

LBUK - Online Support Meeting 20260112

Attendance

Esther, Linda and 15 carers – all women this time

Meeting summary

Key takeaways

- Medication management for Lewy Body Dementia requires careful balance between treating Parkinson's symptoms and cognitive symptoms
- Balance and mobility issues are common concerns; options include medication, physical therapy, and water exercises
- Accessing appropriate healthcare support often requires persistence and self-advocacy
- End-of-life planning discussions are important to have early while cognitive abilities are intact
- Despite challenges, many participants emphasized finding moments of joy and maintaining quality of life
- Support networks, both professional and personal, are crucial for both patients and caregivers

Discussed topics

Medication management for balance and mobility issues

Discussion focused on medication options for managing Parkinson's symptoms while minimizing cognitive side effects.

• Points raised

- Concerned about husband's deteriorating balance and rigidity in hands, feet, and toes; wondering about medication timing
- Shared experience with husband's medications; noted challenges with one causing worse hallucinations
- Recommended slow-release medication starting at low doses; mentioned her mother tolerates it well
- Emphasized importance of consulting with clinicians about individual needs
- Suggested supplements
- Stressed importance of neurologists communicating with psychiatrists about medication

• Conclusion

- Medication that helps Parkinson's symptoms may worsen cognitive symptoms and vice versa
- Slow-release medication at low doses might help with balance while minimizing side effects
- Non-pharmaceutical approaches can complement medication

Healthcare support and advocacy

Participants discussed challenges in accessing appropriate healthcare support and the need for self-advocacy.

- **Points raised**

- Expressed frustration about lack of specialist care; hasn't seen neurologist or psychiatrist in 3 years
- Advised being persistent with GPs for referrals to specialists
- You need to be 'bossy' and ASK/Demand
- Mentioned Parkinson's UK as helpful resource for referrals to Parkinson's nurses
- Emphasized need to be proactive and persistent with healthcare providers
- Shared positive experience with care coordinator in Newcastle
- Suggested bringing someone independent to appointments for support
- Described year-long wait for NHS neurologist appointment

- **Conclusion**

- Healthcare support varies significantly by location
- Persistence and self-advocacy are essential for accessing appropriate care
- Support can come from various sources: specialists, nurses, care coordinators, and charities

Mobility assistance techniques

Discussion about specific techniques to help with mobility challenges.

- **Points raised**

- Described challenges getting husband from sitting to standing position; mentioned "scissor gait" and "Lewy lean"
- Suggested hand massage and calf stretches to help with dystonia
- Recommended stationary cycling for balance and mobility:
<https://www.lewybuddiesuk.org/wwfm-posts/what-worked-for-me-rapid-cycling>
- Advocated for water-based exercises to support balance

- **Conclusion**

- Physical therapy techniques like massage and stretching can help with muscle rigidity
- Exercise, particularly rapid cycling and in water, can help maintain mobility and balance
- Assistive devices and proper techniques are important for safe transfers

End-of-life planning and care

Participants shared experiences and advice about planning for end-of-life care.

- **Points raised**

- Shared experience of hospital consultant asking about dying wishes
- Described experience with end-of-life care planning and discussing 'risk feeding' choice, rather than agreeing to a PEG feeding tube
- Explained DNR (Do Not Resuscitate) discussions with medical professionals
- Recommended "The Conversation Game" to facilitate end-of-life discussions:
www.conversationsforlife.co.uk (Note after meeting: the cards are quite expensive – we might consider a bulk buy if Buddies are interested)

- Emphasized importance of having these conversations early while patient can participate

- **Conclusion**

- End-of-life planning is important to do while the person with dementia can still participate
- Physical copies of DNRs should be kept visible/accessible at home
- ReSPECT plans <https://www.resus.org.uk/respect> and other advance directives help guide care decisions

Supporting newly diagnosed individuals

Discussion about coping with a new diagnosis and finding support.

- **Points raised**

- Expressed feeling overwhelmed by husband's recent diagnosis at age 60
- Reassured that the core person remains despite the disease
- Shared that not everyone experiences all possible symptoms
- Check teepasnow.com for resources and practical tips/role plays of myriad situations, including conversation, activities and so forth. Personally, every tip I have used has worked
- Teepa Snow offers training which you pay for, but lots is free, including podcast and on YouTube
- Super helpful explanation about how dementia affects the brain in a Teepa Snow video <https://teepasnow.com/about-dementia/> - keep scrolling down until you reach 'a changing brain'
- Advised enjoying each day and not worrying too much about the future
- Recommended living in the moment while being prepared for the future

- **Conclusion**

- New diagnoses bring grief that requires support and processing
- Finding appropriate counselling and support groups is important
- Focus on present joys while preparing realistically for changes

Travel and maintaining quality of life

Participants shared experiences and advice about traveling and maintaining activities.

- **Points raised**

- Described successful trips to Portugal with husband despite challenges
- Asked about safe ways to travel with husband who gets overwhelmed
- Mentioned airport assistance benefits
- Suggested traveling with additional family members for support
- We had a great seaside holiday in August; now in hospital but enjoying Newcastle United football match last night
- Shared links: www.dementiaadventure.org and <https://www.limitlesstravel.org/disabled-holidays/categories/dementia-friendly-holidays>

- **Conclusion**

- Travel remains possible with proper planning and support
- Airport assistance services can help navigate stressful environments
- Familiar destinations and accommodations may work better than new places

Managing apathy and social engagement

Discussion about handling lack of interest in activities and maintaining social connections.

• Points raised

- Described husband's preference to just sit and watch TV
- Suggested taking charge rather than asking if spouse wants to participate
- Questioned whether to force activities if spouse seems content
- Noted sensory overload can make social settings difficult
- Mentioned apathy as a recognized symptom

• Conclusion

- Apathy is a common symptom that can be challenging to address
- Balance between encouraging activity and respecting preferences is important
- Sensory overload can limit tolerance for social settings

Care home experiences and management

Discussion about experiences with care homes and strategies for advocacy.

• Points raised

- Asked about successful care home management and activities
- Shared positive experiences with her husband in care home; mentioned importance of staff personalities
- Described challenges with lack of dedicated activity coordinators

• Conclusion

- Care home experiences vary widely
- Staff personalities and approaches significantly impact resident experience
- Family advocacy remains important even after placement in care home

Lewy Buddies organization structure

Discussion about welcome calls and group organisation.

• Points raised welcome calls

- Asked for feedback about welcome calls for new members
- Found welcome call very valuable as new member
- Appreciated having conversation before joining group meeting
- Suggested expanding team for welcoming calls to prevent overload

• Points raised Zoom meetings

- In future may consider providing a separate early-stage group and an evening group
- From Chat: Would it be best to all to be on silent so people can't but in, then put hands up?

• Conclusion

- Welcome calls are valued by members and provide personal connection
- Group size management and potential stage-based separation may be considered
- Signing up for meetings before 7 pm on Sunday is required
- We will start with everyone on mute on 9th February and see how it goes
- The practicalities for a team approach for welcome calls are being worked out

And for Londoners – an invitation from the Chat:

“Anyone want to meet for a coffee in London let me know. Kris”

Contact request via Directory:

Kristine B – London SE1 – Carer of spouse living at home – Middle stage

Or send an email to Esther to be put in touch