

LBUK - Online Support Meeting 9 March 2026

Attendance

Esther, Linda and 10 carers – 2 men and 8 women

3 in Scotland – including Linda: Edinburgh, Glasgow, East Renfrewshire

9 in England – including Esther: Tyne and Wear, Yorkshire, Lancashire, Cheshire, Birmingham (2), Essex (2), London.

Key Takeaways

- Consider connecting one-to-one with other Buddies who share similar circumstances, through the Buddy Directory;
- Explore local support groups and services;
- Try to make time for self-care to maintain wellbeing.

Topics discussed:

Tremor management and Parkinson's medications

Concern about reluctance of consultant to prescribe medication to control tremors due to concerns about hallucinations.

- Contact Parkinson's nurse or Admiral nurse for advice and support about balancing medications
- Start with low dose to test impact;
- For Buddies who are relatively fit, and enjoy exercise, Esther recommends rapid cycling on an exercise bike, perhaps at a spin class organised by Parkinson's UK.
- <https://www.lewybuddiesuk.org/wwfm-posts/what-worked-for-me-rapid-cycling>
- <https://www.theracycle.com/conditions/parkinsons-exercise-bike/>

Rivastigmine effectiveness

A Buddy asked about other Buddies experience of the effectiveness of rivastigmine medication.

- Patches are better tolerated than oral medication for some patients;
- Effectiveness varies, with some seeing improvements and others questioning benefits.

Incontinence management challenges

Significant struggles experienced about night time incontinence and difficulties accessing incontinence nurse services.

- District nurse helped with incontinence problems;
- Conveens, an external catheter attached to a urine bag, are worth a try: email help@coloplastcharter.co.uk for advice;
- Persistence is required when services are unresponsive.

Respite care and carer support

Buddy shared experience with respite care during her hip replacement surgery.

- Expressing emotional distress to healthcare providers can trigger better support;
- Esther: Emphasised importance of paying for care (aware that not everyone can afford it but may be able to use a friend or family member or a local charity) to maintain sanity, and as mentioned before introduced carers early so husband got used to strangers helping.

Communication and support improvements

Discussion about how LBUK could improve services and communication among members.

- A plan to improve the service to Buddies with a members' forum is in hand;
- Brief member descriptions will help to find common interests;
- Before this is in place, Buddies may create their own local WhatsApp groups;
- The LBUK Facebook group – a private group – has over 1,500 members and is a good place to share concerns and helpful ideas: <https://www.facebook.com/groups/lewybuddiesuk/posts/>

Experiences in finding a Buddy

Discussion about personal Buddy matches and their value.

- It's worth persevering until you find a good match;
- It's good to meet locally for coffee and a chat, but it's also good to talk on the phone with a carer who really understands what you're experiencing.

Genetic concerns and family history

A Buddy (caring for her mother) is experiencing tremors in her hand and asked about genetic links.

- There is no scientific proof about a genetic link;
- There is anecdotal evidence from some Buddies that there is a family history of LBD and Parkinson's diagnoses.

Varied symptom presentations

A Buddy shared his wife's very different symptom profile compared to others in the group.

- LBD presents very differently across patients;
- Excessive sleeping is a common symptom;
- Some patients remain physically active while cognitively impaired;
- Watch the Powerpoint presentation for more information:
<https://www.lewybuddiesuk.org/lewy-bodies-guide.html>

Maintaining social connections – using day centres

A Buddy shared his experience with day centre care.

- It's important for Buddies to have time away from caring;
- There may be an initial feeling of guilt, but carers must look after themselves as well;
- If there's no suitable centre locally, there may be friends, family or local volunteer visitors who will come to your home for a couple of hours.

Support group access and challenges

- Geographic location significantly affects service access;
- Transportation and timing barriers may prevent use of available services;
- Peer support groups are valuable for shared experiences.
There may be Lewy Buddies living near you.
Might you ask if your GP surgery or clinic would put the attached notice on their notice boards, or could you share it on local social media groups?

Carer wellbeing and exhaustion

Many Buddies mentioned the physical and mental toll of caring.

- Carer exhaustion is widespread and significant;
- Expressing emotional distress can sometimes accelerate service response;
- Balancing work and caring responsibilities is extremely challenging, perhaps even greater for professional carers who have family members with an LBD diagnosis.