

Community of practice

for Lewy body dementia

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Sleep disturbances in Lewy body dementia

Wednesday 3rd July 2024

Outline of webinar

1. Welcome to the Community of Practice and housekeeping - Angela Penny
2. Introduction to Lewy body dementia (LBD)- Angela Penny
3. Understanding sleep disturbances in LBD – Rachel Thompson
4. Case study - Clare Johnson
5. Practical strategies for managing sleep disturbance – Clare Johnson
7. Questions – all
8. Next steps / feedback questionnaire/plans for next session -
Angela Penny

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

'Lewy bodies'

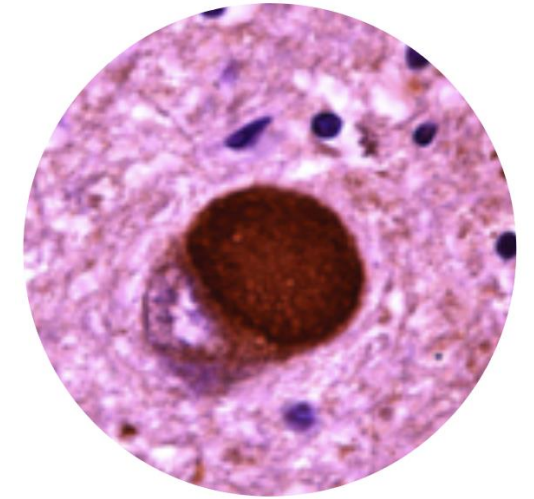
Abnormal protein deposits that disrupt the brain's normal functioning

Discovered by Dr. Friederich Lewy
German neurologist in 1912 in a Parkinson's patient

Made up mostly of a protein called **alpha-synuclein** (also Tau, Synphilin-1, LRRK2)

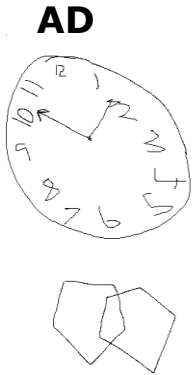
Alpha-synuclein forms into clumps inside neurons, leading to:

- Change in function or death of neurons and
- Loss of production of neurotransmitters: **acetylcholine** and **dopamine**



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Recall: 0/5



3/5

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Cognitive decline and dementia



**Cognitive
Fluctuations**

minute to minute /
hour by hour variation

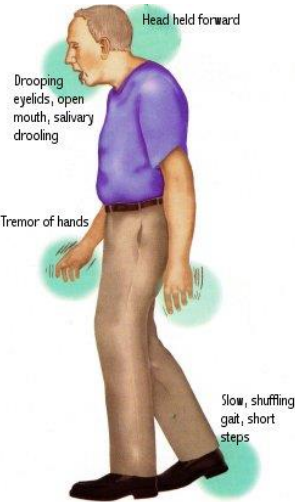


**REM Sleep
behaviour
disorder
(RBD)**

**Visual
Hallucinations**



Parkinsonism



Features of Lewy body dementia

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Domain	Features	
Cognitive	Cognitive fluctuations	Verbal and psychomotor initiation
	Visuospatial and perception	Visual tracking and attention
Behavioural	Visual hallucinations	Anxiety
	Delusions (e.g. Capgras or misidentification)	REM sleep disorder
	Depression	Apathy
Movement/Motor	Bradykinesia (slow movement)	Festinating gait
	Rigidity -stiffness	Freezing
	Tremor	Postural instability with falls
Autonomic	Orthostatic hypotension	Urinary incontinence
	Loss of smell	Sexual dysfunction
	Constipation	Sialorrhea

Adapted from Galvin, 2019 <https://practicalneurology.com/articles/2019-june/lewy-body-dementia-1/pdf>

Understanding sleep disturbance in Lewy body dementia

Rachel Thompson

What's so good about sleep?

Sleep is important for everyone.

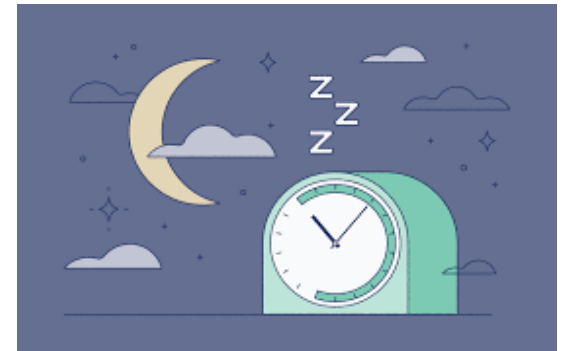
It plays a vital role in managing good health and well being;

- tissue, immune system, brain repair

Dementia can make sleep challenging, for both the person with dementia **and** those who care for them.

Sleep disturbance affects approx.:

- 40% of people with Alzheimer's disease
- 90% of people with Lewy body dementia



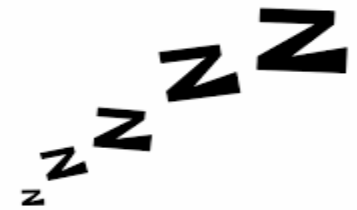
A good night's sleep?

Regulated by 24-hour circadian rhythms – internal body clock

Chemical substance (adenosine) builds up in brain to create 'sleep pressure'

External influences = sunlight and temperature

Recommended approx. 8 hours sleep per night (variations)



Melatonin natural hormone released when it gets dark

- tells the body to prepare for sleep.
- once asleep melatonin slowly decreases in concentration and production
- usually stops once the body notices it is light.

4 or 5 approx. **90-minute** cycles

Each cycle has 4 stages:

- Stages 1 - 3 = non-Rapid Eye Movement (REM) Sleep
- Stage 4 = REM Sleep

Stages	What happens?
Stage 1 (3-5% of sleep)	Falling asleep - a very short light stage of sleep. You can be easily woken and may experience muscle twitching or jerks
Stage 2 (45-50%)	A light sleep as your body is preparing for the deep sleep that is about to come. Your heart rate decreases, body temperature drops, and brain activities slows.
Stage 3 (20-25%)	A deeper stage of sleep when it is more difficult to wake. You may feel disorientated if woken from this stage of sleep. This is the most restorative sleep of all the sleep stages .
Stage 4 (20-25%)	Known as rapid eye movement (REM) sleep. During this stage of sleep our brain activity increases and is when we are mostly likely to dream.

Changes with age?

Change in quality and duration of sleep may be due to:

- more frequent waking
- emptying the bladder more often
- loss/ reduction in non-REM Stage 3 sleep (sleep is less refreshing)
- increase in daytime napping
- reduced drop in body temperature during sleep
- change in circadian rhythms and sleep pressure leading to earlier bedtimes and earlier wake-up times
- lifestyle changes – spending less time outside and reduced activity
- physical health problems e.g. pain, restless legs, incontinence
- less Melatonin secretion

Dementia and sleep



Physical changes to brain:

- 'supra-chiasmatic nucleus' can be damaged - helps regulate sleep by responding to light (located in the hypothalamus)
- internal body clock is affected – wrong signals
- can lead to excessive sleep during the day and sleeping much less at night
- difficulty with recognising time

Sundowning - often caused by tiredness and changes in light

- can lead to confusion, restlessness, agitation and distress.

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Shining a light on Lewy body dementia

Sleep disturbance in Lewy body dementia (LBD)

Approx **90%** of people with LBD experience some type of sleep disturbance

- reduced levels of acetylcholine and dopamine in the brain can disrupt sleep-wake cycle
- can occur years before other symptoms

Lewy bodies in brain can cause:

- REM sleep behaviour disorder – ‘dream enactment’ - arms or legs move or thrash around in bed while asleep
- excessive daytime sleepiness / difficulty staying alert during the day
- Parkinson’s related symptoms:
 - restless legs syndrome, sleep apnoea , stiffness and rigidity, nocturia
- apathy or lack of motivation & reduced activity levels
- not being fully alert when waking from sleep
- nightmares
- hallucinations
- insomnia

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Symptom	Estimated prevalence	Reference
Excessive daytime sleepiness (subjective)	DLB: 11%–100% PDD: 83%	24,80
Insomnia	DLB: 26%–75% PDD: 72%	24,28,80
Nightmares	DLB: 83% PDD: 78%	80
REM behaviour disorder (subjective)	DLB: 13%–76% PDD: 17%	24,30,31,80
REM behaviour disorder (objective)	DLB: 89%	44
Objective sleep alterations:		
• Low sleep efficiency (sleep quality)	• DLB: 54%–70%	35,36,47
• Abnormal nocturnal behaviours	• DLB: 77%	
• Sleep-wake architecture abnormalities	• DLB: 75%	

Abbreviations: DLB, dementia with Lewy bodies; LBD, Lewy body dementia; PDD, Parkinson's disease dementia; REM, rapid eye movement sleep.

Elder et al (2022) Sleep disturbances in Lewy body dementia – a systematic review. *In J Geriatr Psychiatry*
Wiley Open Access

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REM Sleep Behaviour Disorder (RBD)

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Rapid eye movement sleep behaviour disorder (RBD) – prevalent in approx. 80% - 90% of people with DLB ? less prevalent in PDD

Measured by polysomnography or by care partner reports (subjective)

May occur years before onset of other symptoms

Reports of being woken by movement/ being hit / punched/ injury to self, person may not wake up and/or recall

Multiple causes –

- Acetylcholine and dopamine deficiencies - affect sleep wake cycle
- Thalamic dysfunction (linked to cognitive fluctuations) may play a role
- Changes in circadian rhythms

DIAMOND Lewy Assessment Toolkit

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REM Sleep Disorder

(to carer = bed partner)

Have you ever seen the patient appear to “act out his/her dreams” while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No

If answered affirmatively, then RBD is highly likely to be present.

REM Sleep Disorder

(to patient only if no bed partner and they have sufficient cognitive ability to be confident their answer is reliable)

Have you ever been told that you seem to “act out your dreams” while sleeping (punched or flailed arms in the air, shouted or screamed)?

Yes

No



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Sleep strategies for Lewy body dementia

Clare Johnson

Case Study

Mrs A is a 72-year-old lady diagnosed with LBD two years ago.

Lives with her husband in a house.

She is independently mobile at home, but does experience some freezing of gait, particularly in small spaces.

Mrs A can become agitated at times during the day and experiences hallucinations particularly early evening.

There is broken sleep overnight and some REM behaviours disturbing Mrs A but also Mr A.

She regularly nods off watching TV during the day.

Case Study - Reflections

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, own experience, and tips in the Chat box

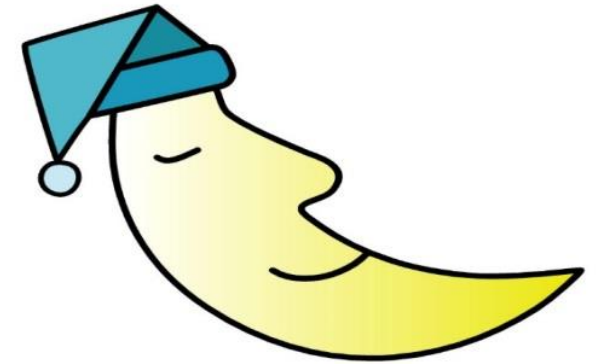
Fatigue

- Due to reduced attention and concentration
- From automatic to 'manual'
- All activities take more effort
- Tremor increases fatigue
- Increased anxiety
- Sleep disorders: Parkinsonism disrupts natural sleep pattern
- Increases the prevalence of agitation and hallucinations.
- Can exacerbate low mood.



Routine Management

- Break day into periods of activity and rest
- Identify lots of different activities, both Physical and Mental
- Make sure your patient enjoys the activities
- Vary Activity
- Advise structured sleep in the day if needed / possible
- Use timetable
- Music is a good media for managing sleep and agitation.
- Make sure medication regime is correct and regularly reviewed.
- Use Sleep Hygiene techniques



Sleep Management

- Avoidance of stimulants in the evening.
- Establish a regular pattern of sleep.
- Comfortable bedding and temperature.
- Use aides to assist movement and comfort.
- Restriction of daytime siestas.
- Advice regarding exercise to induce sleep.
- Exposure to natural light.



Other treatments/ medication

Limited evidence about efficacy of medication

Review medication that may be disrupting sleep e.g. antidepressants, β blockers

Sedatives e.g. Temazepam, can cause harm - increased risk of falls

Z drugs e.g. Zopiclone, Zolpidem may be used for insomnia if severe, disabling or causing extreme distress (**short term**)

Cholinesterase inhibitors (donepezil, rivastigmine) and glutamate receptor antagonists, (memantine)- may increase wakefulness but some studies show improved sleep quality- **give earlier in the day?**

In LBD some evidence for REM Sleep behaviour disorder

- Melatonin (low side effect)
- Clonazepam (small doses)

CBT I for insomnia –cognitive, behavioural, psychoeducational

DREAM START – strategies for relatives of people with dementia

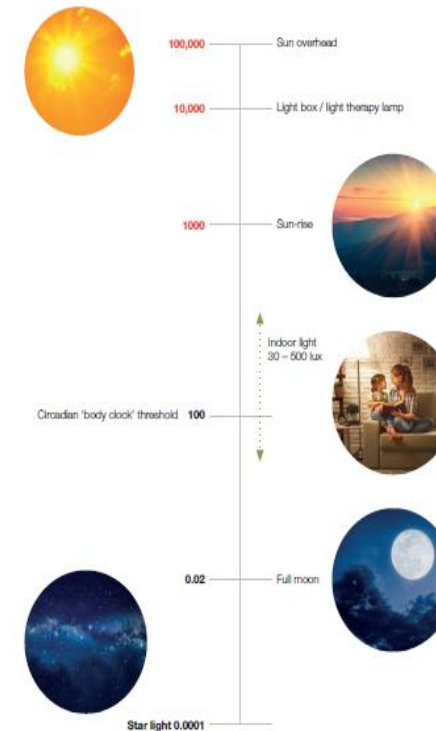
DREAMS : START

Dementia RElAted Manual for Sleep : STRategies for RelaTives

DREAMS SESSIONS

1. Understanding sleep and dementia
2. Light & bed routine plan
3. Daytime activity and routine plan
4. Difficult night-time behaviours
5. Taking care of your own (carer's) sleep
6. What works?

Individually tailored action plan based on specific issues & sleep data



9

Light, dementia and the body clock

You may have noticed that your relative mixes up night and day and is sleepy or wide awake at the wrong times.

One reason for this is that dementia can damage the part of the brain controlling the 'body clock', giving people the wrong signals about night and day.

So people with dementia can be sleepier in the day or awake at night.

As we get older, our ability to see light through our eyes also gets worse, so less light gets to the body clock in the brain. This can be worse in those with dementia.

"Losing track of time... day and night mixed up."

"Yes, I suppose many people with dementia are inside quite a lot. People get very distressed around four or five o'clock especially in the winter."



KEY POINT:

Ensuring people with dementia receive enough light during the day, especially in the morning, is extremely important for their sleep at night.

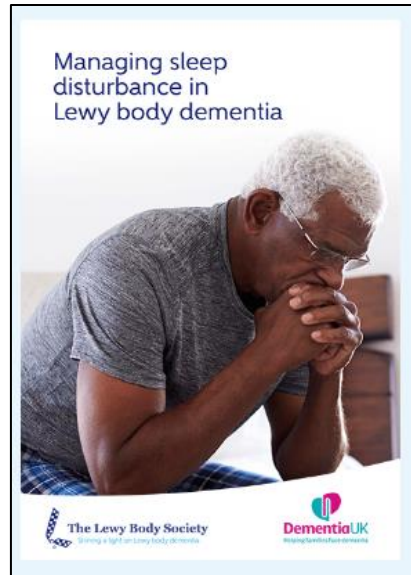


Resources



www.thesleepcharity.org.uk

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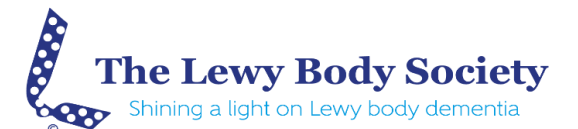
www.lewybody.org



www.livingwithdementiatoolkit.org

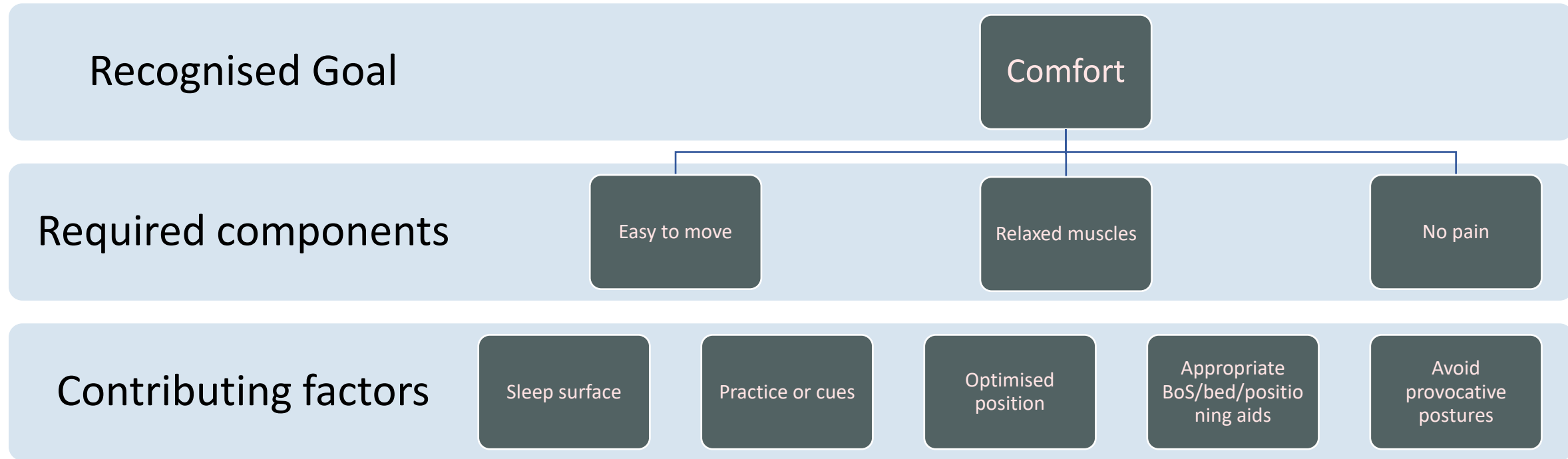


www.dementiauk.org



Are you lying comfortably?

Louise Rogerson - MSCP
Physiotherapist



Thanks for listening

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Next steps

- Complete our short survey on how you found the session today
- Next meeting Wednesday 9th October – Communication in Lewy body dementia
- Lewy body website update and how to join the Community of Practice