

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'.

## Caregiver Burden in Lewy body dementias: Challenges in Obtaining Diagnosis and Providing Daily Care

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.



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FIGURE 1. LBD IS A SPECTRUM DISORDER WITH HETEROGENEOUS ONSET.



**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<sup>1</sup>)
- Mood or psychiatric disorder (24 percent)

### Discussion.

In contrast to Alzheimer’s disease, significantly more LBD caregivers are women<sup>2</sup> and are more often the spouse of the affected person<sup>3</sup>. 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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<sup>1</sup> 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.

<sup>2</sup> 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.

<sup>3</sup> 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 21<sup>st</sup> 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



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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.



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TABLE I: COMPARISON OF SYMPTOMS IN DEMENTIA WITH LEWY BODIES AND PARKINSON'S DISEASE DEMENTIA.

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



Diagnostic Criteria:	<p style="text-align: center;"><b>Probable DLB:</b></p> <ul style="list-style-type: none"> <li>• Dementia plus 2 Core</li> <li>• Dementia plus 1 Core &amp; 1 Suggestive</li> </ul> <p style="text-align: center;"><b>Possible DLB:</b></p> <ul style="list-style-type: none"> <li>• Dementia plus 1 Core</li> <li>• Dementia plus 1 Suggestive</li> </ul>	<p style="text-align: center;"><b>Probable PDD:</b></p> <ul style="list-style-type: none"> <li>• Parkinson's, Dementia plus 2 Core</li> </ul> <p style="text-align: center;"><b>Possible PDD:</b></p> <ul style="list-style-type: none"> <li>• Parkinson's, Dementia plus 1 Core</li> </ul>
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### 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:



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- 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](http://www.lbda.org).**

### References

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**To learn more about LBD,  
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LBD Caregiver Link:

I-800-LEWYSOS

I-800-539-9767

[lbda@lbda.org](mailto:lbda@lbda.org)

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404-935-6444

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