

Feasibility and benefits of online psychosocial groups for family carers affected by Lewy body dementia



DementiaUK
Helping families face dementia

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Background

- The Consultant Admiral Nurse service for Lewy body dementia (LBD) provides biopsychosocial support to families.
- Lewy body dementia accounts for 10-15% of all dementias and people often have complex physical and psychological needs.
- Family carers of people with LBD often experience poor mental and physical health, reduced quality of life and high levels of strain/burden.
- Psychoeducational group support can reduce stress, support coping and reduce isolation.

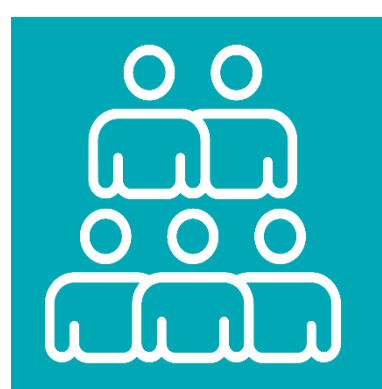
Aims

To develop a programme for family carers of people with Lewy body dementia to:

- increase understanding of Lewy body dementia
- develop coping skills
- promote self-care and wellbeing
- plan for the future
- reduce feelings of isolation

Method

- Family carers were invited to attend an online psychosocial group programme.
- Sessions lasted 2-hours over 6-weeks.
- All participants were supporting someone in the earlier stages of the condition, had not had previous support or training in Lewy body dementia, and were interested in meeting other family supporters/carers.
- Between July 2022 and December 2024, four carer groups were delivered (5 – 8 per group)



Wellbeing

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)¹, a 14-item scale of mental wellbeing was used- pre and post programme.

1. **The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)** <https://warwick.ac.uk/>

Programme feedback

Carers were asked to provide feedback via a survey about their reasons for attending and the difference the programme had made.

Programme sessions

1. Introduction to Lewy body dementia
2. Exploring the impact of caring
3. Understanding symptoms and changes in behaviour
4. Developing caregiving strategies
5. Reviewing strategies & promoting self-care
6. Planning for the future



Wellbeing

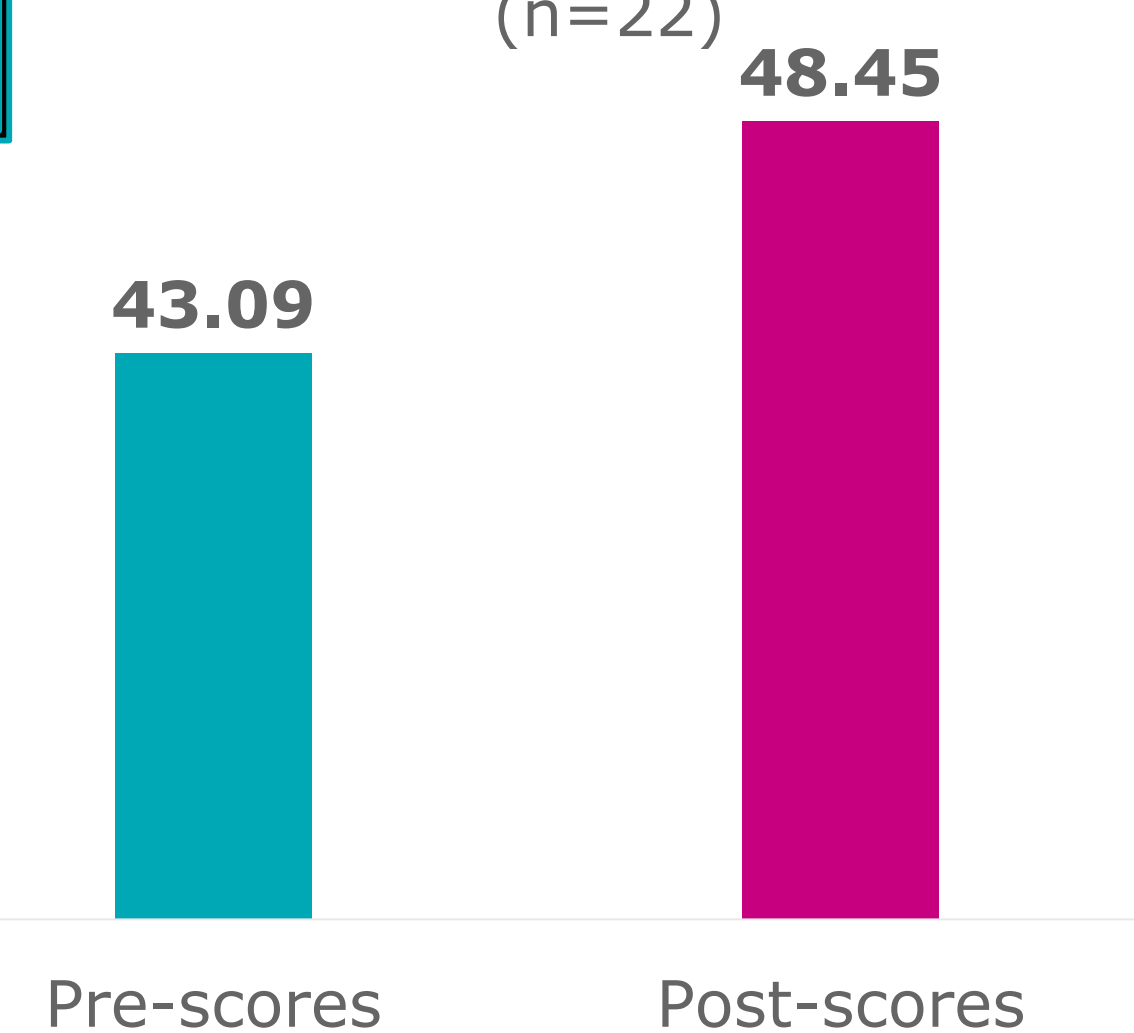
22 carers completed the WEMWBS - 4 separate groups

Mean wellbeing scores increased from 43.09 (sd=7.47) before the sessions, to 48.45 (sd=8.51) after the sessions, showing an increase in mental wellbeing.

The paired t-test analysis concluded that there was a statistically significant increase in wellbeing scores ($t(21) = -5.364, p=0.002$)



Mean carer wellbeing scores (n=22)



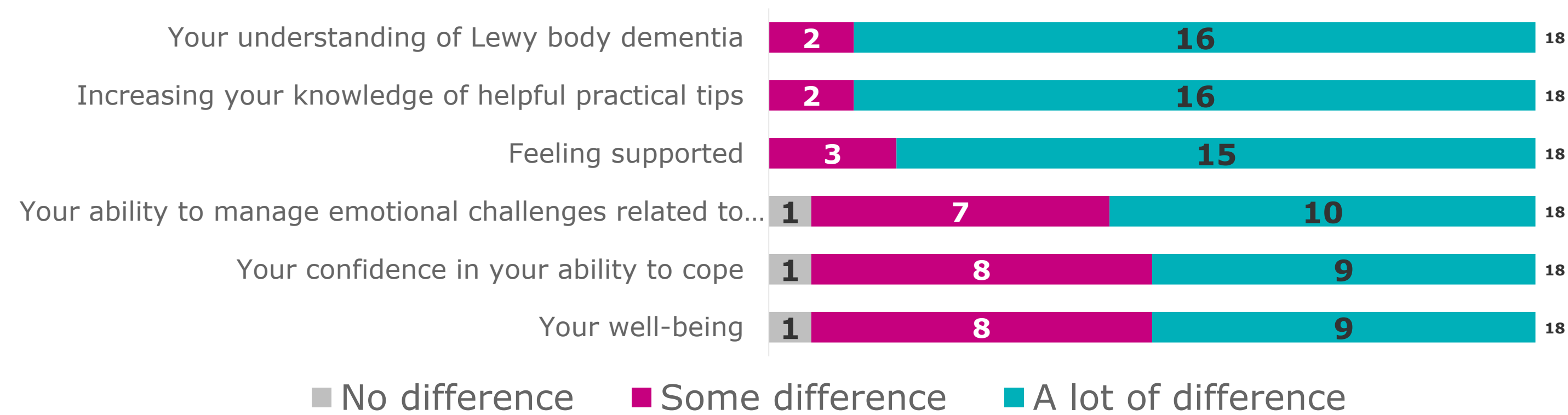
Programme feedback

18 carers completed an online feedback survey

Making a positive difference

Carers reported on the positive difference the programme had made to them:

The group made a positive difference to...



Other feedback included reducing isolation, having peer support, improving self-care and wellbeing, developing coping skills, and increased knowledge and understanding

[I] learnt a lot from the other members and their approach to the life we are all leading.



Meeting others caring for someone with LBD has made me feel less isolated and we have been able to share experiences and learn from each other

Peer support

It was very comforting meeting other carers and having more knowledge on the illness

Reducing isolation

Being part of the group with others who understood helped ease my sense of isolation as well as increasing my knowledge and skills

Knowledge & understanding

Help in gaining calming mechanisms for myself Through understanding the illness

Coping skills

Hearing about the latest research and scientific understanding of Lewy Body Dementia.

Self-care & wellbeing

Realising how important it is to look after my health and well-being ...

I found the work on reframing thoughts really useful and have seen an immediate impact on how I feel about being a carer

Conclusion

Initial feedback and outcomes indicate this intervention was acceptable and made a positive difference to coping & wellbeing for those who took part. Further research is required to fully evaluate the impact and benefits of online psychosocial groups for family carers of people with Lewy body dementia at different stages of their role.