

Lewy Body Society response to the NICE draft quality standard for dementia

February 2019

Background

The Lewy Body Society, established in June 2006 in the UK, was the first charity in Europe exclusively concerned with Lewy body dementia. Our mission is to fund clinical research to improve the diagnosis and treatment of the disease. We also raise awareness of Lewy body dementia among the general public and those in the medical profession and decision making positions, and we provide information resources for patients and carers.

Our overall response to the draft quality standard

In general, we support the draft quality standard and believe that it does focus on the key areas for quality improvement. However, we feel that there is too little focus on the sub-types of dementia, with a risk that there may be a lack of recognition of the diversity of experience of people living with different types of dementia.

We note the comments made by Parkinson's UK in the initial stakeholder exercise that informed the draft standard about the need to improve diagnosis of dementia with Lewy bodies and Parkinson's dementia, and welcome the evidence that they provided.

Others also referred to sub-types. For example the Royal College of Psychiatrists said:

"People with non-Alzheimer's form of dementia should also have access to improved assessment and treatments (e.g. vascular disease, lewy body disease...) with some access to subtype specific treatment pathways."

We welcome this statement in the narrative of the briefing paper:

"Stakeholders felt that identifying a dementia subtype in a specialist diagnostic service is a quality improvement area, as knowing the subtype will determine how dementia is managed. Getting a diagnosis in the right setting also allows for planning services and coordinating care."

However, it isn't clear in the draft standard how this view from stakeholders has been responded to. The issue of dementia sub-types may be implicit throughout the entire standard – for example personalised care plans would of course be dependent on the type of dementia – but we believe more explicit acknowledgements of the types of dementia would be helpful.

We are also disappointed to see that training is no longer considered a national priority for improvement. We believe that while there has been an improvement of awareness about dementia generally, and training is now more fully embedded across the health and care sector than it was when the quality standard was last revised, there is still a need for further training on dementia sub-types. We hear very regularly from patients, and the carers of people with Lewy body dementia, that they come into contact with professionals (particularly in primary and social care) who do not have knowledge of Lewy body dementia. This appears to be backed up by the evidence provided by the Alzheimer's Society, Alzheimer's Research UK and others in the briefing paper.

Comments on Standard 2 – diagnosis

We know that Lewy body dementia is under-diagnosed. Currently, only 6 per cent of people identified as having dementia are diagnosed with LBD, yet autopsies find that 10-15 percent of dementia patients have LBD pathology.¹ Some clinical studies have found 15-20 per cent of dementia patients had clinical symptoms consistent with LBD. Other evidence has shown that although the clinical picture is consistent with LBD the autopsy data shows a mixed pathology e.g LBD and Alzheimer's disease. Although there is currently no simple test for LBD, careful clinical evaluation of the patient and their symptoms can form the basis of a reasonably confident diagnosis.

Access to a timely and accurate diagnosis is a constant concern for the families who contact us. Without a correct diagnosis, patients and families do not get the right information and support about how to live with the condition. This can be devastating, especially when an incorrect diagnosis causes additional anxiety and a failure to manage particular symptoms of LBD.

As a carer (for her husband of 48 years, who now has a LBD diagnosis) recently told us:

"It was Alzheimer's disease for 4yrs, until I asked for another her opinion. It's been a battle getting a proper diagnosis."

Another told us:

"My husband was eventually diagnosed with DLB 2 years after being told, following an MRI scan, that he didn't have Parkinson's Disease. And that was that. No follow up or suggested further diagnostic services. Given the close links between Parkinson's and DLB this should have been a logical first step. We missed out on therapies and treatments that would have improved the quality of both our lives. His diagnosis came about because I began keeping a blog and made a self diagnosis that was supported by the NHS consultant at last. I knew nothing about DLB then - hadn't heard of it but

¹ <https://www.alzforum.org/news/conference-coverage/dementia-lewy-bodies-research-ready-clinical-trials>

now am gaining knowledge and understanding through experience and research. A further glitch we have had is that, in this area, (Wirral), Neurological services and movement disorders are dealt with by different and quite separate NHS Trusts. One is fairly on the ball but the other is over stretched and waiting times are appalling.”

If dementia patients are given a wrong diagnosis, they may not get the correct treatment, which can be dangerous, or even life threatening. Delusions and hallucinations are often present with LBD. If patients have not been recognised as having LBD and are given antipsychotics (not recommended) then they can suffer a severe reaction to this class of drugs. In addition, people with DLB cannot tolerate the anticholinergics often given to the elderly for urinary incontinence.

In a further example, sleep problems (REM sleep disorder) affect almost all LBD patients. There is a safe medicine for treating REM sleep disorder that can make a big difference to the quality of life of people with LBD and their carers.

We therefore support the current guidance that anyone with suspected Lewy body dementia receives a referral to a specialist service for appropriate investigations and diagnosis.

We do not consider that sufficient funding is currently available for access to specialist dementia services and would like to see these services given a greater priority. The Lewy Body Society would support a target for the minimum time period between referral and diagnosis for dementia, as is the case with other conditions, to encourage transparency and accountability.

Comments on Standards 5 and 6 – treatment and review

We support these standards and believe that training and support must be given to medical professionals to ensure they comply with them. Too often, patients with Lewy body dementia and their carers tell us that they don't feel their views are listened too, and that they are not offered the most appropriate treatment.

A patient with LBD recently told us:

“I get tired of Doctors saying that they know about Lewy Body Dementia, when they clearly don't have a clue. Many keep recommending high doses of medication, when they should realise that we don't cope with high doses of some medication. When my wife tells them they look stunned.”

Comments on Standard 7 – training and support for carers

It is a huge challenge for health professionals to provide education and support for carers when the symptoms can vary so much between different types of dementia. A single programme for carers which did not have *significant* content about dementia sub-types would fail to meet the needs of Lewy body dementia carers.

We appreciate that the draft standards says that the training should be tailored to the needs of the carer. It goes on to list a number of ways in which carers' needs might vary – for example in relation to their employment status – but does not mention the different types of dementia. Again, we believe that a more explicit mention would ensure that the needs of Lewy body dementia carers are more likely to be met.

END