



THE LBD DIGEST

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Hospitalizations in LBD

Crisis situations can unfortunately be common for people living with Lewy body dementia (LBD) and their families. In one study, the hospital emergency room was the most common place to seek help, but ERs are often unfamiliar with LBD. Across three research studies, the top three reasons that people with LBD were admitted to the hospital were infection, falls, and increased confusion/hallucinations.

While the goal of any hospital stay is to get better, there are some risks when people with LBD are hospitalized. Many doctors are not familiar with Lewy body dementia, so families sometimes know more about the diagnosis than the hospital team. People with LBD can get more confused in the unfamiliar setting of the hospital and hallucinations can worsen. When hallucinations or agitation are bad and hospital staff are concerned about safety for the person with LBD or the medical team, they might prescribe an antipsychotic medication to try to help the person with LBD. People with LBD can have reactions to some of these antipsychotic medications, though. For all these reasons, LBD specialists prefer to keep people out of the hospital if at all possible. Sometimes people need to be hospitalized, though, for example if they have a bad infection or fall and break a hip.

Hospitalizations are usually unexpected, so it is best to prepare in advance. The Lewy Body Dementia Association and the Parkinson Foundation have excellent resources to help people with LBD and their families prepare for and manage hospitalizations (see box below). Here are some caregiver tips from these resources:

- Tell the ER and hospital physicians about the Lewy body dementia diagnosis
- Inform your primary care physician and/or neurologist about the hospitalization
- Consider asking that antipsychotics be identified as an "allergy"
- Ask to be notified if medications are started or stopped
- Introduce yourself to nurses and let them know about LBD
- Be proactive – be present as much as you can, provide reassurance, help maintain routines

LBDA Medical Alert Wallet Card: <https://www.lbda.org/lbd-medical-alert-wallet-card/>

LBDA Caregiver Tips for Hospital Stays: <https://www.lbda.org/caregiver-tips-for-hospital-stays/>

Parkinson's Foundation Hospital Safety Kits: <https://www.parkinson.org/resources-support/hospital-safety-kits>

Identifying Factors Predicting Accurately End-of-Life in Dementia with Lewy Bodies and Promoting Quality End-of-Life Experiences: the PACE-DLB Study: Study recruiting people with moderate to severe dementia with Lewy bodies (DLB). The person with DLB and their caregiver must participate together. Find more information here: <https://ufhealth.org/research-study/pace-dlb>. Call 352-733-3004 or email PACE-DLB@neurology.ufl.edu for more information.

Multi-Stakeholder Engagement for Interdisciplinary Telehealth in Lewy Body Dementia: Study recruiting people with mild to moderate Lewy body dementia (LBD). The person with LBD and their caregiver must participate together. Find more information here: <https://lbd.neurology.ufl.edu/tele-lbd/>. Call 352-733-2419 or email noheli.bedenfield@neurology.ufl.edu for more information.

Characterizing FLUctuating COgnition EXperiences in Lewy Body Dementias to Improve Care and Research: Study recruiting people with LBD who experience fluctuations. The person with LBD and their caregiver must participate together. Find more information here: <https://lbd.neurology.ufl.edu/flux-lbd/>. Call 352-448-8111 or email Tracy.Tholanikunnel@neurology.ufl.edu for more information.

Lewy Body Dementia Association’s 2023 Community Webinar Series

Are you interested in learning about Vision in LBD?
Join the LBDA on Wednesday, August 16th at 12PM ET.

Register for this webinar: <https://www.lbda.org/event/vision-in-lewy-body-dementia/>

CONTACT US



To contact your UF Health Lewy Body Dementia Support Team call (352) 733-2419 or email us at DLB-support@neurology.ufl.edu.



Are you a caregiver in need of support?

Join our monthly Virtual Lewy Body Dementia Caregiver Support Group!

- Every 4th Friday of the month from 2-3PM
- Connect by telephone:
 - Call the toll-free number
 - +1 (646) 558-8656
 - Input Meeting ID: 540-200-2903
- Connect online:
 - <https://uflphi.zoom.us/j/5402002903>

