

Community of practice

for Lewy body dementia

Tuesday 14th November 2023

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Welcome & housekeeping

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Outline of webinar

1. Welcome to the Community of practice today - Angela Penny
2. Hallucinations and delusions in LBD – Rachel Thompson
3. Introduction to case study
4. Break out rooms / discussion
5. Psychosocial management of hallucinations and delusions in LBD
- Rachael Webb
6. Pharmacological management of hallucinations and delusions in LBD and research - Alison Killen
7. Questions – Angela Penny
8. Next steps / plans for next session

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Introduction to Lewy body dementia

Hallucinations and delusions

Rachel Thompson
Consultant Admiral Nurse Lewy
body dementia



Lewy body dementia (LBD)

'The most common disease you have never heard of'

- Second most common cause of neurodegenerative dementia – 10-15% ^{1 & 2}
- Approximately **125,000** people with Lewy body dementia in UK
- Lewy body dementia (LBD) includes both:
 - **Dementia with Lewy bodies (DLB)** – 4-7.5% ¹
 - and
 - **Parkinson's disease dementia (PDD)** – 3.6- 9.7% ³
- Dementia in Parkinson's disease (PD)=30% overall ³
 - 50% who live with PD>10 years ¹
 - 80% who live with PD>20 years ¹

1 Vann-Jones & O'Brien, 2014; 2 Kane et al, 2018; 3 Aarsland et al, 2008

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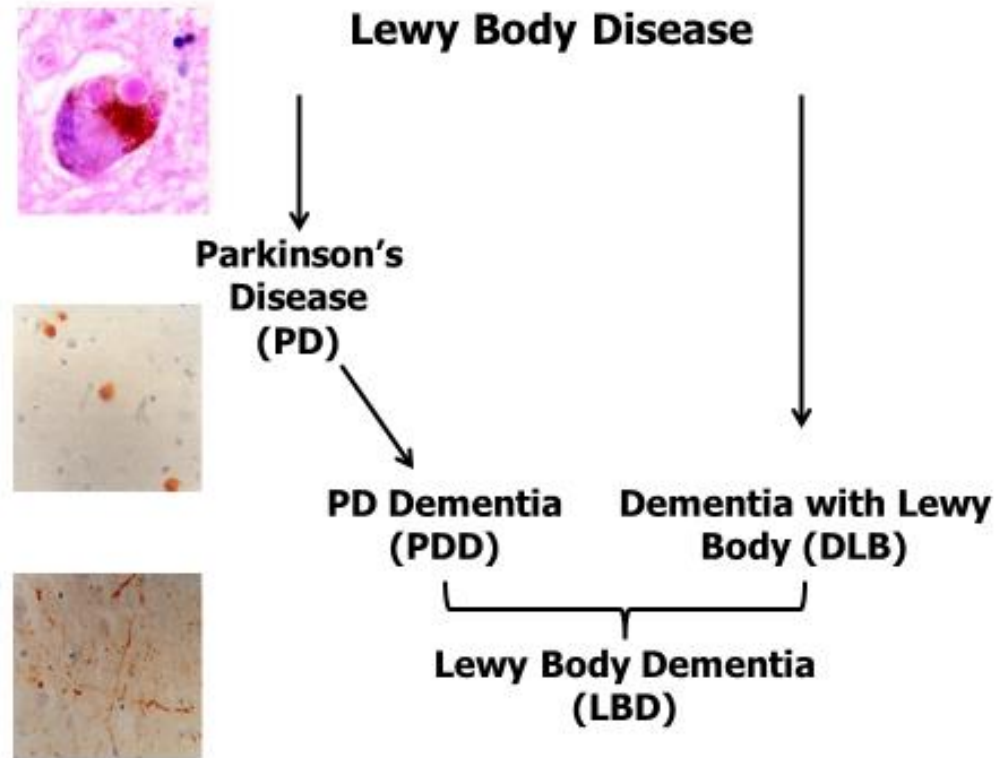


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Lewy body disease

Lewy body disease =

Parkinson's disease (PD), Parkinson's disease dementia (PDD) and Dementia with Lewy bodies (DLB)



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Lewy body dementia – the ‘one year rule’ ¹

Parkinson’s disease dementia (PDD):

dementia starting 1 year or more **after** well established Parkinson’s disease

Dementia with Lewy bodies (DLB):

dementia that occurs before or at the same time as parkinsonism or within 1 year of onset of motor symptoms

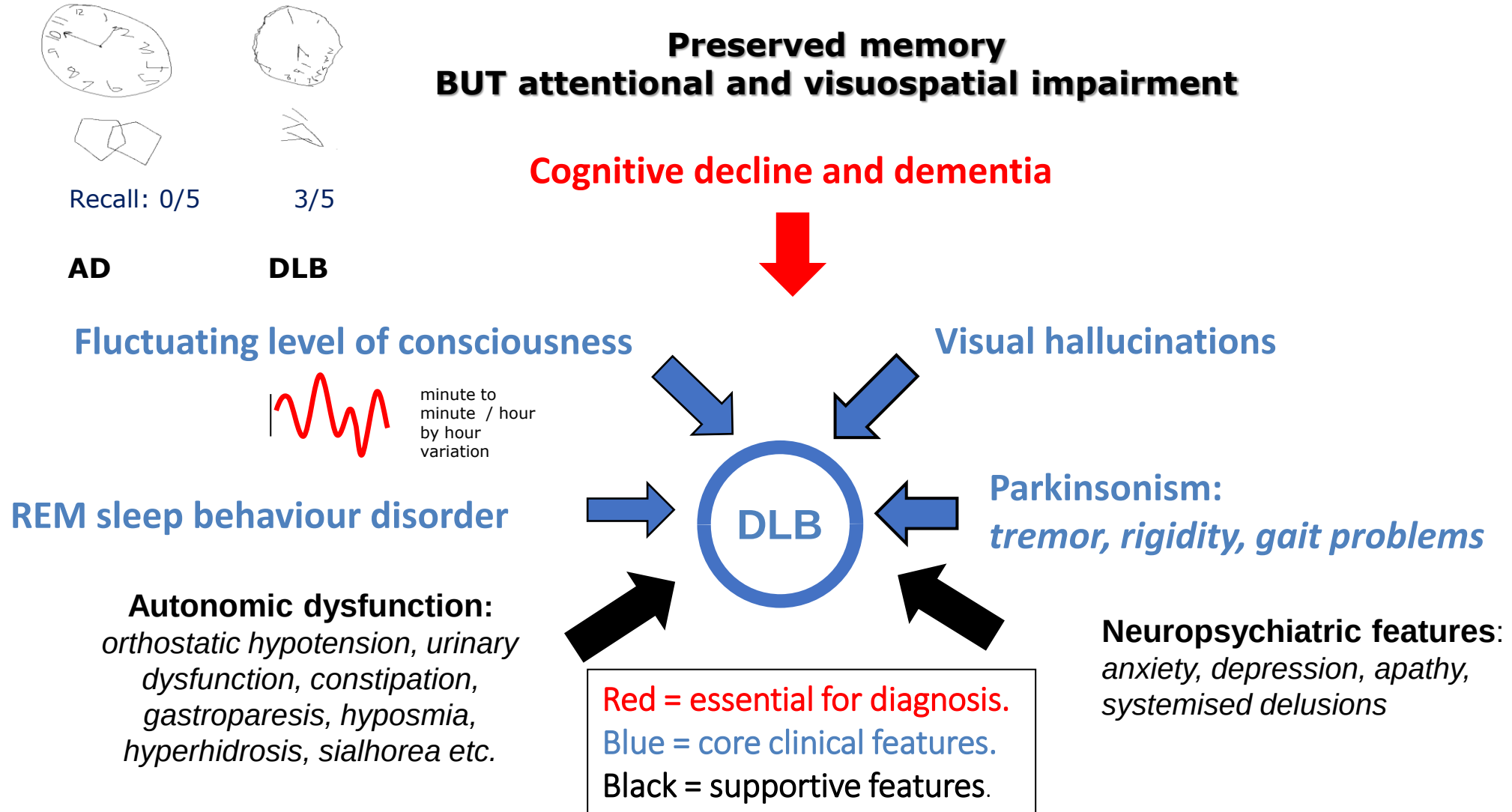
1. McKeith et al, 2005

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Revised criteria for Dementia with Lewy bodies (DLB)



Visual – perceptual changes

Vision is an active
process informed by
previous experiences

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Illusions and pareidolia

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Visual hallucinations in Lewy body dementia

Brain 'wiring' becomes faulty but no single brain region responsible

Changes in the brain can lead to misinterpretation of visual information

- dopaminergic, acetylcholine and serotonergic systems affected

Both sensory input and interpretation of information are affected

- White matter changes may be found particularly at the back of the brain
- Thalamus (mid brain) can lose volume

Minor hallucinations

Hallucinations may occur in other modalities e.g. auditory, olfactory

Passage hallucinations-

occur at the side of vision

Presence hallucinations –

feels like someone is nearby



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John Doyle, Self portrait 1832-93

Complex visual hallucinations

Approx **70-80%** of people with LBD will experience visual hallucinations

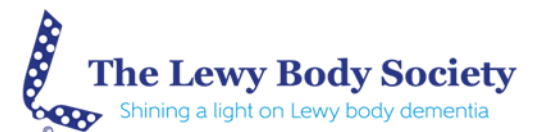
Usually complex , well formed and recurring

More common in the evening / at night

Often animals, people, children – colourful & 3- dimensional

May or may not be upsetting / distressing

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Another presence

<https://anotherpresencefilm.com/>

- a film about dementia, hallucinations and altered perceptions

Delusions in Lewy body dementia

Delusion = false belief not based on reality

- may be fixed but in LBD can change or fluctuate

Different types

- Accusations of theft – more common in Alzheimer's disease and may be linked to memory problems
- Delusions of infidelity 'Othello syndrome'
- Delusions of misidentification –
 - 'Capgras' – (includes 'Fregoli' syndrome - being followed)
 - Clonal pluralisation – multiple copies of objects, places, people

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Capgras syndrome

Capgras = 'delusion of misidentification'

May be linked to hallucinations/ misperceptions

Can be several versions of the person - may be 'good' or 'bad'



The infographic features a woman with a distressed expression in the center. Surrounding her are four thought bubbles containing delusional beliefs: 'HE IS NOT MY HUSBAND', 'SOMEONE ELSE IS ACTING AS MY HUSBAND', 'HE HAS BEEN REPLACED BY AN IMPOSTER', and 'A STRANGER IS LIVING IN MY HOUSE'. Below the woman, a red banner contains the text 'WHAT IS CAPGRAS SYNDROME?'. At the bottom, a definition is provided: 'Recurrent and transient belief that a familiar person, often a close family member or caregiver, has been replaced by an identical looking imposter'.

WHAT IS CAPGRAS SYNDROME?

Recurrent and transient belief that a familiar person, often a close family member or caregiver, has been replaced by an identical looking imposter

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Case Study

- Husband (68) Craig - recent diagnosis with Parkinson's dementia/ Lewy body dementia (Parkinson's for 9 years managed well with medication)
- Wife (66) Sally - primary caregiver - arthritis & poor mobility
- 3 adult children – 1 daughter lives nearby –worried about changes

Craig

- experiencing visual hallucinations- people and animals in the house
- seeing different versions of Sally – asking who she is
- disturbed sleep and hiding things

Sally

- getting cross / frustrated with behaviour – thinks Craig is 'doing things on purpose'
- constantly telling Craig who she is but is upset he may stop recognising her
- struggling due to disturbed sleep and pain with arthritis

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Case study reflection

Consider the following:

As a professional supporting this family:

- What advice might you offer to the person with dementia?
- What advice might you offer to the family caregiver (s) ?
- What other actions might you take?
- What resources are you aware of that may be helpful ?

Type any comments / feedback in the Chat box

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Psychosocial management of hallucinations and delusions in LBD



**Rachael Webb,
Admiral Nurse, Lewy body dementia**

Tips for Managing Hallucinations

Generally it is better not to disagree or challenge what a person is seeing:

- Calmly encourage a person to talk about they experience
 - Is it frightening or distressing ?
- Offer reassurance – acknowledge experience
 - Let them know you can't see the same as them, but that you realize it feels real for them
- Advise to check out reality – can they touch them, talk to them
- Offer distraction, do another activity, use a different 'sense'
- Change lighting
- Move to another room

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Tips for Managing Hallucinations

- Ensure regular eye – checks
- Look at the environment e.g. mirrors, highly patterned carpets & curtains, changes in flooring, objects that can be misinterpreted, increase lighting
- Keep a diary – to identify potential triggers
 - Consider physical causes e.g. delirium, tiredness
- Seek advice about medication
 - Cholinesterase inhibitors/ NMDA receptor antagonist
 - Reduce / review Parkinson's medication
 - Atypical antipsychotics

If the person has insight, try explaining that their condition is making their brain see and interpret things differently

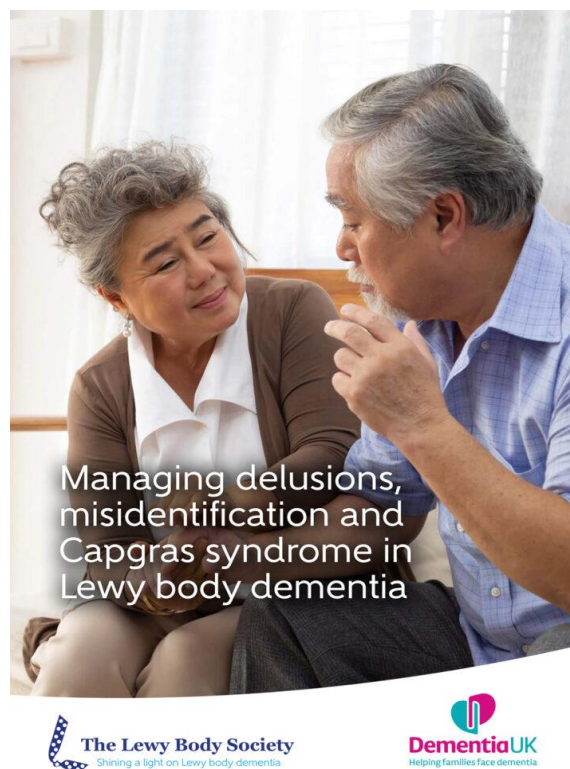
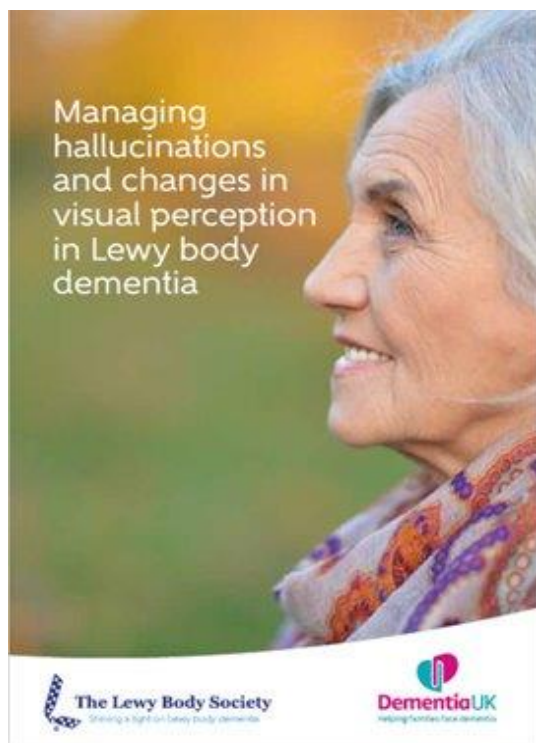
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Tips for managing delusions, misidentification and Capgras

- Encourage familiarity –
 - talk as you enter the room
 - go out and come back in again,
 - talk on the phone
 - Change clothing
- Check how 'fixed' the delusion is
- Try not to challenge or disagree
- Offer reassurance – validate concerns, even if it is upsetting that they do not recognize that person.
- Ensure safety / go into another room if needed
- Seek expert advice & support

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Resources:



Available to download on the Lewy Body Society – Website

www.lewybody.org/information-and-support/information-leaflets/

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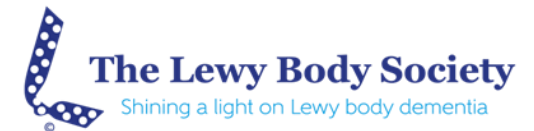


Pharmacological management of hallucinations and delusions in LBD and research

Alison Killen
Health Psychologist & Research Associate
Newcastle University



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Causes of hallucinations and delusions in LBD

- ❖ Condition related
- ❖ Medication side effects
- ❖ Due to delirium

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Acetylcholinesterase inhibitors

Donepezil

- ❖ 5 mg daily at bedtime, increased if tolerated to 10 mg daily

Rivastigmine

- ❖ 1.5 mg twice daily, increased in steps of 1.5 mg twice daily up to a maximum 6 mg twice daily. (or transdermal patch 4.6/9.5/13.3mg)

Galantamine

- ❖ 8 mg daily for 4 weeks, then increased to 16 mg daily for at least 4 weeks; maintenance dose 16–24 mg daily

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Side effects (Donepezil)

Common:

- ❖ Nausea, vomiting, anorexia, diarrhoea, fatigue, insomnia, headache, dizziness, syncope, abnormal dreams, hallucinations, agitation, aggression, muscle cramps, urinary incontinence, rash, and pruritus.
- ❖ Can influence the ability to drive, especially during the first weeks after initiation or dose increases.

Rare:

- ❖ Sinoatrial block, atrioventricular (AV) block
- ❖ Be alert for bradycardia

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Other medications

Memantine

- ❖ Study in progress
- ❖ 5 mg daily, increased in steps of 5 mg at weekly intervals to a maximum of 20 mg daily

Melatonin

- ❖ Helps regulate sleep, minimal side effects, should not increase daytime sleepiness
- ❖ Starting dose 2mg an hour before bed

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Antipsychotics

Delusions - a false belief held with strong conviction despite evidence to the contrary

Traditional antipsychotics (e.g. haloperidol)

- ❖ Avoid
- ❖ Leads to worsening parkinsonism, sedation, immobility in a high percentage of DLB patients
- ❖ Risk of neuroleptic malignant syndrome (NMS) a rare, life-threatening medical emergency characterized by fever, generalized rigidity, and breakdown of muscle tissue that can cause renal failure and death.

Atypical antipsychotics

- ❖ Safer but used with extreme caution in DLB, avoid olanzapine and risperidone
- ❖ Patients with PDD have a lower risk of an adverse reaction to these antipsychotics
- ❖ Quetiapine is a safer atypical antipsychotic in PDD and DLB
- ❖ Low, slow approach, typically 6.25 mg to 50 mg a day
- ❖ Clozapine also effective but needs frequent blood monitoring (risk of agranulocytosis)

Delirium related hallucinations

Check for any underlying physical causes which may be causing a delirium if there is a sudden change in behaviour, and hallucinations start or increase.

- ❖ Infection
- ❖ Constipation
- ❖ Dehydration

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Medication review

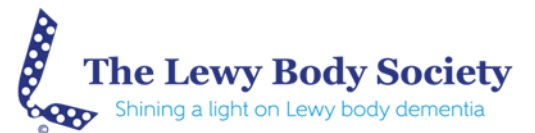
Medications with significant anticholinergic effects should be reviewed and if possible, stopped

Examples:

- ❖ Amantadine,
- ❖ Certain antidepressants e.g. Paroxetine
- ❖ Some antihistamines e.g. Chlorpheniramine
- ❖ Oxybutynin, solifenacin, tolterodine

Also review Levodopa - causes hypersensitisation of dopaminergic neurones in the Nigro-striatum.

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Current research

CAN-PDP: Cannabidiol (CBD)

- Is CBD an effective treatment for hallucinations and delusions in Parkinson's?
- recruiting until March 25

TOP HAT:

- Trial of ondansetron as a Hallucination Treatment for Lewy Body Dementia
recruiting until Jan 24

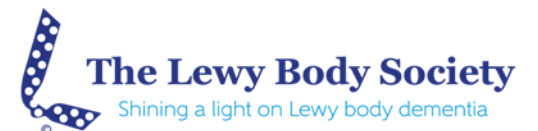
UCL imaging study

- Brain networks involved in hallucinations

University of Oxford

- Why some people with Parkinson's develop hallucinations
recruiting until Jan 24

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Finding research studies in LBD

Parkinson's UK

[Homepage | Parkinson's UK \(parkinsons.org.uk\)](https://parkinsons.org.uk)

Join Dementia Research

[Join dementia research - register your interest in dementia research : Home \(nihr.ac.uk\)](https://www.nihr.ac.uk)

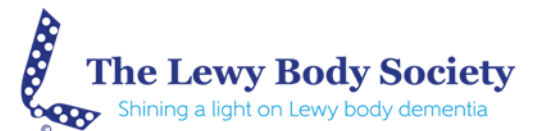
Lewy Body Society

[Home - Lewy Body](https://www.lewybody.org)

Fox Trial Finder

[Fox Trial Finder | Parkinson's Disease \(michaeljfox.org\)](https://www.michaeljfox.org)

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Next steps

- Meeting 3 in 2024 – date to be arranged – check the Lewy Body Society website
- You can find the community of practice page on the professionals' tab on the Lewy Body Society website
- www.lewybody.org
- Thank you for watching!

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