

Lewy body dementia Admiral Nurse Service evaluation summary 2020-21

Background

Admiral Nurses are specialist dementia nurses who provide psychological support, expert advice and information to help families affected by dementia, particularly those with complex needs. People with Lewy body dementia experience complex physical and psychological needs and those caring for them often have significantly higher levels of stress and depression compared with other carers. In 2019, the Lewy Body Society funded a two-year project for a Consultant Admiral Nurse specialising in Lewy body dementia, in partnership with Dementia UK.

Aims

The aim was to provide professional leadership and consultancy, education and training, and expert clinical practice, nationally, through:

- raising awareness of Lewy body dementia
- increasing understanding of the needs of families affected by Lewy body dementia
- offering direct support for families with complex needs and where local Admiral Nurse support was not available

Methodology

A 'mixed methods' approach was used, collecting qualitative and quantitative data:

- Activities with families and supporting best practice work were captured on a clinical database
- Family carers and people living with dementia were contacted to take part in a survey about their experience of the service once clinical work had been completed
- Professionals taking part in training were asked to complete a pre- and post-training tool to measure changes in knowledge and approach to care



Photo: Rachel Thompson, Consultant Admiral Nurse, Lewy body dementia

Referrals to the service



71
family carers and people living with Lewy body dementia were directly supported following a referral

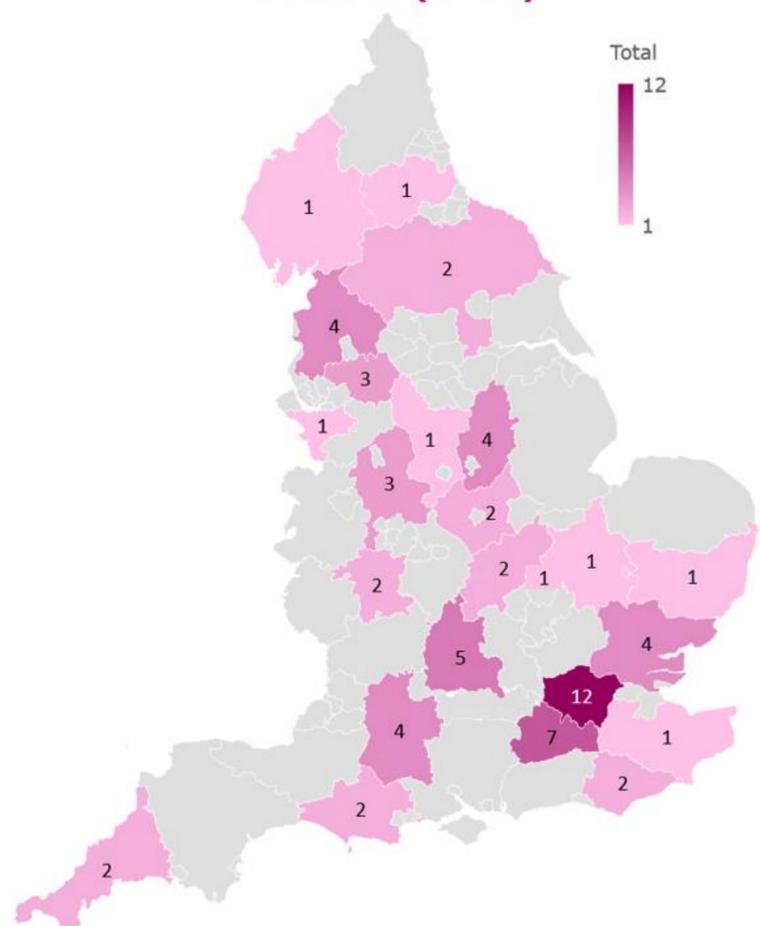
The most common reasons for referral were:

- significant difficulties with managing distressing symptoms (**38%**)
- significant distress in relation to caring/adjusting to the diagnosis/changes in relationships (**31%**)
- difficulty with managing medication, co-morbidities (**12%**)

Families were supported across England

- London had the greatest number (**12**) of families supported in the first year
- Three carers living in other (non-UK) countries were also supported

Location (n=68)

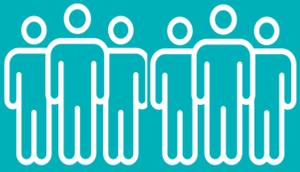


Location data was plotted using Bing Maps app in Excel

Delivering support

620

activities supporting families



The service adapted to the Covid-19 pandemic by delivering support to families mostly through telephone calls, video calls and email.

Families' needs are assessed to ensure person-centred care and support is provided by the service, as follows:

- help with developing coping skills and strategies
- enhancing knowledge and understanding of Lewy body dementia
- emotional support and counselling, including adjusting to bereavement and loss

The Admiral Nurse support provided to professionals included advice (n=77) and delivery of education and training sessions (n=39) in relation to Lewy body dementia.

164

activities supporting professionals

Outcomes

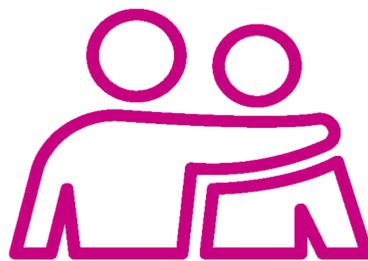
Making a difference to families

Thirty family carers and **five** people living with Lewy body dementia provided feedback about their experience of the service*.

Carers said the Admiral Nurse had contributed to:

- their ability to continue as a carer (**28**)
- avoiding a care or nursing home move (**10**)
- reducing GP appointments for their needs (**10**)
- reducing GP appointments for the person living with dementia (**9**)
- avoiding A&E visits for person living with dementia (**8**)

All or almost all carers and people living with Lewy body dementia said the Admiral Nurse had made a difference to:



All people living with Lewy body dementia and carers are **extremely likely to recommend the service**

"She has helped both of us understand how to communicate with each other more positively... and gave us... some great tools to use to maintain our relationship alongside the dementia."

Family carer

"I was diagnosed with dementia with Lewy bodies... I wasn't given any information or follow-up services... and felt lost and hopeless. [The Admiral Nurse] has made a tremendous difference and has greatly given me an understanding of Lewy body dementia. She has answered all of my questions... given us coping mechanisms... She has been my lifesaver."

Person living with Lewy body dementia

"The Admiral Nurse... has made a really significant contribution to my ability to care for my husband and to cope with the everyday stress of 24/7 caring."

Family carer

"My ability to cope"
(34 out of 34)

"My understanding of Lewy body dementia"
(34 out of 34)

"My knowledge of other services that can support"
(33 out of 33)

"My ability to manage symptoms"
(30 out of 31)



* No question in the survey was mandatory therefore response rate to questions varied

Training delivered had a positive impact on Admiral Nurses' knowledge about Lewy body dementia and their approach to care



168 Admiral Nurses completed a pre-training questionnaire designed to measure knowledge and approach to the care of families affected by Lewy body dementia, with **142** completing the questionnaire at post-training. The percentage of **correct answers across all of the questions increased from pre- to post-** – the percentage increase in correct answers varied by question and ranged from 11.9% to 65%.