

LBUK - Online Support Meeting 20260209

Attendance

Esther, Linda and 12 carers – 3 men and 9 women

Meeting summary

Key takeaways

- The Top Hat Phase2 drug trial - to see if Ondansetron is effective in reducing LBD and PDD hallucinations - is still accepting participants until July: Email o.zubka@ucl.ac.uk
- CHC funding experiences were shared, highlighting the "postcode lottery" nature of approvals across different regions and the importance of detailed record-keeping of symptoms and care required.
- Parkinson's symptoms in Lewy body patients can be reduced/managed through medication though medication adjustments may require balancing mobility against cognitive side effects
- Medication refusal due to paranoia/delusions is a common challenge, with potential solutions including patch medications appropriately placed where they cannot be easily removed by the patient

Discussed topics

“TOP HAT” Parkinson’s UK and UCL Ondansetron drug trial for hallucinations

Discussion about the UCL drug trial for ondansetron to treat hallucinations in Lewy body patients.

• Points raised

- This is a double-blind random trial which means some participants receive the drug and others a placebo with no-one knowing if they are on the medication or a placebo until the end of the trial. However, one Buddy reported reduced severity of hallucinations while on the medication/placebo.
- Shared that her husband is on the trial, and it seemed to help reduce frightening hallucinations; he came off it and got worse, so he's now back on it
- Explained Ondansetron is licensed for severe vomiting in cancer patients and post-operative vomiting
- Potential side effects will be explained when enrolling for the trial
- The Buddy whose husband is part of this trial reported constipation was a side effect for him. This was managed by medication
- Noted the UCL trial is still accepting participants until July - email: o.zubko@ucl.ac.uk
- The Buddy's husband who has restarted the trial was not aware if her husband had been on the placebo or not.

CHC (Continuing Healthcare) funding

Buddies shared their experiences with applying for and receiving CHC funding.

• Points raised

- A Buddy's mother received full funding after being in a care home for 12 months; their assessment involved 11 categories where patients need to be ranked "severe" in 2-3 areas that her mother's mobility issues combined with Lewy body symptoms likely secured the funding
- One Buddy currently in the process of applying, completed checklist with GP and was told family members can't apply directly. However Linda looked at <http://www.nhs.uk> From there you can access a document called Continuing Care, Social Care, and support guidelines which says family members can apply. Age Concern also provide information for understanding and eligibility for CHC
- A Buddy reported waiting 3 months for social services to allocate a social worker
- One Buddy received 8-weeks CHC funding after husband's hospital stay, but feels pressure to show limited improvement to maintain funding - if patient shows limited improvement surely that could **end** funding as it can be taken away
- One Buddy was going through an appeal process; involved local MP to move things forward after delays
- Highlighted issues with unqualified assessors and emphasised that "well-managed needs" are still needs that qualify for funding
- Asked if CHC applies to home care (not just care homes)
- Confirmed the funding can apply to both care homes and home care situations

Parkinson's symptoms in Lewy body patients

Discussion about managing Parkinson's symptoms that occur alongside Lewy body dementia.

• Points raised

- One Buddy was concerned that her husband has significant Parkinson's symptoms including shaking when anxious
- She shared that her husband was put on a drug at diagnosis which helped with shaking
- One husband shared that his wife's severe Parkinson's symptoms including freezing when crossing thresholds
- One Buddy explained how her husband experienced all-over shaking/fitting that could last for hours; hand massage and favourite music helped calm him
- Mentioned a Parkinson's bracelet (Beech Band) that can help some people <https://www.parkinsons.org.uk/news/2024/were-investing-beech-band-wearable-device-aims-to-manage-parkinsons-symptoms>
- One Buddy found that reducing her husband's Parkinson's medication reduced paranoia but worsened mobility
- There's always a risk that medication to help with cognitive deterioration will affect movement and vice versa – always monitor the effect of new medications and report problems at once
- Positive experiences were described with Parkinson's support groups and their exercise sessions.

Medication refusal and administration challenges

Discussion strategies for people with a diagnosis who refuse medication due to paranoia or delusions.

• Points raised

- One Buddy has found her mother is refusing medication, believing she's being poisoned; asked about antidepressants in patch form
- Another Buddy's mother had similar issues; mentioned patches and creative approaches to hiding medication
- This particular mother can taste medications even when hidden in food
- Confirmed there are antidepressant patches available; suggested placing patches in a hard-to-reach place to reduce chance of removal
- Recommended a medication review to reduce the number of medications
- Suggested reviewing all medications as one Buddy's husband's paranoia was caused by Parkinson's medication

For professional advice about medications contact the LBD specialist Admiral Nurses: Rachel Thompson and Rachel Korosi: Phone: 0800 888 6678, or email helpline@dementiauk.org

Hearing aid challenges

Discussion about managing hearing aids for people with LBD.

• Points raised

- One Buddy's husband has broken multiple hearing aids due to difficulty handling them with Parkinson's symptoms
- Shared similar experiences and suggested requesting an audiology referral through GP
- Mentioned headband-style hearing aids might be more suitable
- Noted challenges with hearing tests for people with dementia

Lewy Buddies organisation updates

Updates about the Lewy Buddies UK charity and resources.

• Points raised

- Mentioned the Facebook group has about 1,400 members compared to 170 in the directory <https://www.facebook.com/groups/lewybuddiesuk>
- Announced an unsolicited £10,000 donation to the charity. Plans are under discussion by the Trustees for using these funds for improving software for the Buddy Directory
- Recommended "Robin's Wish" on Amazon Prime about Robin Williams and his experience with Lewy body dementia: <https://tinyurl.com/2cfdsme6>
- Shared information about Carefree Space charity that offers discounted hotel breaks for carers: <https://carefreespace.org/>