on their cognition and behavior.

neuroleptic drugs/neuroleptics: See antipsychotic drug.

neuroleptic malignant syndrome (NMS): Rare neurological disorder caused by an adverse reaction to neuroleptic drugs, characterized by high fever, unstable blood pressure, muscular rigidity, and autonomic dysfunction. In severe cases, NMS can be fatal. People with LBD who are treated with neuroleptics are at risk for developing NMS.

neuroleptic sensitivity: An adverse reaction or event to a neuroleptic drug such as Parkinson-like side effects including rigidity, immobility and difficulties with posture. Individuals with Lewy body dementias have particularly high, sometimes fatal, neuroleptic sensitivity.

neurotransmitter: Chemical that transfers from one neuron to another cell, causing it to either increase or decrease the activity of the receiving neuron. It is thought to be the primary way that neurons communicate with each other in the brain.

NMDA antagonist: Class of drugs which inhibit the action of N-methyl d-aspartate (NMDA). They are mainly used as anesthesia for animals and sometimes for humans. Certain NMDA receptor antagonists such as memantine can be used to treat dementia.

sedative: See depressant.

SNRI (serotonin-norepinephrine reuptake inhibitor): Class of antidepressant which increases levels of both serotonin and norepinephrine. It is used to treat depression and other mood disorders such as anxiety and obsessive-compulsive disorder.

SSRI (selective serotonin reuptake inhibitor): Common class of antidepressant used to treat depression and anxiety. SSRIs function by reducing the reabsorption of serotonin by certain nerve cells in the brain.
**stimulant:** Class of medication used to increase alertness and awareness. Stimulant effects commonly include increased heart rate, blood pressure, and respiration rate.

**traditional (or typical) antipsychotic medications:** An older generation of antipsychotic medications used to treat hallucinations, delusions and agitations by blocking dopamine in the brain. Drugs in this class carry a black box warning from the U.S. Food and Drug Administration, indicating that for older adults with dementia, the medication carries a significant risk of serious or even life-threatening adverse effects. **WARNING:** Due to the risk of severe neuroleptic sensitivity reactions, neuroleptic malignant syndrome, parkinsonism, somnolence and orthostatic hypotension, these medications should be avoided in LBD.

**Acknowledgements:**
LBDA would like to thank the following individuals for their assistance and expert review of this publication: Jennifer G. Goldman, MD, MS, Rush University Medical Center; Daniel Weintraub, MD, University of Pennsylvania; Bradley R. Williams, PharmD, CGP, University of Southern California.

**Sources:**
# Appendix: Medications Listed by Brand Name

<table>
<thead>
<tr>
<th>Brand Name</th>
<th>Generic Name</th>
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<tbody>
<tr>
<td>Adderall</td>
<td>amphetamine with dextroamphetamine</td>
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<tr>
<td>Ambien</td>
<td>zolpidem</td>
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<td>Aricept</td>
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<tr>
<td>Celexa</td>
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<td>Desyrel</td>
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<td>Requip</td>
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<td>Seroquel</td>
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<tr>
<td>Sinemet</td>
<td>carbidopa/levodopa</td>
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<td>Symmetrel</td>
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<td>Xanxax</td>
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<td>Zoloft</td>
<td>sertraline</td>
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<tr>
<td>Zyprexa</td>
<td>olanzapine</td>
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To learn more about LBD, visit www.lbda.org

LBD Caregiver Link:
1-800-LEWYSOS
1-800-539-9767

By supporting the work of LBDA, you too will be

Increasing Knowledge
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lbda@lbda.org

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<table>
<thead>
<tr>
<th>Book Title</th>
<th>Authors</th>
<th>Description</th>
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<tbody>
<tr>
<td>Aging Together</td>
<td>Susan H. McFadden and John T. McFadden</td>
<td>This book proposes a radical reconstruction of our societal understanding of old age. Rather than categorize elders based on their respective cognitive consciousness, they contend that the only humanistic, supportive, and realistic approach is to find new ways to honor and recognize the dignity, worth, and personhood of those journeying into dementia. This inclusive vision calls for social institutions, especially faith communities, to search out and build supportive, ongoing friendships that offer hospitality to all persons, regardless of cognitive status.</td>
</tr>
<tr>
<td>A Caregivers Guide to Lewy Body Dementia</td>
<td>Helen Buell Whitworth &amp; Jim Whitworth</td>
<td>This book is written in everyday language and filled with personal examples that connect to the readers own experiences. The book provides an accurate, detailed view of the disease in easy to understand terms. The book includes quick fact and quick tip boxes that summarize facts and caregiving tips for easy reference, a comprehensive resource guide including respite care, nursing homes, and neurologists, and a glossary of terms and acronyms related to Lewy Body Dementia.</td>
</tr>
<tr>
<td>A Dignified Life</td>
<td>Virginia Bell and David Troxel</td>
<td>This book helps families combat the burnout and frustration that often accompany the task of caring for an Alzheimer's patient. It provides a complete model for care built around creative and effective communication and meaningful activities and includes touching stories that demonstrate how the Best Friends method continues to improve the lives of those who have Alzheimer's disease and those who care for them.</td>
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<tr>
<td>Ambiguous Loss: Learning to Live with Unresolved Grief</td>
<td>Pauline Boss</td>
<td>In this original and humane account of the ravages of uncertainty faced by those who lose a loved one, the author draws on her research and clinical experience to suggest strategies that can cushion the pain, and offers heartening narratives of those who cope with ambiguous losses and manage to move on.</td>
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<tr>
<td>Contented Dementia</td>
<td>Oliver James</td>
<td>This guide shows how much can be done to maximize the quality of life for people with the condition. The SPECAL method (Specialized Early Care for Alzheimer’s) outlined in this book works by creating links between past memories and the routine activities of daily life in the present. Drawing on real-life examples and user-friendly, tried-and-tested methods, this lifesaver provides essential information and guidance for care partners, relatives, and professionals.</td>
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Creating Moments of Joy
By: Jolene Brackey
Jolene Brackey has a vision that will soon look beyond the challenges of Alzheimer's disease and focus more of our energy on creating moments of joy with short-term memory loss. Life is made up of moments, but, our memory is made up of moments, too. We are not able to create a perfectly wonderful day with someone who has dementia, but it is absolutely attainable to create a perfectly wonderful moment. Five minutes later, they won't remember what you did or said, but the feeling you left them with will linger.

Dancing with Dementia
By: Christine Bryden
This book is a vivid account of the author's experiences of living with dementia, exploring the effects of memory problems, loss of independence, difficulties in communication and the exhaustion of coping with simple tasks. She describes how, with the support of her husband Paul, she continues to lead an active life nevertheless, and explains how professionals and care partners can help.

Finding Hope When Dreams Have Shattered
By: Ted Bowman
Here are stories about how people have found hope in the face of tragedy and loss. The author has added a commentary or reflection to many of them.

Forget Memory: Creating Better Lives for People with Dementia
By: Anne Basting
In this book, author Anne Basting emphasizes the importance of activities that focus on the present to improve the lives of persons with Alzheimer's disease and other dementias. The book provides specific examples of programs that stimulate growth, humor, and emotional connection; translates into accessible language and addresses how advances in medical research and clinical practice are already pushing radical changes in care for persons with dementia.

From AA to AD, A Wistful Travelogue
By: Michael Donohue
This is a story of my journey, about my paying the dues to qualify, about the tools of AA explaining how they are the key to abstinence and to a better life. It discusses the tool at work in my life and finally with acceptance AD. I examine the spiritual and mystical qualities that are at work seen through the eyes of a Christian, a Jew, and a Buddhist. These experiences have opened my mind to the deeper consequence of living.
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<tr>
<td>Healing Your Grieving Heart: 100 Practical Ideas</td>
<td>Alan D. Wolfelt</td>
<td>With sensitivity and insight, this series offers suggestions for healing activities that can help survivors learn to express their grief and mourn naturally. Acknowledging that death is a painful, ongoing part of life, they explain how people need to slow down, turn inward, embrace their feelings of loss, and seek and accept support when a loved one dies. These ideas and activities are aimed at reducing the confusion, anxiety, and huge personal void so that the living can begin their lives again.</td>
</tr>
<tr>
<td>Lewy Body Dementia: Causes, Tests and Treatment Options</td>
<td>Adam Wainwright, MA, Erik Stevenson MD and Deanna R. Miller, RN</td>
<td>In this book, the authors provide the reader with an abundance of information that is easy to understand and can be applied to the lives of those that are affected by this disease whether they are friends or family. If you or a loved one are suffering from LBD, this informative book gives you all the information you need to know.</td>
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<tr>
<td>Living Your Best With Early-Stage Alzheimer’s</td>
<td>Lisa Snyder</td>
<td>This book fills an enormous void by providing a straightforward, practical guide on coping with the diagnosis, effectively managing symptoms, finding meaningful activity, planning for the future, strategies for easier communication, participating in research and clinical trials, and much more. This book is a working guide to help the person with Alzheimer's feel empowered to move forward in life in light of this diagnosis.</td>
</tr>
<tr>
<td>Losing My Mind: An Intimate Look at Life with Alzheimer’s</td>
<td>Thomas DeBaggio</td>
<td>This intensely intimate and moving account of a 57-year-old writer afflicted with the early onset of Alzheimer's disease is a work, like &quot;Tuesdays with Morrie&quot; that paints a vivid picture of memory--and the pain that comes from its loss.</td>
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<tr>
<td>Loving Someone Who Has Dementia</td>
<td>Dr. Pauline Boss</td>
<td>Loving Someone Who Has Dementia is a new kind of caregiving book. It's not about the usual techniques, but about how to manage ongoing stress and grief. The book is for caregivers, family members, friends, neighbors as well as educators and professionals—anyone touched by the epidemic of dementia. Dr. Boss helps caregivers find hope in &quot;ambiguous loss&quot;—having a loved one both here and not here, physically present but psychologically absent.</td>
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<tr>
<td>Mayo Clinic Guide to Alzheimer’s Disease (NEW EDITION)</td>
<td>Edited by: Dr. Ronald Peterson, M.D., Ph.D.</td>
<td>This book offers you real help in understanding aging and its effects on your mind and memory. Find valuable medical insight and practical guidance to help with: coping with Alzheimer's, how to improve memory and reduce the occurrences of memory lapses, strategies for keeping your brain active, drugs that can ease Alzheimer’s symptoms, and drugs that commonly cause memory loss even in people who don't have Alzheimer's.</td>
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<tr>
<td>Relentless Goodbye: Grief and Love in the Shadow of Dementia</td>
<td>By: Ginnie Horst Burkholder</td>
<td>The author of this book shares from the heart about caring for a spouse who is slowly slipping away to Lewy body dementia (LBD). The book is about the gritty and glorious substances of life--how illness and health, faith and doubt, grief and acceptance all flow together in the river of change. It leads each of us to a greater awareness of our own life experiences.</td>
</tr>
<tr>
<td>Speaking Our Minds – Personal Reflections from Individuals with Alzheimer’s</td>
<td>By: Lisa Snyder, LICSW</td>
<td>In Speaking Our Minds, seven diagnosed individuals of various ages and backgrounds express their thoughts and feelings about what it is like to have Alzheimer's disease, to live with it day to day, and to cope with its impact on their lives. Their stories cover personal history, diagnosis, family and social interactions, philosophical and religious perspectives, and the many neurological and psychological dimensions of the disease that permeate their lives.</td>
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<tr>
<td>Still Alice</td>
<td>By: Lisa Genova</td>
<td>&quot;Still Alice&quot; is a compelling novel about a 50-year-old woman's sudden descent into early onset Alzheimer's disease, written by a first-time author and reminiscent of &quot;A Beautiful Mind&quot; and &quot;Ordinary People,&quot; this work packs an emotional punch.</td>
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<td>The 36 Hour Day</td>
<td>By: Nancy Mace and Peter Rabins</td>
<td>This updated guide is filled with new information on medical research and the delivery of care. Includes resources for families and adult children who care for people with dementia, the latest information on nursing homes and other communal living arrangements, and more.</td>
</tr>
<tr>
<td>Ten Thousand Joys Ten Thousand Sorrows</td>
<td>By: Olivia Ames Hoblitzelle</td>
<td>The author not only writes about the inspirations and spiritual perspectives that sustained them, but gives an intimate account of how they faced loss, crisis, and eventually death. An indispensable guide for anyone dealing with loss, each chapter includes a self-help section with reflections, suggestions, and seed thoughts.</td>
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<td>Book Title</td>
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<td>Through the Seasons: An Activity Book for Memory Challenged</td>
<td>Cynthia Green and Joan Beloff</td>
<td>This book helps family members and caregivers engage memory-challenged adults in simple, enjoyable activities that provide stimulation and enhance communication. This large-format color picture book is divided into themes representing the four seasons. The topics and activities incorporate all five senses to facilitate connections and conversations with memory-challenged persons across a wide range of cognitive function. It also helps memory-impaired individuals to retain dignity and remain active companions, even as their communication skills become increasingly limited.</td>
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<td>What if it’s not Alzheimer’s: A Caregivers Guide to Dementia</td>
<td>Lisa Radin and Gary Radin</td>
<td>This book is the first comprehensive guide dealing with frontotemporal dementia (FTD). It follows recent worldwide collaboration in research and provides the most current medical information available, a better understanding of the different classifications of FTD, clarity regarding the role of genetics, and information about the various drugs that are now being used with FTD patients, as well as nonmedical options.</td>
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<td>When Your Loved One Has Dementia: A Simple Guide for Caregivers</td>
<td>Joy Glenner</td>
<td>This book is designed to support the caregivers and help them understand the needs and feelings of the person for whom they are caring. A central focus is the goal of sustaining a loving family relationship between the caregiver and the patient. It teaches the basics of dementia care while emphasizing communication, understanding and acceptance, and personal growth through the caregiving experience. The result is a guide that integrates the practicalities of caregiving with the human emotions that accompany it.</td>
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<td>Who Says Men Don’t Care?</td>
<td>James V. Gambone, Ph.D.</td>
<td>A REAL BREAKTHROUGH FOR MALE CAREGIVERS... A CAREGIVING GUIDE WRITTEN EXCLUSIVELY FOR MEN! Who Says Men Don’t Care? A Man’s Guide to Balanced and Guilt Free Caregiving, is unique because it is written specifically for four generations of male caregivers. The premise of the Guide is that men care differently than women, and these differences present both opportunities and potential problems in all male caregiving situations. Knowing who you are can make you a healthier and more balanced caregiver.</td>
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<td>The Unexpected Caregiver</td>
<td>Kari Berit</td>
<td>As their parents grow older, growing numbers of Baby Boomers find themselves thrust into a caregivers role, often with little warning or preparation. The Unexpected Caregiver not only gives tools and resources, but also helps baby boomers re-connect with Mom and Dad.</td>
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<td>The Behavioral Neurology of Dementia</td>
<td>Bruce L. Miller and Bradley F. Boeve</td>
<td>This book covers a broad range from common conditions such as Alzheimer's disease, Parkinsonian disorders, vascular and frontotemporal dementia, to the more obscure such as Creutzfeldt-Jakob disease. Subtypes of mild cognitive impairment are presented and the early prodromes of neurodegenerative diseases are explored. Simple approaches to bedside mental status testing, differential diagnosis and treatment, genetic testing, interpreting neuropsychological testing and neuroimaging findings, and assessing rapidly progressive dementias, paraneoplastic syndromes and disorders of white matter give guidance to both the novice and expert in dementia.</td>
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<td>A Dignified Life: The Best Friends' Approach to Alzheimer's Care - A Guide for Care Partners</td>
<td>Virginia Bell, David Troxel</td>
<td>A Dignified Life offers caregivers an antidote to the burnout and frustration that often accompanies the role of caring for a person with Alzheimer's and dementia. Rather than struggling through a series of frustrations and failures, A Dignified Life shows the new generation care partners how to bring dignity, meaning, and peace of mind to the lives of both those who have Alzheimer's and dementia and those who care for them.</td>
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<td>Sexuality and Dementia: Compassionate and Practical Strategies for Dealing with Unexpected or Inappropriate Behaviors</td>
<td>Douglas Wornell, MD</td>
<td>It is very common for a person with dementia to exhibit unexpected or inappropriate sexual behavior and yet few resources exist to help partners, family members, caregivers, and others address it. Neuropsychiatrist Dr. Doug Wornell provides a compassionate and detailed understanding of the issue and strategies for how to cope. Tackling a difficult subject without shame or embarrassment, Sexuality and Dementia offers essential information and practical solutions so that people with dementia and their partners can have stronger and happier relationships.</td>
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<td>The Spaces Between Your Fingers</td>
<td>Matthew Ross Smith, Dan Waldron</td>
<td>This is one of those rare books that, in just a few minutes, will transform the way you see the world around you, beginning with the simplest, most ordinary, most overlooked of things: the spaces between your fingers. It’s a parable about a grandfather vanishing into the blur of Alzheimer’s, and the secret way of remembering that he taught his grandson, so they could always find each other. The story inspired The Spaces Between Your Fingers Project, a nonprofit that helps people with Alzheimer’s pass on their memories by writing them on postcards and mailing them to their kids and grandkids. 100% of author royalties are donated to fund SBYF Project writing programs.</td>
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Additional Books

Living With Lewy’s  
Amy and Gerald Throop

An Unintended Journey  
Janet Yagoda Shagam

The 36-Hour Day  
Nancy Mace, MA

Learning to Speak Alzheimer’s  
Joanne Coenig Koste

Coping with Behavior Change in Dementia  
Beth Spencer and Laurie White

Activities for the Family Caregiver: LBD: How to Engage, How to Live.  
Scott Silknitter, R.O.S.

Dementia with Lewy Bodies & Parkinson’s Disease Dementia  
Dr. J. Eric Ahlskog, MD

The End of Life Handbook  
David Feldman, PH.D, A.  
Andrew Lasher, Jr., MD

Caregiving: How to Survive and Get Out Alive  
Joy Walker

Not published yet, but coming out soon:

Caring for a Loved One with Dementia: A mindfulness-based guide for reducing stress and making the best of your journey together  
Marguerite Manteau-Rao

LBD Memoirs:

Life in the Balance (by a doctor with PDD)  
Thomas Graboys, MD

Dignifying Dementia: A Caregiver’s Struggle  
Elizabeth Tierney
Staying connected

A place to write down information of those you want to keep in touch with.

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