

INTRODUCING

THE COMMUNITY OF PRACTICE

WEBINAR:

COMMUNICATION MATTERS IN LEWY BODY DEMENTIA

09.10.2024

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Community of practice

for Lewy body dementia

Communication matters in Lewy body dementia – the role of the MDT

Wednesday 9th October 2024

MEET OUR TEAM



Dr Alison Killen CPsychol (Health)
Research Associate - Newcastle Biomedical
Research Centre



Fiona Lindop MBE
Specialist Physiotherapist - University Hospitals of
Derby & Burton NHS Foundation Trust



Dr Allison Bentley
Research Associate - University of Cambridge



Rachael Webb
Admiral Nurse LBD - Dementia UK



Angela Penny
Speech & Language Therapist - Airedale NHS
Foundation Trust



Rachel Thompson
Admiral Nurse LBD - Dementia UK



Clare Johnson
Specialist OT Parkinsons - University Hospitals of
Derby & Burton NHS Foundation Trust



**Could you complement our team? We are looking
for a Parkinson's Nurse to join the CoP core team.**

COMMUNICATION MATTERS: THE ROLE OF MDT

1. Welcome to the Community of Practice and housekeeping - Alison Killen
2. Introduction to Lewy body dementia (LBD)- Alison Killen
3. Communication difficulties for patients with LBD and SLT management – Anna Volkner and Angela Penny
4. Supporting families and carers to communicate with people living with LBD – Alison Killen
5. Patient and carer perspectives on communicating with health and social care professionals - Allison Bentley
6. Questions – all
7. Next steps /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’

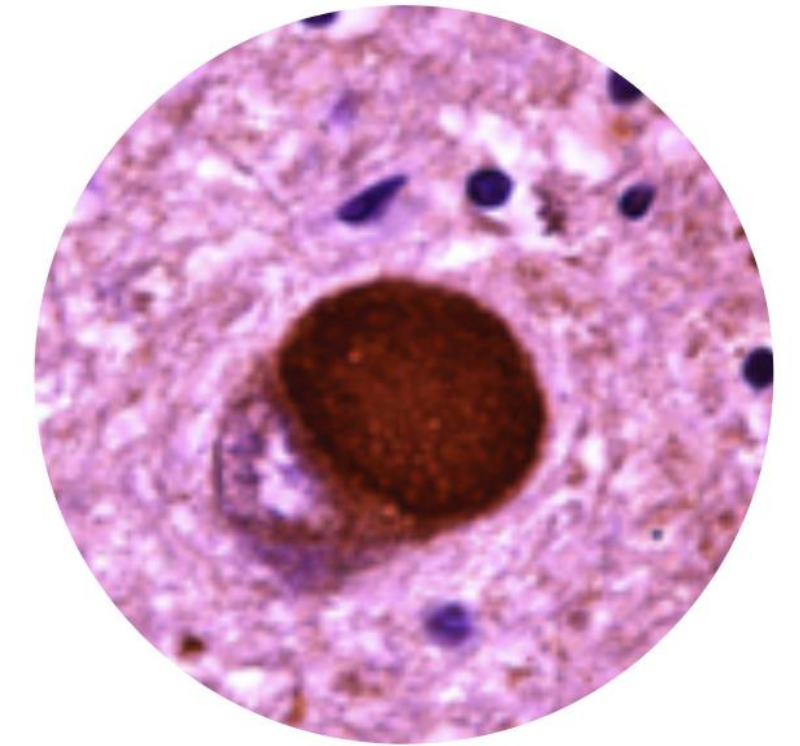
Abnormal protein deposits that disrupt the brain's normal functioning

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

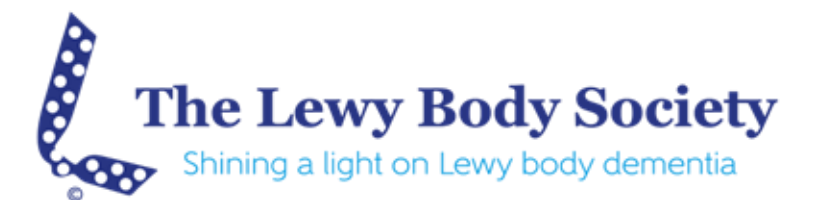
Made up mostly of a protein called **alpha-synuclein** (also Tau, Synphilin-1, LRRK2)

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**



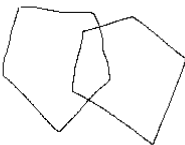
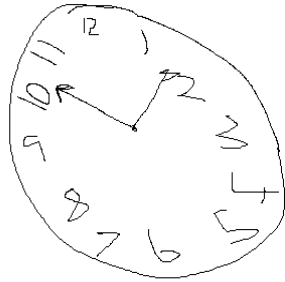
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Lewy body dementia

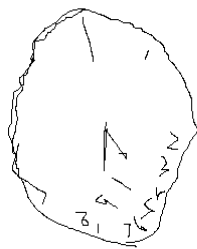


AD



Recall: 0/5

DLB

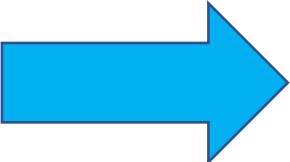


3/5

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Cognitive decline and dementia

Core clinical features



Cognitive
Fluctuations

minute to
minute / hour
by hour variation



REM Sleep
behaviour
disorder
(RBD)

Visual
Hallucinations



Parkinsonism



Features of Lewy body dementia

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>

Role of Speech & Language Therapy in LBD

Angela Penny – SLT

Role of SLT in LBD

- Education about communication & swallowing
- Support for carers/spouses including referral and signposting
- Assessment & management of symptoms:
 - (Swallowing)
 - Dysarthria – eg voice and volume
 - Linguistic & cognitive communication difficulties
 - Conversation participation
 - Impact of other symptoms

Frontal lobe:

Motor speech
Form and express
word sounds.
Also - Attention
Planning
Problem solving
Social skills
Judgement

Parietal lobe:

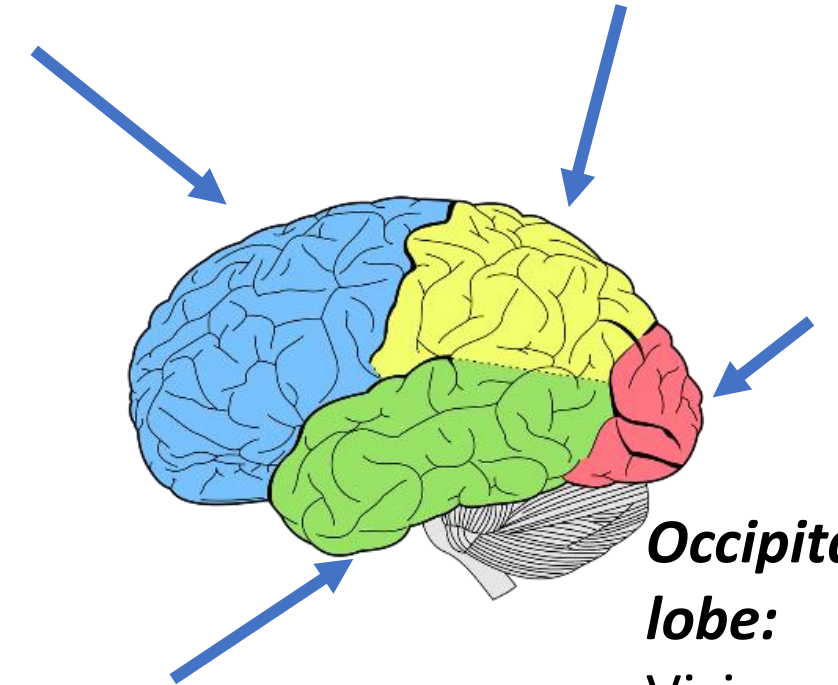
Processing
language

Temporal lobe:

Understanding
language

Occipital lobe:

Vision
Perception



SLT management

- Less focus on rehabilitation and more on compensation and strategies for day to day life
- Communication partner training
- Alternative and augmentative communication (AAC) methods eg communication books
- Life story work
- Support around decision making, advanced planning, mental capacity

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Communicating with someone living with dementia
takes practice and will never be perfect

Dr Anna Volkmer – Senior Research Fellow Language & Cognition
University College London

There are many levels understanding

- Can I hear it?
- Is it a language I know?
- Is it a word I know?
- What does the sentence mean?
- How does this relate to everything else I know?

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There are many levels of speaking

- What do I want to say?
- What are the words?
- How do I put them in order?
- What are the sounds?
- How does my mouth make those sounds?

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Checklist of strategies

- ✓ Put yourself in their shoes
- ✓ Turn off background noise
- ✓ Provide instruction one at a time
 - ✓ Clarify don't correct
- ✓ Ask opinion questions, not testing questions

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Put yourself into the shoes of a person with dementia....

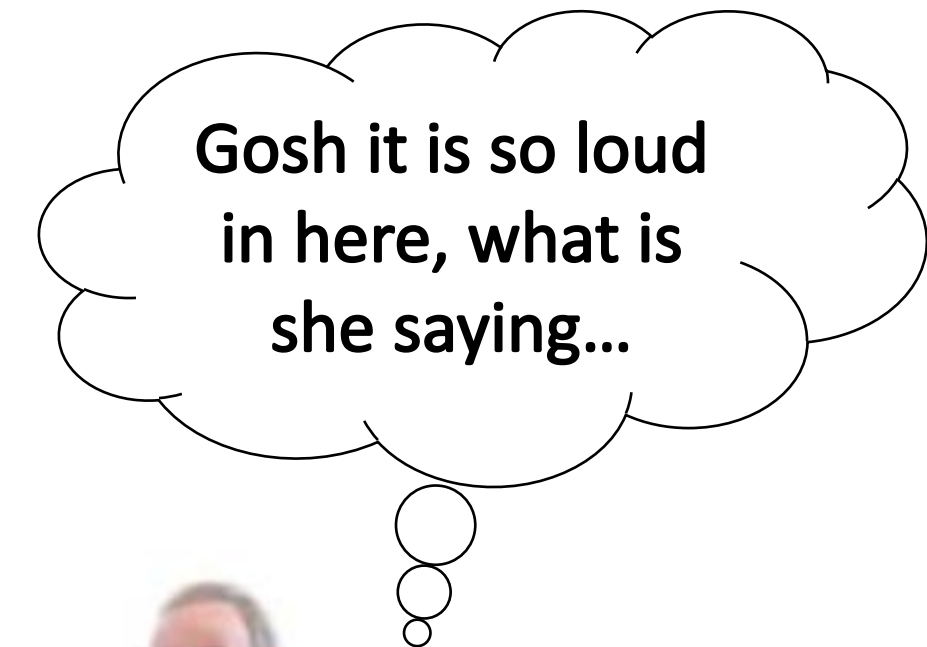
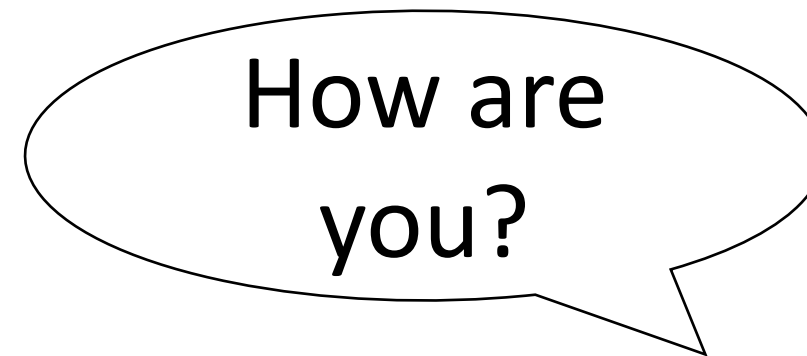
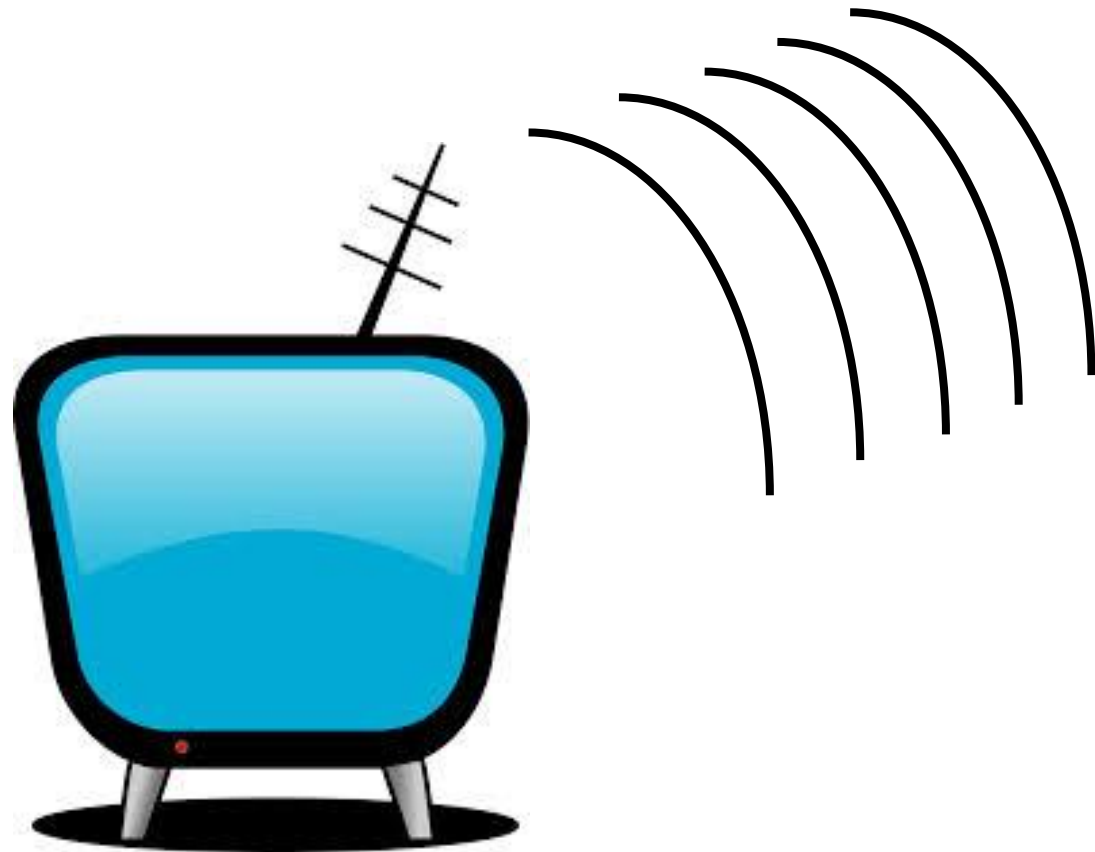
Why won't he talk to me? I have so much to do. Why should I bother.

I want to talk to her.
But, this is so difficult and frustrating. I just can't be bothered.

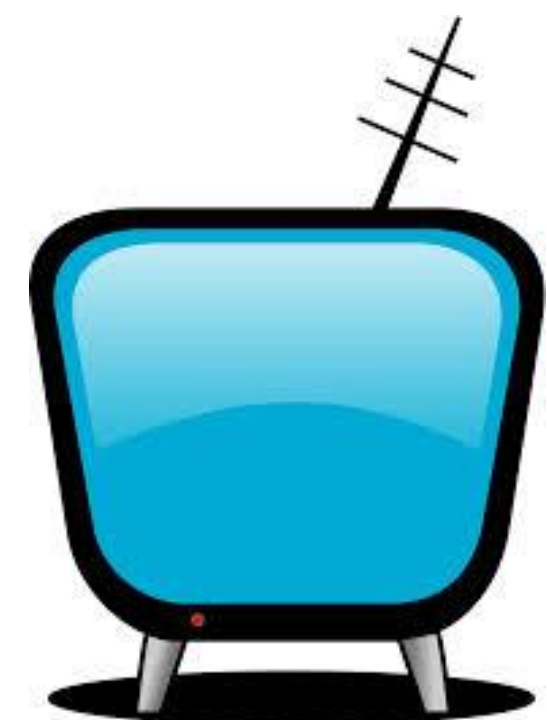


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The environment



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Shall we chat
somewhere
quiet?



Thank
goodness...

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Providing instructions

I need you to go to the post office after you have been and put that chair upstairs, the one with the gold cushion, place it in the corner with the green one and then you can collect that parcel from me in the kitchen to take round the corner and.....

I am
completely
lost...



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Can you get the
chair please?

Yes! Of
course!



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How to clarify something

You don't mean salt,
you said that wrong. I
think you have
forgotten the word.

I feel so
embarrassed.



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Did you want the
sugar?

Yes! That is
exactly what
I meant.



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Asking a question

How many grandchildren have you got? Can you remember their names?

This is a test. And I don't know the answer!



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Which is your favourite
photo of your
grandchildren? What are
they like?

My grandchildren
are so lovely.



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Ask the person what helps

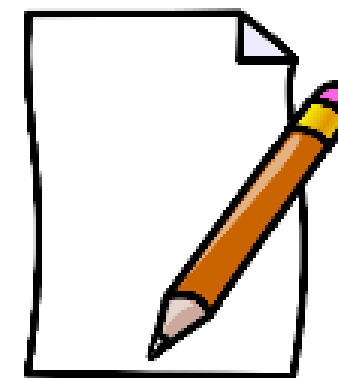
Shall I give you more time?



Shall I help find the word?



Shall we use gesture, drawing, writing or pointing?



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David's communication timeline



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Supporting families and carers to communicate with people living with LBD

Dr Alison Killen – Research Associate
NIHR Newcastle Biomedical Research Centre

LBD related communication challenges in families

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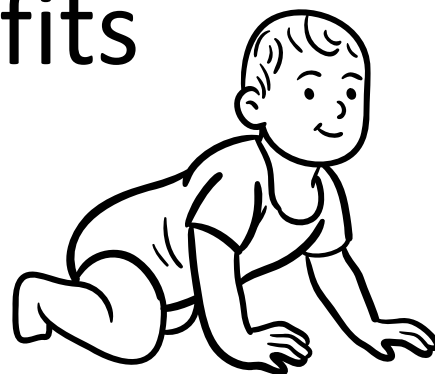
LBD factors

- Hallucinations/delusions
- Fluctuations
- Speech volume
- Apathy
- Sleep
- Life stage



Communication with children/teens

- Family dynamics
- Adult cues
- Age related concerns
- Benefits



Case discussion

Bob is a 78-year-old retired miner. He lives with his wife, Jean and adult son, John. His daughter Sally and grandson Jake visit frequently.

Bob was diagnosed with DLB two years ago. He has been having visual hallucinations for over a year, but these have recently become more frequent. Out of his lounge window Bob says he can see his old workmates. They are wearing their pit gear on their way to work.

Bob has a delusional belief that these miners are digging up his flower beds to search for coal. When they find it, Bob's house will become part of the mine and Bob will have to leave.



Family responses

Jean

Don't be so daft Bob you're talking nonsense.

John

Great they can buy the house, and we can get somewhere bigger.

Jake

Tell me about when you worked down the pit grandad what was it like?

Sally

I understand that the miners are real to you Dad. I'm sorry that you are feeling upset/frightened/angry. I can't see them. Do you think your eyes may be playing tricks on you?



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Family responses

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How might these responses make Bob feel and react?

Jean

Don't be so daft Bob you're talking nonsense.

– *belittled, withdrawn, reluctant to share.*



Family responses

Jean

Don't be so daft Bob you're talking nonsense.

John

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How might these responses make Bob feel and react?

John

Great they can buy the house, and we can get somewhere bigger.

– family in collusion, reinforced anxieties, danger of John being caught out.



Family responses

Jean

Don't be so daft Bob you're talking nonsense.

John

Great they can buy the house, and we can get somewhere bigger.

Jake

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How might these responses make Bob feel and react?

Jake

Tell me about when you worked down the pit
grandad what was it like?

- Distracted from his concerns, validated over his work role, included, mood lifted by social interaction.



Family responses

Jean

Don't be so daft Bob you're talking nonsense.

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How might these responses make Bob feel and react?

Sally

I understand that the miners are real to you Dad. I'm sorry that you are feeling upset/frightened/angry. I can't see them. Do you think your eyes may be playing tricks on you?

–Emotions validated, empathised with, understood, respected, reassured.



What Bob might be trying to communicate

- Fearful - leaving his house to go into care
- Bored – missing the activity of work
- Unvalued - no longer a provider for his family
- Lonely/socially isolated



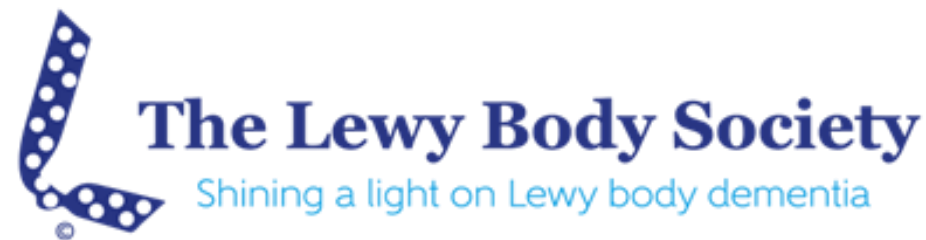
Key points for family communication

- Consider the pre-LBD relationship
- Focus on acceptance
- Find/respond to needs in the delusion/VH
- Be aware of fluctuations
- ‘Best interest’ reality orientation
- Untruths - consistent, congruent with lifestyle



Patient and family carer perspectives on communicating with health and social care professionals

**Allison Bentley – Research Associate
University of Cambridge**



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Joan and Peter - One couple's story



Age 68

Female

Short history of mobility/Parkinson's symptoms

Hospital admissions

Memory and cognitive changes

Diagnosed with Lewy body dementia

Unclear if PDD or DLB due to occurrence of presenting symptoms

Dependent on other people:

- Husband
- Health and Social Care professionals
- Voluntary sector

Bentley, A., Salifu, Y., & Walshe, C. (2021). Applying an Analytical Process to Longitudinal Narrative Interviews With Couples Living and Dying With Lewy Body Dementia. *International Journal of Qualitative Methods*, 20. <https://doi.org/10.1177/16094069211060653>

Communication with hospital teams - 1

A fall and fractured hip resulted in a hospital admission, which was essentially the start of Peter's caring role and reduced independence for Joan:

Peter: *"[S]o many different people turning up, different doctors, you couldn't tell necessarily who would be the best person to talk with. And er I think it's always difficult if you start to challenge the service, [but] I felt it was important to alert them to what **Joan's** needs were. I don't think I made myself very popular but ...If you don't shout, no one listens."*



Context:

- Concern about Parkinson's medication
- Worry/ loss of control
- New role as advocate
- Navigating services
- Learning the language of medicine

Communication with hospital teams - 2



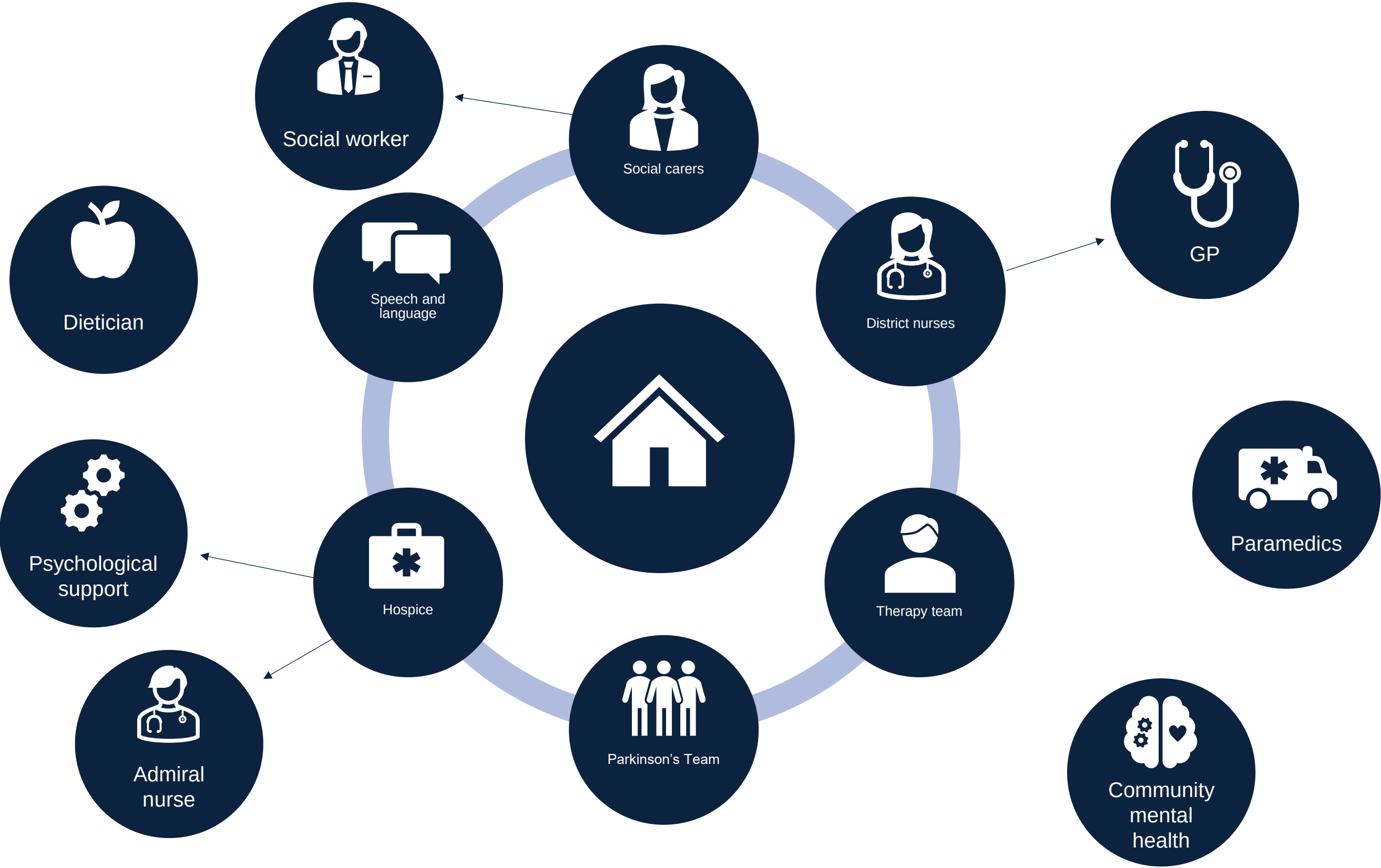
Joan had another fall with recurrent pneumonias which resulted in another hospital admission where *'things went from bad to worse'*.



Peter: “....they were very good, it was like moving into a private hospital, individual room, wet room, not that you ever got to use that but it was lovely and the consultant she was excellent. So after a few days I was taken into a discussing what's going to happen and er it was agreed that we could fast track the healthcare but on the understanding that that's only given because of the acute nature of Joan's needs, and that um they wouldn't see any other real reason to resuscitate, if necessary, which isn't always a very nice conversation....”

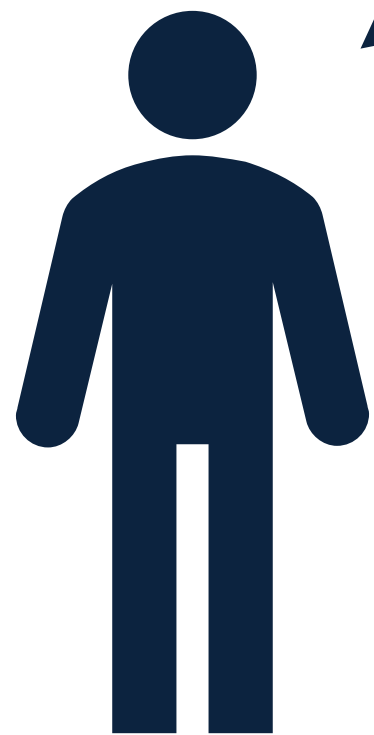
Discharged home with NHS Continuing healthcare for palliative care

Care at home for palliative care



Communication with community teams – Peter's perspective

PETER: *“part of this healthcare is [physiotherapy and] occupational therapy, and they're quite adamant that they doesn't think it will do Joan any good to move out of the bed at this stage. They measured Joan's blood pressure. Now again that was relatively low, although Joan's had low blood pressure for years but I understand they have a protocol. I find it quite annoying that they're not prepared to see how it goes rather than say we can't do it.....”*



Anyway, I got angry,... then they started treating me like an infant, why do all these people speak so loudly, this is my question, I didn't say that to them, and then they speak to you as if 'are you alright, do you need to sit down... they said we're not going to be able to move Joan for the foreseeable future, so we're stuck really. But I said well I'm not prepared to accept that long term....So that's frustrating,...”

Joan's perspective



*Joan: "I was capable of being able to walk, whereas now I'm mostly being prisoner here.
Interviewer: Prisoner here, you mean in bed?
Joan: Mmm. I have all my um meals... It's frustrating...Unfortunately they concluded that I wasn't ready to be released."*

Missing life as a couple – Peter adapting



PETER: “.....the thing I miss most is it’s difficult to do things together as we would have done before, to get out would be lovely I mean I can but obviously Joan can’t but um I think that’s what we miss most isn’t it, just to go places and do things together.”

PETER: “I think I told you we had a little bit of a run in the first time. I got a bit upset, and um shouldn’t have done, but this time I kept very calm and I sort of anticipated the outcome anyway, ‘cos I thought they’re not going to give us the go ahead”.

Communication with social care

Peter was adjusting to changing roles and relinquishing some of the physical care. Initially, Peter *'felt quite redundant'* from his caring role when the social care visits were increase to 4x a day.

He found *'not really doing anything with any particular purpose...except to keep the day going'* very difficult, but *'I know I've got to look after medication'* and *'learn the best way to help Joan eat'*.

Eventually support from the social care team meant he can take up hobbies the carers had become *"more friends than carers now"*

'when Joan came under the continuing healthcare after the second visit to the hospital, they – the commissioners or whoever said oh well if they can manage it we'll keep them on and that's been the case so that's good. You do get to know them very well, they're more friends than carers aren't they now.'

Communication with General Practitioner

Conversation with Peter and Joan present

Peter: "She [the GP] spent a good hour with us didn't she, so she went through all the medication that Joan's now not on or on and um also talked about the future and what er what reality is which I suppose is fair. And er knowing obviously in her experience what can be the case, but um anyway... It's helpful but not really what you want to talk about if you can avoid it,"



Conversation with just Peter

Peter: "the doctor, I think she did it very well, she was trying I think to gauge what I felt and also to as best she could what Joan felt, she was broaching with Joan as well, and she was saying how pneumonia, I mean politely was saying if you are to die it is a softer way to die than other [ways], which wasn't so easy to hear but I could take what she meant, you know she was saying to Joan are you afraid of dying sort of thing, and Joan sort of said no, but I don't think she wants to"

Working as a team with paramedics

By the final interview Peter's caring and nursing skills involve working with the medical team he initially challenged



PETER says they have *“had one or two scares about er pneumonia coming back”* but he monitors **Joan's** condition – *‘I’ve got monitors and things, I can check her oxygen saturation, I can check blood pressure’*.

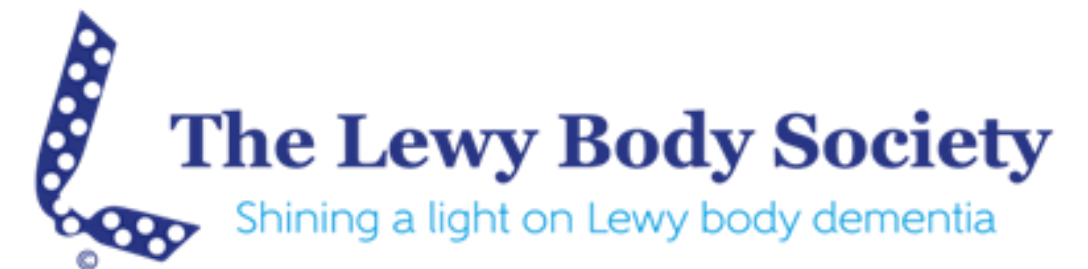
PETER: “we’ve had a paramedic come and then an ambulance once or twice but then after consideration it’s been felt more appropriate to try and help Joan here.... they’re quite keen not to take us to A&E which I’m quite happy about - and they’ve often said that with the consultation of the doctor and then me we’ll give you antibiotics here and that’s worked.”

Thanks for listening



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Complete our short survey on how
you found the session today...



Communication Resources

1. How to speak to someone with Lewy body dementia (20 min you-tube)

This is Episode 9 of a special 10-episode series filmed by the Lewy Body Dementia Resource Center (US) to help families, health care professionals, and the general public understand LBD.

<https://www.youtube.com/watch?v=-coZL5QeNLk>

2. Conversations in dementia with Lewy bodies: Resources and barriers in communication.

Int J Lang Commun Disord. 2023 Mar;58(2):419-432. doi: 10.1111/1460-6984.12799. Epub 2022 Dec 20. <https://pubmed.ncbi.nlm.nih.gov/36537165/> (Research paper)

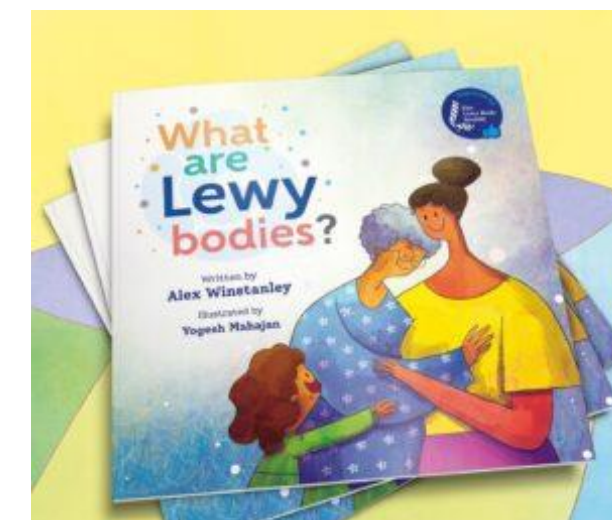
3. <https://www.lewybody.org/new-book-to-help-children-understand-lewy-body-dementia/>

4. [My Dad has Parkinson's – Parkinson's shop \(parkinsons.org.uk\)](https://parkinsons.org.uk/my-dad-has-parkinsons/)

[My Gran has Parkinson's – Parkinson's shop \(parkinsons.org.uk\)](https://parkinsons.org.uk/my-gran-has-parkinsons/)

[My Grandad has Parkinson's – Parkinson's shop \(parkinsons.org.uk\)](https://parkinsons.org.uk/my-grandad-has-parkinsons/)

[My Mum has Parkinson's – Parkinson's shop \(parkinsons.org.uk\)](https://parkinsons.org.uk/my-mum-has-parkinsons/)



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Shining a light on Lewy body dementia

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