

## Research shortfall on common form of dementia highlighted

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Joan Grose had Lewy body dementia. Credit: University of Exeter

New research published in *The Lancet* has highlighted the scarcity of evidence on the prognosis of dementia with Lewy bodies, the second most common cause of degenerative dementia, which affects 100,000 people in the U.K.

The disease differs from more commonly understood forms of <u>dementia</u>, such as Alzheimer's, in a number of ways, yet research is comparatively scarce. A new paper, led by Kings College London and the University of Exeter Medical School, brings together all existing evidence and identifies where future research should focus to guide clinical practice.

Professor Clive Ballard, of the University of Exeter School, a co-author



on the research, said: "Dementia has a number of sub-types, but until now the majority of research has focussed on the progression of Alzheimer's Disease. We need to understand the long-term health outcomes of dementia with Lewy bodies in order to support millions of patients worldwide, as well as physicians and the provision of health-care services. It also helps inform the need for society to support for people with dementia in the community."

Dementia with Lewy bodies accounts for 15 per cent of all people with dementia. In this form of disease, the proteins  $\alpha$ -synuclein and ubiquitin build up abnormally to form masses called Lewy bodies.

The disease affects brain function in terms of visual perception and spatial awareness and attention, rather than memory, as typically associated with other forms of dementia. Severe hallucinations, sleep disturbance and apathy are common early on in the disease. Equally distressing symptoms including dizziness, fainting, difficulty standing and fluctuating consciousness tend to be prevalent later on in the disease.

The combination of symptoms presents particular challenges for patients, carers and the healthcare system. People with dementia with Lewy bodies are also have a high risk of adverse reactions to antipsychotic drugs, which can lead to higher rates of death and stroke.

The research paper reported evidence that this combination of symptoms is particularly distressing for carers, and also leads to a particularly poor quality of life for people with dementia with Lewy bodies, significantly lower than those who have Alzheimer's Disease.

It also reported evidence that people with dementia with Lewy bodies spend at least three times as many days in <u>dementia care</u> as people with Alzheimer's <u>disease</u>.



The paper reports that the majority of evidence to date concludes that dementia with Lewy Bodies carries a higher cost to the health service than other forms of dementia. This is because of increased or longer-term use of high-cost accommodation such as nursing homes, increased pharmacotherapy, and increased use of outpatient care, community services, and informal help.

According to Professor Dag Aarsland, from King's College London: "Although dementia with Lewy bodies is the second most common form of neurodegenerative dementia, it has received only a fraction of research investment and focus. There are no licensed therapies for <a href="brain function">brain function</a> or psychiatric symptoms outside of Japan, no treatment measures that are evidence-based and do not involve drugs, and very few studies trialling new interventions. This is a particularly cruel form of dementia, which takes an enormous toll on people who have it, their families and carers, as well as on the health service. We must make studies of new treatment for dementia with Lewy bodies an urgent priority."

The paper, The prognosis of dementia with Lewy bodies, is published in *The Lancet*, by Christoph Mueller, Clive Ballard, Anne Corbett and Dag Aarsland.

**More information:** Christoph Mueller et al. The prognosis of dementia with Lewy bodies, *The Lancet Neurology* (2017). DOI: 10.1016/S1474-4422(17)30074-1

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