

Lewy body dementia Admiral Nurse Service

Summary Evaluation Report
June 2020 to May 2021



DementiaUK

Helping families face dementia



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



The Lewy Body Society

Shining a light on Lewy body dementia

About the Lewy body dementia Admiral Nurse service

At a glance:

- **87** referrals to the service
- **71** family carers and people living with dementia supported
- **620** clinical interventions delivered
- **164** supporting best practice activities delivered – including training to **168** Admiral Nurses
- **73** liaison activities with professionals

Admiral Nurses are 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 to 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.

This report summarises achievements in Year One to evidence the activities delivered by the service, its reach and impact, and people's experiences.

Our methodology

We **collected** information about:

- referrals to our service and reasons
- families supported by our service, including demographics
- clinical interventions and supporting best practice activities delivered



We **surveyed** carers and people living with Lewy body dementia about their experiences of our service (once clinical work had been completed), including the difference the service made.



We used a **pre- and post-training tool** with professionals to evidence change in knowledge and approach to care.

66% of referrals came from the Dementia UK Helpline.

82 new referrals
5 re-referrals

Nature of referrals:

The service accepts referrals from the Admiral Nurse Dementia Helpline where initial triage identifies the following:

- probable/confirmed diagnosis of Lewy body dementia ie Dementia with Lewy bodies (DLB) or Parkinson's disease dementia (PDD)
- needs not being met by local Admiral Nurse services
- family/friends experiencing difficulty in adjustment/coping; problems with managing distressing symptoms; and/or negative impact on quality of life and relationships



The service adapted to the coronavirus pandemic by offering support to families mostly through telephone, video or email contacts

Who was supported by the service?

63 carers

8 people living with Lewy body dementia

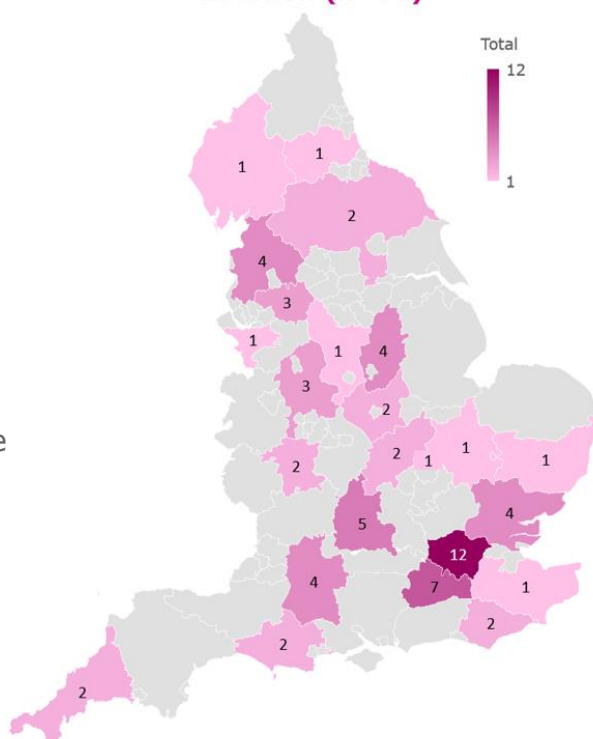
Carers (including families with more than one carer) were:

- mostly female (49); 12 were male
- white British (48); 10 had another ethnicity recorded
- the spouse or partner of the person with dementia (31); 21 were their child
- mostly aged 51-70
- mostly retired (27); 18 were working

Demographic information recorded for people living with dementia includes those referred plus those being cared for by carers referred:

- 30 were male and 20 female
- 43 were white British; 6 had another ethnicity recorded
- around two-thirds were aged 61-80
- 46 were retired
- 38 had a diagnosis of Dementia with Lewy Bodies, 14 Parkinson's disease dementia,
- 7 were recorded as having young onset dementia

Location (n=68)

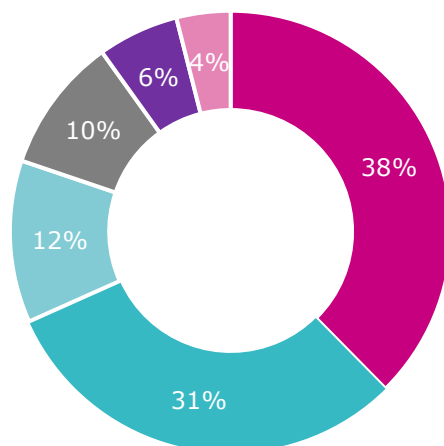


Location data* shows family members being supported across England. London had the greatest number of families supported in the first year (12). Three carers living in other (non-UK) countries were also supported.

Why were people referred?

156 reasons for referral were recorded. The top three reasons below made up 80% of all reasons recorded:

- Significant difficulties with managing distressing symptoms
- Significant distress in relation to caring/ adjusting to the diagnosis/ changes in relationship
- Difficulty with managing medication, co-morbidities etc.
- Other
- Change in presentation of the person with dementia and/or high level of distress
- Referrer requests assessment and/or triage



*Location data was plotted using Bing Maps app in Excel

Supporting families



How we helped

The Lewy body Admiral Nurse service delivered a range of clinical interventions to support families. **620 interventions** (categorised under four intervention types) were delivered to families through telephone, video and email contacts:

- **48%** other clinical including triage, assessment and one-off advice/support
- **38%** psycho-education and emotional support
- **10%** START (Strategies for Relatives) programme to support development of coping strategies
- **4%** couple/dyadic work

A range of activities (n=1,230) were carried out during these interventions:

Developing coping strategies and skills (psychological wellbeing)	312	25%
Sharing knowledge and information	302	25%
Emotional support/counselling (psychological wellbeing)	215	17%
Assessment	178	14%
Managing and promoting physical wellbeing	90	7%
Adjustment, loss and bereavement	72	6%
Advance care planning	49	4%
Managing risk	12	1%

An in-depth look at some of the interventions delivered

Psycho-education and emotional support (usually over 2-4 sessions)

- focus on education and skills-building, specifically in relation to managing complex symptoms such as hallucinations/delusions, sleep disorder etc
- sharing of individualised information
- emotional support focusing on resilience/coping strategies

START intervention (over 8 sessions)

- for family carers who demonstrate some anxiety/depression in relation to their role
- manualised intervention that supports the development of coping strategies (adapted for Lewy body dementia)

Couple/dyadic intervention (usually over 4-6 sessions)

- offered where the person with dementia is able /willing to take part
- may require separate sessions to identify individual needs
- aims to help identify problems and/or conflicts, identify values and preferences, and focus on improving communication, problem-solving skills and future planning

“My Admiral Nurse has made an invaluable difference to my life as a carer. We went through the eight sections of the manual together every fortnight and I learnt so much. I was able over the two weeks between the sessions [to] put some of what I'd learnt into practice. I feel confident and satisfied now, that I can deal with my husband... I am very grateful for all the help I received. Thank you.”
Carer, 75-84

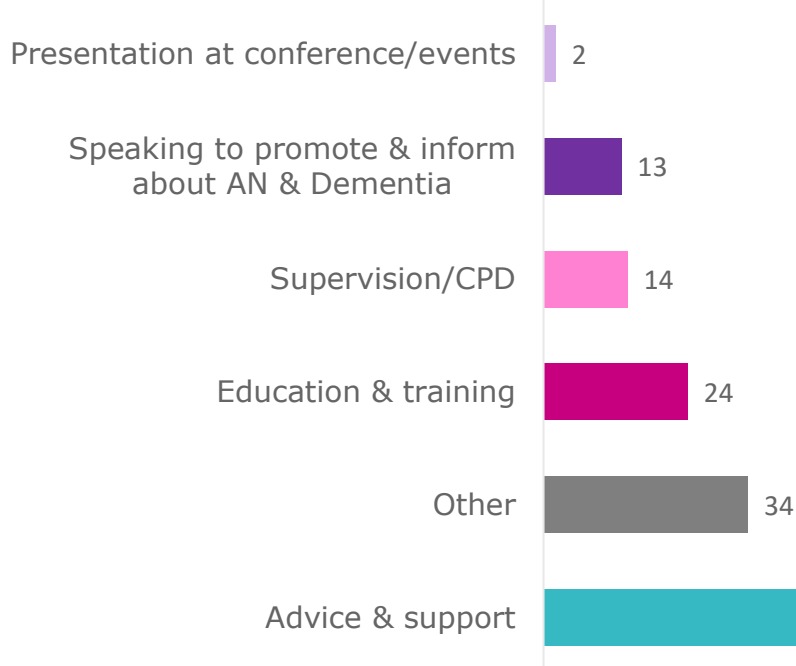
Supporting best practice



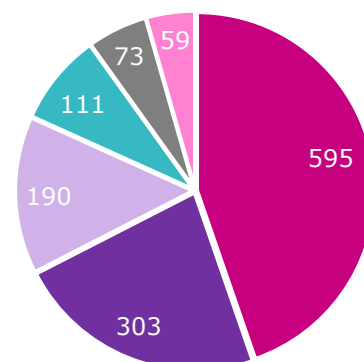
Alongside working directly with families, the Admiral Nurse delivers activities to promote and support best practice in Lewy body dementia care.

- 164 supporting best practice (SBP) activities were recorded from December 19 to May 21. The most commonly delivered activity was 'advice and support' (n=77)
- 1,331 attendees of a SBP activity were recorded (NB a person may have attended more than one activity and will have been recorded as an attendee each time.) The largest number of attendees was recorded against 'education and training' (n=595)

Supporting best practice activity type (n=164)



Attendees/recipients by SBP activity type (n=1,331)



Changes in knowledge and approach to care

Training on Lewy body dementia was delivered to 168 Admiral Nurses. This included a pre- questionnaire to gain an understanding of current knowledge and approach to the care of families affected by Lewy body dementia, and post-questionnaire to measure any changes in this. 168 Admiral Nurses completed the pre-questionnaire and 142 the post-questionnaire. The percentage of correct answers across all of the questions increased from pre- to post- – this varied by question and ranged from 11.9% to 65%.

Outcomes for families*

Positive experience of the service

On the NHS Friends and Family test, all carers and those living with Lewy body dementia said that they would be 'extremely likely' to recommend the Admiral Nurse service to someone they know who needed similar care and support (n=35.)

"I would highly recommend the Admiral Nurse to anyone who is struggling to understand and cope with looking after someone with LBD." **Carer**

Delivering person-centred care

Empathy is a key element in delivering person-centred care, therefore a validated tool, designed to measure empathy in context of a therapeutic relationship within a consultation – CARE (Consultation and Relational Empathy) measure – was included in the feedback surveys.

It is based on a broad definition of empathy in a clinical context which involves an ability to understand the patient's situation, communicate that understanding and act on that understanding with the patient in a helpful (therapeutic) way.

Results from the surveys showed that the care delivered by the service was rated highly with all carers (n=30) and those living with Lewy body dementia (n=5) saying the Admiral Nurse was 'excellent' or 'very good' across all of the items on the CARE Measure.

Quality of life and wellbeing

Three tools were trialled with carers and/or the person living with dementia. A small number of each were completed with an assessment and review score – Hospital Anxiety and Depression Scale (n=11), Scales measuring Impact of Dementia on CARers (n=11) and Short Warwick-Edinburgh Mental Well-being Scale (n=2). All measures showed improvement in scores from assessment to review.

* 30 carers and 5 people living with Lewy body dementia completed a survey asking about their experience of the Admiral Nurse service (including care received and the difference the service had made to them.) No question in the survey was mandatory therefore response rate to questions varied.

CARE measure items

(©CARE SW Mercer, Scottish Executive 2004)

The measure includes 10 items which are scored from excellent (5) to poor (1)

- Making you feel at ease
- Letting you tell your 'story'
- Really listening
- Being interested in you as a whole person
- Fully understanding your concerns
- Showing care and compassion
- Being positive
- Explaining things clearly
- Helping you to take control
- Making a plan of action with you

"She has helped both of us understand how to communicate with each other more positively. And answered so many of our questions. She listened without any judgement and gave us both, individually and separately, some great tools to use to maintain our relationship alongside the dementia... Thank you, your knowledge, your understanding, your time, along with your kind, gentle, non judgemental, professional approach has made a world of difference to us both." **Carer, 55-64**

Outcomes for families*

Making a difference

Use of health and social care resource

Carers said the Admiral Nurse had contributed to:

10 reducing GP appointments for them as a carer

28 their ability to continue as a carer

10 avoiding a care or nursing home move for the person living with dementia

9 reducing GP appointments for the person living with dementia



8 avoiding A&E visits for the person living with dementia

Improving lives

Carers and people living with Lewy body dementia felt that the service was making a difference to key aspects of their lives. All or almost all of those responding said the service had made a difference to their ability to cope, manage symptoms, their understanding of Lewy body dementia, and their knowledge of other services that can offer support.

The Admiral Nurse made a positive difference to:

	Yes	No
My ability to cope	34	0
My understanding of Lewy body dementia	34	0
My knowledge of other services that can offer support	33	0
My ability to respond to and manage symptoms of Lewy body dementia	30	1

The service also helped families to maintain relationships – all of the people with Lewy body dementia said the service had made a difference to their ability to sustain relationships, and almost all carers (23 out of 24) said it had made a difference to their ability to communicate with the person they cared for.

“I was diagnosed with dementia with Lewy body... 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**

“Cannot put into words the difference [the Admiral Nurse] has made to my life. Listening to me and being allowed to say how I really feel was such a relief... [She] is the only person who has explained to me about Lewy Body dementia and made me feel as if I was beginning to understand what was happening to my husband.”

Carer, 75-84

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Improving lives



Twenty-four carers and five people living with Lewy body dementia provided additional feedback on the difference the service had made to them and their families. For some people, contact with the Admiral Nurse came at a very low point in their journey, when they felt they could no longer carry on. For one carer in particular, whose access to services had been limited due to the Covid-19 pandemic, this had been so difficult they felt the support from the Admiral Nurse had saved them from suicide.

"[My Admiral Nurse] has been a lifeline during the days and sleepless nights that I had been worrying about my stressful situation caring for my husband for 12 years. Her support has been unwavering... Before [my Admiral Nurse] came along I was afraid to ask for help from others and today I can gladly say how much I've grown in confidence and no longer afraid to ask for help... My anxiety and stress levels have dropped to almost zero and I feel that I can now face whatever difficulties my caring responsibilities throw at me.

I have been given help and guidance in addressing problems with professionals with regards to problems/changes in my husband's condition. I am no longer afraid to face the future knowing that [my Admiral Nurse] is always on hand to listen, support, guide and understands what I am going through as a carer.

I have made good changes with regards to thinking through situations and putting things in place for future use in ensuring that relevant documents are in place I now understand the importance of taking care of myself by relaxation and taking time out to enjoy some 'me' time in order to be able to continue to care for my husband. [My Admiral Nurse] is very knowledgeable, kind and a very good listener and communicator. Thank you for [my Admiral Nurse.]" **Carer, 55-64**

"Directly due to lockdown and the virus [my Admiral Nurse] has saved me from suicide. She is the only support and help I have received from February 2020 when my husband was diagnosed.... The knowledge I have of Lewy Bodies is directly from [my Admiral Nurse.]" **Carer, 75-84**

"The Admiral Nurse made a huge difference in the way I cared for my husband. I had reached a point in his care where I didn't know where to turn for help as my husband's condition had reached the point where I feared for my own life. Without the Admiral Nurse I feel myself and my husband would have reached crisis point with my husband being admitted to a mental health unit." **Carer, 65-74**



References for tools and measures used

1. The Hospital Anxiety and Depression Scale (HADS)
svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf
2. Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2008, all rights reserved. corc.uk.net/outcome-experience-measures/short-warwick-edinburgh-mental-wellbeing-scale-swemws/
3. Scales measuring the Impact of Dementia on Carers (SIDECAR)
decideproject.co.uk/study-outputs/sidecar/
4. © CARE SW Mercer, Scottish Executive 2004: the CARE Measure was originally developed by Dr Stewart Mercer and colleagues as part of a Health Service Research Fellowship funded by the Chief Scientist Office of the Scottish Executive (2000-2003)
caremeasure.stir.ac.uk/