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Dementia with Lewy bodies

The more who know, the fewer who suffer



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How common is DLB

- Second most common type of degenerative dementia after Alzheimer disease (AD)
- 1 in 6 cases of dementia (around 15 per cent)
- Estimated 130,000 people in UK



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Distinctive clinical features

- Progressive dementia: loss of attention and executive function
- Visual hallucinations
- Parkinsonism
- Cognitive fluctuations
- Problems with regulating internal organs
- Sleep disorders
- Sensitivity to antipsychotic drugs



Memory

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- May be largely intact in the early stages
- Later problems more *retrieving* than storing memories





Early Symptoms

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- Driving difficulty: getting lost, misjudging distances, or failing to see stop signs or other cars
- Impaired job performance



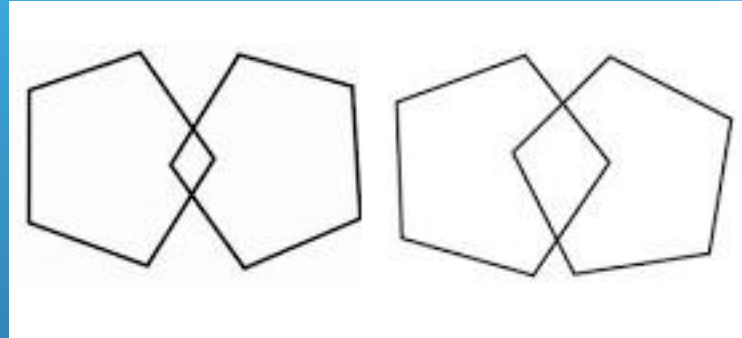


Diagnosis

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Visuospatial impairments point to DLB:

- Overlapping pentagons
- Clock drawing
- Serial sevens
- Spelling WORLD backward



AD patients show losses in short-term memory and orientation as the earliest problems in MMSE (the Mini Mental State Examination)



Fluctuations

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- Fluctuations in cognition and levels of alertness:
 - Last from seconds to days
 - Can be interspersed with periods of near-normal function
- May occur early in the course of DLB
- Feature in **60 to 80 percent of cases**
- Severity, duration, and type of symptoms varies, even for same person. May be:
 - **Subtle:** brief decline in ability to perform an activity of daily living
 - **Dramatic:** like a stroke or seizure:
 - “Blanking out” or losing consciousness
 - Confusion, disorganised speech or bizarre behaviour
 - Speech or movement halted
 - Excessive sleepiness



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Visual Hallucinations

- Affect **two out of three people** with DLB
- Range from:
 - Well-formed images of people (often children) or animals to more abstract visions such as shapes or colours
 - **Enjoyable to frightening** - often disconcerting for carers
 - Glimpse something ‘out of the corner of the eye’ to extremely complex hallucinations (e.g. ongoing dialogue with a deceased loved one)
- Person may or may not have insight that they are hallucinating.

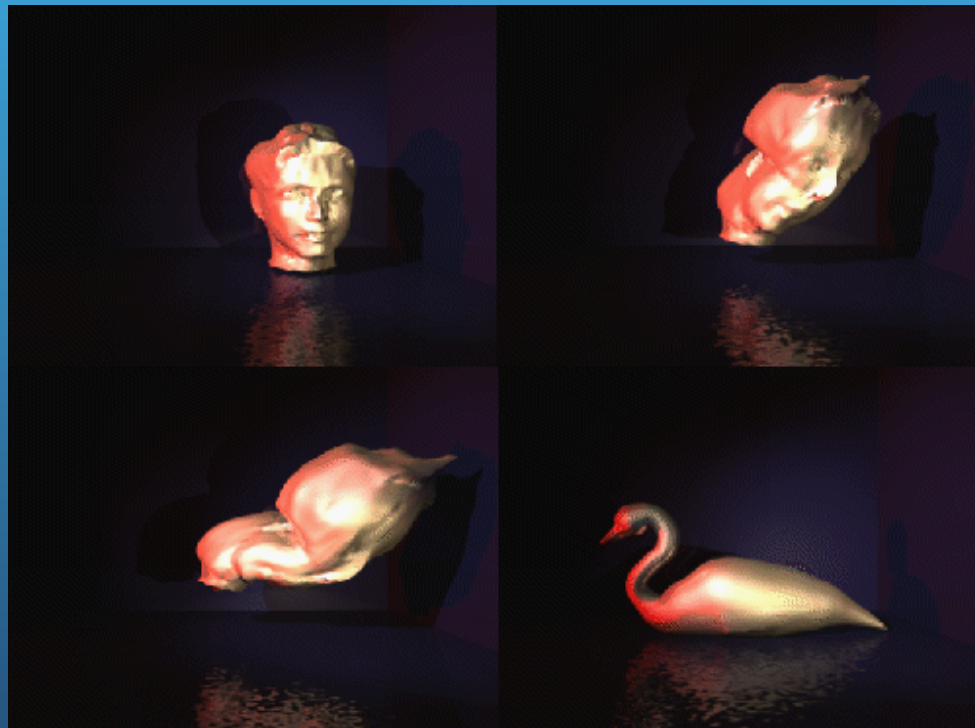




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Visual Misinterpretation

Object seems to move, zoom toward or away from the person with DLB, or change shape.





Parkinsonism

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- Seen in **seven out of ten** people with DLB:
 - Slow movement and lack of movement
 - Rigid limbs and/or
 - Problems with gait
- Can be as severe as in idiopathic Parkinson disease (PD), but usually milder
- Tremor may also occur, but is much less common and less severe than in PD



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REM Sleep Behaviour Disorder

- Vivid dreams in REM sleep without usual muscle relaxation
- Affects **85 per cent of people** with DLB
- People "act out" their dreams, especially when they are vivid or frightening:
 - Fleeing from or fighting an attacker
- Can injure person with DLB or their partner
- Nonviolent behaviours:
commonly include making speeches, eating, sexual behaviours, urinating, defecating or clapping
- Person with DLB may not remember the episode
- Clonazepam or melatonin usually help



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Sensitivity to Antipsychotic Drugs

- Approximately **30 to 50 per cent of people** with DLB have severe sensitivity to neuroleptics, causing:
 - Severe, sometimes irreversible parkinsonism
 - Impaired consciousness
 - Start or worsening of confusion or autonomic system problems
 - **Twice or threefold** increased risk of death
- Can affect people without parkinsonism
- Reaction is more common with conventional medications, but also occurs with newer drugs
- Not related to dose
- Severe reactions to neuroleptics are less common in patients with Parkinson disease (with or without dementia) and are not seen in AD
- **History of tolerating antipsychotic drugs does not exclude DLB** or the possibility of future neuroleptic sensitivity



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Falls and Faints 1/2

- Repeated falls:
 - Affect **up to a third of patients** with DLB
 - May be very early symptom
 - May occur with or without trigger
 - May be related to:
 - parkinsonism,
 - cognitive fluctuations, or to
 - ‘blood rushes’ or ‘dizzy spells’ (orthostatic hypotension) seen **in 3-5 out of 10 people with DLB**
- Syncope or transient loss of consciousness:
 - Episodes of altered or loss of consciousness are common:
 - Passing loss of consciousness, or
 - Being awake but mute and staring blankly.
 - May even resemble ‘cataplexy’ in which people suddenly lose muscle tension and fall to the floor.



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Falls and Faints 2/2

- May also be due to an extreme cognitive fluctuation or like the motor "freezing" seen in idiopathic PD;
- Can be very severe and look like multiple systems atrophy.
- Need to rule out other causes such as seizures, stroke, transient ischemic attack, or cardiac arrhythmia



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Autonomic Dysfunction

- Autonomic symptoms are more widespread and severe than in PD and may include:
 - Urinary incontinence (often an early sign in DLB)
 - Urinary retention
 - Constipation and other gastrointestinal symptoms
 - Impotence
 - Problems with swallowing
 - Variable heart rate
 - Delusions
 - Depression
 - Other hallucinations (hearing, smelling or feeling things)





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Campaigning

Awareness-raising

Experts by
experience

Peer support

Professional
development

Service development
(in partnership)



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Thank you for your interest

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