



Improving the diagnosis and management of neurodegenerative dementia of Lewy body type in the NHS (DIAMOND-Lewy)

Following the success of the first DIAMOND-Lewy newsletter, we hope this latest instalment will be as well received and that you continue to find our updates useful and interesting. We are now nearing the end of the second year of the five year DIAMOND-Lewy Study which is funded by the National Institute for Health Research (NIHR). The study is broken down into a number of smaller studies, which we call work packages. These are described individually in more detail below by some of the researchers who are most involved with them.

Lewy Body Dementia is a form of dementia which unfortunately is often not recognised or misdiagnosed. Its profile been raised considerably following recent reports in the global media that the late actor/comedian Robin Williams was showing signs of the disease. More than ever there is a greater public awareness of the need to recognise and diagnose Lewy body dementia and this is the primary aim of DIAMOND-Lewy. As you will see from this Newsletter, we have made excellent progress so far but none of this would be possible without the support of many. We anticipate 2016 will continue to be a very busy time for the team as we will continue our efforts to develop a better, more consistent approach to the management of Lewy body dementia.

As promised we will continue to produce regular newsletters as the programme progresses. If you have any comments about the newsletters, or would prefer not to receive them, please do let us know. *Andrew West, Programme Manager*



Work Package 1



Our team, Allison Bentley and Dr Ajenthan Surendranathan in Cambridge, and Sally Barker and Dr Joe Kane in Newcastle, are now nearing completion of work package 1A, looking at the frequency of dementia with Lewy diagnosis in both Cambridgeshire and the North East, with 75 patients recruited to the study. We are now reviewing in detail the medical notes of those who have consented to analyse how their clinical care differs to other patients with dementia (of whom we have also recruited 58).

Work has also started on work package 1B, where we are looking at memory problems in Parkinson's disease. The aim is to compare the clinical care of Parkinson's disease patients with and without memory problems, to see if there are differences. With the kind help of geriatricians, neurologists and Parkinson's specialist nurses we are now recruiting patients in both locations.

Dr Ajenthan Surendranathan (above) & Allison Bentley, Research Nurse

In the News: Robin Williams had Dementia with Lewy Bodies

It has recently been revealed that the American actor and comedian Robin Williams (21 July 1951 – 11 August 2014) was suffering from undiagnosed dementia with Lewy Bodies. Professor Ian McKeith, founder of the Consortium on Dementia with Lewy Bodies and part of the DIAMOND-Lewy team, has written about Robin Williams' condition for The Conversation. He article can be read on the Newcastle University Press Office website at: <http://www.ncl.ac.uk/press/news/2015/11/robinwilliamshaddementiawithlewybodies/>



Work Package 2

Our initial work with professionals explored their views of the assessment tool and management toolkit. The findings have been used to refine the tools and develop an implementation strategy for Work Package 5 (WP5).

We hope the implementation strategy will facilitate the use of the tools in the cluster randomized trial (WP5) which is due to start next year.

Patients and carers generally found the questions in the assessment tool easy to understand; some suggestions for improving the wording were made and have been used in refining the tool. Interviews with patients and carers highlighted a range of day-to-day concerns and the importance of the interpersonal aspects of consultations. We drew on these data to develop some key management principles which have been included in the management toolkit.

*Claire Bamford,
Senior Research Associate*

Work Package 3

The purpose of WP3 is to establish best practice guidelines for treating people with LBDs, and to present these in a way that clinicians working in the NHS can easily understand and use. Previously we carried out a systematic review of all the research studies that have ever been published on the topic. Complementing this we had valuable input from two patient and public involvement (PPI) workshop events that were focussed upon identifying good and bad practice in LBD clinical management, based on their own experiences. We also engaged an expert panel in excess of 30 individuals, selected nationally and internationally and representing NHS and academic clinicians, nursing, physiotherapy, OT and pharmacy. By means of what is called a Delphi process, they have helped us to refine our guideline which is now being assembled based upon the three streams of evidence (systematic review, PPI principles and Delphi statements) and these have been delivered for feasibility assessment in WP4. We have already received some early feedback from WP4 and are now developing several versions of the management toolkit including a visual flow-chart so that clinicians can more easily apply the guidelines when seeing people with LBD in their daily practice.

*Prof Ian McKeith &
Dr John-Paul Taylor*

Work Package 4

From the summer to November we have piloted our assessment and management toolkits in Gateshead Health NHS Foundation Trust. This NHS Trust has both Old Age Psychiatry and Parkinson's Disease services and so is well placed to allow us to test the questions in the assessment toolkit and the advice in the management toolkit. We engaged medical and nursing staff in both services and consented twelve of them to try out the toolkits. Following this Claire Bamford and colleagues have been busy meeting with these clinicians and asking about their experiences so we can improve these toolkits ready for the full trial in work package 5. The toolkits were piloted with more than 20 people from both services and Claire and others in work package 2 have also been interviewing them to help us further improve the final version of these toolkits.

Prof Alan Thomas

Our News ...

Congratulations to Allison Bentley, DIAMOND-Lewy Research Nurse, Cambridge

Allison Bentley has recently been awarded a NIHR CLAHRC (Collaboration for Leadership in Applied Health research & Care) East of England fellowship. Previously a District nurse and Community Matron, Allison has developed an interest in the physical (autonomic) symptoms associated with Lewy body disease. The aim will be to examine the frequency and severity of reported autonomic symptoms and interview people living with Lewy body dementia and their carers about the impact of living with the physical symptoms.

Work Package 5

This Work Package is currently at the developmental and approval stages and will commence early in 2016. It involves introducing the management toolkit into routine NHS care in eight different services in four NHS Trusts. A pilot cluster randomised trial (a type of randomised controlled trial in which groups of subjects (as opposed to individual subjects) are randomised) will be conducted to test the management toolkit. There are two strands to the study: WP5A will focus on DLB and will run in memory assessment services; WP5B will focus on PDD and will run in movement disorder (neurology and geriatric) services.



We are extremely grateful for the help of all the patients and their families who have given their time to us over the past year.

**Festive Greetings from
The DIAMOND-Lewy Team**

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