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## **An Open Letter to the U.S. Department of Health and Human Services Feedback on the Draft Framework for the National Plan to Address Alzheimer's Disease**

The Lewy Body Dementia Association (LBDA) supports and applauds the development of a national plan to address Alzheimer's disease and related disorders.

With appreciation for the magnitude of the task at hand and the complexity of the issues, LBDA is providing limited feedback that is a) relevant for dementia in general and b) an important consideration specific to the spectrum of Lewy body dementias (LBD): dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD).

An estimated 1.3 million Americans have LBD, which features progressive dementia plus varying combinations of symptoms (especially at onset), ranging from parkinsonism, fluctuating cognition and visual hallucinations, to REM sleep behavior disorder, a severe sensitivity to antipsychotic medications, mood disorders and autonomic dysfunction. Both clinical diagnoses within the LBD spectrum feature Lewy body pathology, but the timing and severity of symptom onset differs.

Dementia with Lewy bodies represents approximately 20 percent of all dementias and is the most frequent dementia type misdiagnosed clinically, most often as Alzheimer's. Features that differentiate LBD from Alzheimer's at the early stage include visual hallucinations, REM sleep behavior disorder and results of neuropsychological assessment.

Most older adults with Parkinson's disease have some degree of cognitive impairment at the time of diagnosis. Approximately 80% of people with Parkinson's will ultimately develop dementia. The prevalence of cognitive impairment and dementia in Parkinson's disease has not yet become common knowledge among clinicians. There is no general public awareness about dementia in Parkinson's disease. Caregivers of people with PDD report to LBDA that the progression to dementia ultimately proves to be their most difficult caregiving challenge.

### **It's not always Alzheimer's.**

We appreciate the importance of communicating the plan in a manner that is both straightforward and understandable by the general public. While Alzheimer's disease is the most common form of dementia, there are millions of Americans whose lives are deeply affected by related disorders like stroke, LBD and frontotemporal degeneration; while they receive nominal mention in the background material as being included in this plan, there is no mention of them in the draft agenda.

Public awareness and education is one of the core goals of the draft agenda. LBDA urges the names of related disorders be included in the opening statement of the draft agenda, so that educating the public about the most common forms of dementia begins now and continues throughout the advancement of the National Plan to Address Alzheimer's Disease, through public relations efforts of federal agencies, disease advocacy organizations and academia.

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As the plan receives coverage in the media, deliberate inclusion of related disorders will also minimize disenfranchisement of Americans affected by lesser-known, non-Alzheimer's dementias like LBD, many of whom might easily infer the omission indicates the federal government does not appreciate that their plight is as fraught with burden as those dealing with Alzheimer's disease.

### **Diagnosis**

While improving the timeliness of diagnosis is important, the Lewy Body Dementia Association strongly recommends the inclusion of the word 'differential' when referring to diagnosis.

A general dementia diagnosis or an inaccurate diagnosis of Alzheimer's disease leaves people with LBD at risk for exposure to potentially severe or irreversible medication side effects. (Approximately 50% of people with DLB who are exposed to neuroleptics will experience a severe reaction.) Inaccurate diagnosis also prevents the opportunity to prepare families for the complexity of LBD symptoms, treatment and high toll of LBD caregiving. Accurate differential diagnosis not only leads to more appropriate therapeutic interventions but also improves the selection for study candidates in research trials.

Primary care physicians must become more familiar with the top four causes of dementia, specifically Alzheimer's, LBD, stroke and frontotemporal degeneration. Delayed or inaccurate diagnoses are further compounded by the low percentage of referrals from primary care physicians to specialists. Simple screening tools to highlight when a referral is warranted for differential diagnosis are urgently needed, especially for people with LBD.

### **Care Quality**

When assessing the care needs of persons with dementia, it is essential to look beyond the cognitive deficits and their impact on employment, incidental activities of daily living and activities of daily living. In the case of Lewy body dementias, care quality must also address motor symptoms (such as the risk of falls), behavioral problems, sleep and autonomic issues. Other professionals who regularly provide care for people with dementia include specialists treating sleep and autonomic symptoms as well as physical, occupational and speech therapists.

### **Care Guidelines across Care Settings**

Given the increased rate of hospitalization of people with dementia, hospitals should be included in the list of care settings for which dementia care guidelines and measures are to be developed. Many hospitals are not equipped to provide adequate care to people with dementia, especially those with behavioral problems, leading to excessive or avoidable treatment with antipsychotic medications. (This is especially dangerous to the person with LBD, who may experience modest to significant decline without a return to their baseline from as little as a single dose of haloperidol.) Additionally, consideration should be given to non-cognitive symptoms, such as motor problems, which affect activities of daily living and increase fall risk.

As LBD is a multi-system disorder, routine care coordination between multiple physicians is particularly challenging with LBD. By changing medications without consulting the treating neurologist, another physician may unknowingly exacerbate any one of several LBD symptoms.

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### **Patient and Family Support**

In addressing the long term care needs of people with dementia, caregivers need more accessible resources to provide quality care for the person with dementia in their own home as long as possible, while also maintaining balance of the equally important quality of life for the family caregiver.

Patient advocacy groups should be included in the draft framework as an important source of counseling, support and information to patients and families upon a differential diagnosis.

### **Public Awareness**

The general public needs to be educated about the difference between dementia and the disease processes that cause it, much like the education the public received about HIV and AIDS. Few people understand that dementia is sometimes treatable. Educating the public that dementia is a symptom requiring medical attention, not a disease in itself, will help de-stigmatize both dementia and the many related clinical diagnoses.

In order to improve the reporting to physicians of all dementia-related symptoms beyond memory problems alone, such as those seen in stroke and LBD, it is imperative that the general public learn that the most common causes of dementia are Alzheimer's disease, stroke and LBD, and what symptoms should be reported to their physicians.

The Lewy Body Dementia Association is encouraged at the expansive nature of this draft agenda, especially as it pertains to the impact of dementia disorders not just on the patient but on the family caregiver as well. We look forward to following the progression of your work with great anticipation.

Sincerely,



Angela Herron  
President, Board of Directors  
Lewy Body Dementia Association