

## SHORT REPORT

# ‘It’s just incredible the difference it has made’: family carers’ experiences of a specialist Lewy body dementia Admiral Nurse service

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## Abstract

**Background:** Lewy body dementia (LBD) is characterised by a complex array of symptoms. Being a family carer of someone with LBD can be challenging, and is associated with high levels of stress, depression and anxiety. Admiral Nursing services support family carers of people with dementia in the UK by providing tailored information, advice and therapeutic support. Recently, the Admiral Nurse model has been adapted to the needs of more specific populations, including the introduction of a new, specialist LBD Admiral Nurse.

**Objective:** to explore family carers’ experiences of the LBD Admiral Nurse service.

**Methods:** fourteen family carers of people with LBD were interviewed about their experiences of the LBD Admiral Nurse service. Interview transcripts were analysed using thematic analysis.

**Results:** four themes were identified: theme 1 described how participants valued the LBD Admiral Nurse’s specialist expertise, which contrasted with the lack of knowledge they encountered in other services. In theme 2, participants described how the practical, tailored support provided by the LBD Admiral Nurse enabled them to better manage a variety of caring-related challenges. Theme 3 captured the emotional benefits that participants gained from being able to talk to someone who understood their situation. In theme 4, participants explained how the reliability of the LBD Admiral Nurse’s support helped them feel supported in their role.

**Conclusions:** the specialist knowledge and expertise of the LBD Admiral Nurse enabled family carers to better support the people they cared for, and to relieve some of the emotional stress associated with caring.

**Keywords:** Parkinson’s, caregiver, neuropathology, neurodegeneration, spouse, older people

## Key Points

- Caring for someone with Lewy body dementia (LBD) is challenging.
  - Admiral Nursing is a UK-based model for supporting people with dementia and their families.
  - A new, specialist LBD Admiral Nurse role has recently been developed.
  - The specialist tailored knowledge and guidance that the LBD Admiral Nurse provided helped family carers to better understand and care for the person with LBD.
  - Family carers were able to relieve some of their negative emotions by talking through their situation with an LBD Admiral Nurse who was reliable, knowledgeable and experienced.
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## Introduction

Lewy body dementia (LBD) is an umbrella term for dementia with Lewy bodies and Parkinson disease dementia [1]. The conditions share an overlapping clinical profile that includes: fluctuations in cognition, attention and alertness; recurrent visual hallucinations; sleep disorders and Parkinsonism features [2, 3]. Differential diagnosis is predominantly based on the temporal order of symptom onset: dementia with Lewy bodies is diagnosed when dementia occurs before the onset of Parkinsonism, whereas Parkinson's disease dementia is diagnosed when Parkinsonism precedes dementia by 1 year or more [3].

Providing care to people with LBD can be physically and emotionally challenging, with carers reporting a complex array of negative feelings and emotions [4]. Many carers also report having inadequate social support networks [5], and being unable to meet their own social and emotional needs [6]. These circumstances have significant negative impacts on carers' physical and mental health [5, 7, 8].

One means of support for carers of people with dementia in the UK is Admiral Nursing: a model supported by the charity Dementia UK, in which registered nurses specialising in dementia care aim to improve the quality of life of families affected by dementia [9]. Admiral Nurses follow a biopsychosocial approach that includes the provision of information, advice, psychological and emotional support, as well as help and support with coordinating and navigating health and social care services [10]. They also train, educate and support generalist health and social care professionals in dementia care [9].

More recently, the Admiral Nurse model has been adapted to particular populations, including people with young-onset dementia or learning disabilities [11]. Due to the complexity of the needs of people with LBD [12], 'The Lewy Body Society' (a UK charity who raise awareness, provide education and information, and fund research into LBD), working in partnership with Dementia UK, recently funded a Consultant Admiral Nurse post specialising in LBD. As part of this post, the LBD Admiral Nurse supports UK-based carers of people with LBD who are referred from the Admiral Nurse Dementia helpline. This support includes individualised, multicomponent interventions that have known effectiveness at reducing stress, depression and anxiety in carers of people with dementia [13, 14], including psychoeducation and coping strategies; STrategies for RelaTives (START; [15]) and relationship counselling for spousal couples [16], as well as bespoke, clinical advice and information, and signposting to local services and other resources and information, such as those provided by the Lewy Body Society, Dementia UK and the DIAMOND Lewy Toolkit (<https://research.ncl.ac.uk/diamondlewy/>). Support is delivered remotely through telephone or online video meetings.

As part of a wider evaluation of the effectiveness of this specialist LBD Admiral Nurse provision, the aim of the current study was to explore family carers' experiences of the LBD Admiral Nurse service.

## Methods

### Participants

Participants were family carers of a person living with LBD who had had at least three points of contact with the LBD Admiral Nurse. Carers meeting these eligibility criteria were informed about the study by the LBD Admiral Nurse. Interested carers were then sent an information pack containing an invitation letter signed by one of the researchers (KHD), along with an information sheet and consent form, reply slip and stamped envelope addressed to the researcher.

### Procedure

Ethical approval for the study was provided by the University of Manchester proportionate University Research Ethics Committee. All interviews were conducted between September 2020 and September 2021, by KHD or ZA, either by telephone or over a video conferencing platform. Both interviewers were experienced researchers (Supplementary File 1, Supplementary data are available in *Age and Ageing* online) who followed a semi-structured topic guide (Supplementary File 2, Supplementary data are available in *Age and Ageing* online) that included: what help/support/interventions the Admiral Nurse had offered, and the participant's experiences of these; how useful they considered aspects of the service to be; and potential ways in which the service could have been made more useful.

### Analysis

Anonymised transcripts of the interviews were analysed using thematic analysis [17, 18]. A two-stage approach was used for coding: first, bottom-up, open-coding was used by one researcher (KHD) to apply descriptive codes to a subset (six) of the transcripts. The analysis team (KHD, ZA, AP and LJEB) then used these codes to create a coding framework, which was used to code the remaining transcripts. Very few new codes had to be added in this second coding stage to capture points not covered in the initial coding framework, providing evidence for the adequacy of our sample size.

The first author (LJEB) organised the codes from all 14 transcripts into a set of provisional themes. These were then reviewed and refined through discussion with the full analysis team.

## Results

Twenty-five carers were invited to participate. Twenty-three of these expressed interest, and so were sent an invitation pack. Fifteen of these subsequently contacted the research team and consented to take part. The data for one participant were subsequently excluded as they had been interviewed with the person they cared for, which was not in-line with the study protocol.

The remaining 14 participants (13 female and 1 male) ranged in age from 49 to 80 years (mean age = 67 years), and were all White British. Nine were married to the person with

**Table 1.** Key points, and illustrative quotes, from each theme. Note that all names are pseudonyms

Theme	Key points	Illustrative quotes
Theme 1: the need for specialist knowledge	<ul style="list-style-type: none"> <li>• Participants expressed frustration about the lack of knowledge about LBD amongst the health and social care service, which made it difficult to access help and support.</li> <li>• Participants reporting lacking knowledge about LBD themselves, which affected their ability to provide care.</li> <li>• Participants expressed a strong need to talk to someone with specialist knowledge of LBD.</li> <li>• The clear and detailed knowledge and expertise about LBD that the LBD Admiral Nurse provided increased participants' confidence in the advice she gave.</li> </ul>	<ul style="list-style-type: none"> <li>• 'You speak to your own GP and they don't really know much about it [LBD]'. (Hilary)</li> <li>• 'I don't think I fully understood it [LBD] myself because I was still thinking he [my husband] had Parkinson's . . . just that we were not coping with it'. (Irene)</li> <li>• 'I feel what I want is to speak to somebody who has got real experience of Lewy Body dementia'. (Barbara)</li> <li>• 'She [the LBD Admiral Nurse] actually knew what she was talking about, so I had confidence'. (Barbara)</li> </ul>
Theme 2: the value of practical guidance that is tailored to individual needs	<ul style="list-style-type: none"> <li>• The practical advice and guidance provided by the LBD Admiral Nurse was seen to have tangible, positive impacts on carers' situations.</li> <li>• The breadth of support mentioned ranged from understanding and dealing with symptoms, changes to medication, signposting to other services, support for the carer, and planning for the future.</li> <li>• The practical advice and guidance provided was particularly valued because it was tailored to each person's situation, and because it was presented in a realistic way, as suggestions that might require further trouble-shooting, rather than guaranteed solutions.</li> <li>• The advice and guidance provided also helped some participants to access other services by providing the knowledge, confidence, or 'voice' to ask for what they needed.</li> </ul>	<ul style="list-style-type: none"> <li>• 'She [the LBD Admiral Nurse] sent me a video of feeding people in late dementia and that was really, really helpful'. (Cathy)</li> <li>• 'It's about me, if you like, its keeps coming back to that. And, basically, you know, sort of bringing the subject round to what I want, and what I can do to improve my life'. (Helen)</li> <li>• 'She [the LBD Admiral Nurse] does not say, "If you do this it will be fine," but, "Let's try this," or "Let's try that"'. (Lily)</li> <li>• '. . .because of the lengthy email she [the LBD Admiral Nurse] wrote that I sent onto our GP. The GP possibly paid a little bit more attention'. (Annie)</li> </ul>
Theme 3: being able to talk to someone who understands	<ul style="list-style-type: none"> <li>• Many participants talked about the stresses and strains they experienced as a result of caring for someone living with LBD.</li> <li>• Many participants found it difficult to talk to friends and family about their experiences.</li> <li>• Sharing what they were going through with the LBD Admiral Nurse provided a valuable way of relieving some of the stress and complex emotions that they were experiencing.</li> <li>• Participants valued the fact that the LBD Admiral Nurse's level of experience and expertise enabled her to really understand what they were going through. This helped them to interpret the cause of their feelings as being due to the situation rather than their own failings or weakness.</li> </ul>	<ul style="list-style-type: none"> <li>• 'I am not getting any healthier and the stress is the worst thing of all'. (Barbara)</li> <li>• 'I didn't find it easy to talk to other people really [ . . . ] you kind of try and protect other people, and your friends don't want you wittering about other things'. (Helen)</li> <li>• 'I build up anger. [ . . . ] She [the LBD Admiral Nurse] allows you to say these words'. (Lily)</li> <li>• 'The fact that she [the LBD Admiral Nurse] could immediately understand what I was saying and explained to me why I was having these problems'. (Irene)</li> </ul>
Theme 4: gaining security from support that you can rely on	<ul style="list-style-type: none"> <li>• Participants particularly valued the reliability and dependability of the support provided by the LBD Admiral Nurse.</li> <li>• This contrasted with participants' previous experience of health and social care services that were perceived as disjointed, unreliable and/or uncoordinated.</li> <li>• Participants were aware of how many others could benefit from the finite time that the LBD Admiral Nurse had, and some expressed a sense of guilt, or wariness, at taking up too much of her time.</li> <li>• Despite this, the LBD Admiral left participants with a sense of security in the availability of her support.</li> </ul>	<ul style="list-style-type: none"> <li>• '[What I find most useful about the LBD Admiral Nurse is] the fact that she is dependable . . . If she says she will ring at a certain time, she will ring'. (Janet)</li> <li>• 'There's just no flipping coordination between social services and HTT [home treatment team] and our own GP'. (Ruth)</li> <li>• 'I guess you feel like you can't use up too much of her time'. (Sandra)</li> <li>• 'She [the LBD Admiral Nurse] always says, "You can ring if there is something major and you need my help and need to speak to me." [ . . . ] And that's good. That's really good to know there is that back up'. (Maggie)</li> </ul>

LBD that they cared for; four were the son/daughter and one was a sibling.

Four themes were identified in the data (Table 1).

## Discussion

The aim of this study was to explore family carers' experiences of the LBD Admiral Nurse service. Theme 1 demonstrated

the value that participants placed on the LBD Admiral Nurse's level of knowledge and expertise. In line with previous studies [12], this contrasted with the lack of knowledge and awareness of LBD that participants reported experiencing within the general health and social care system. In addition to addressing carers' reported need to better understand the more challenging symptoms of LBD themselves [6], this theme therefore highlights the importance of the

consultancy and training elements of the Admiral Nurse role [9] for increasing knowledge and awareness of LBD amongst generalist health and social care professionals: something that could help to minimise the delays that people with LBD experience in getting accurate diagnoses and appropriate support [6,19].

Theme 2 highlighted the perceived value of the practical, and tailored, advice and information that the LBD Admiral Nurse provided. In line with evaluations of general Admiral Nursing support [20], participants also reported how the LBD Admiral Nurse helped participants to find the words and confidence needed to request appropriate help elsewhere. Although the importance of tailoring interventions to individual needs is increasingly recognised in many domains of health and social care [21,22], it is particularly important for conditions like LBD, where symptoms are complex, variable and heterogeneous [12]. This highlights the benefit of having a specialised LBD Admiral Nurse role, which can provide bespoke support to meet the diverse needs of this population.

Theme 3 described how talking to someone knowledgeable helped carers to relieve, understand and rationalise some of the negative feelings they experienced. Given the known associations between caring-related negative feelings and depression, anxiety and quality of life [8], these findings suggest that the LBD Admiral Nurse's specialist expertise and empathy could have a significant positive impact on carers' health and wellbeing, and help to foster resilience.

The final theme highlighted the particular value that participants placed on the reliability of the LBD Admiral Nurse service, which contrasted with participants' previous experiences of uncoordinated, unreliable and disjointed care. Participants recognised the finite nature of the LBD Admiral Nurse's time, and some reported rationing their use of the service to respect this. Taken together, this suggests that even infrequent support can engender a sense of safety and security if that support is perceived to be dependable.

This study has some limitations. First, carers were recruited after having had three contact points with the LBD Admiral Nurse. The data therefore do not represent the views of those who disengaged at an earlier point. Second, most participants were female, and all were White British. This is important given that carers for people with dementia from Black and ethnic minority backgrounds face additional barriers to engaging with formal support services [23], and differ in their support needs [24]. Third, the data for this study were collected during the coronavirus disease of 2019 (COVID-19) pandemic, when levels of caring-related stress, anxiety, isolation and loneliness were heightened [25–27]. However the challenges of supporting people with LBD have been well documented before the pandemic [1, 5–7, 12], suggesting that the specific benefits of the LBD Admiral Nurse described by the participants are unlikely to be limited to the specific context of COVID-19.

In conclusion, this study highlights key features of the specialist LBD Admiral Nurse role that could help to

improve the lives of families affected by LBD. These findings are particularly encouraging given that all support was delivered remotely, thus providing a model that is scalable, and has broad geographical reach. Future work should assess the effectiveness of specialist LBD Admiral Nurse services at improving the quality of life of the families of people with LBD, and determine how such services should be adapted to meet the needs of a more diverse population.

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