



THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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Handling the Holidays with Lewy Body Dementia

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It's the most wonderful time of the year... unless you live with someone with memory and thinking problems (dementia). Traveling, large family gatherings, and long days of celebration can be particularly challenging for people with Lewy body dementia (LBD). Here are some ideas for making the holidays easier.

1. Celebrate in familiar places. It is easy for people with dementia to become confused in new places. If you need to travel, try to pick a familiar destination and limit the number of new situations (e.g. airports). If you're hosting, consider whether family should stay with you. It can be helpful for visitors to stay at a nearby hotel or rental.
2. Prepare visiting family members. If family members haven't seen the person with LBD recently, warn them about what has changed. Make sure visitors have realistic expectations.
3. Keep a schedule. Having a daily routine is important for people with LBD. Keeping to this schedule even during the holidays can be helpful. Make sure the person with LBD gets breaks during the day for naps or time alone.
4. Involve the person with dementia. Plan activities that the person with LBD can do. People with dementia often connect with music – have a family sing-along. Decorating cookies is an easy activity to do seated.
5. Expect a post-gathering letdown. People with LBD can sometimes rally themselves for big events or family gatherings. Afterwards, though, they may be more fatigued or more confused than usual.

The holidays are a great time to make special memories. Thoughtful planning can help make family celebrations a success.

Research Corner

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 DLB 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.

Hurricane Preparation

As hurricane season continues through the end of November, it is important to prepare ahead of time. When thinking of how to prepare, the Alzheimer's Association recommends you focus your time on (1) creating an emergency kit and (2) creating an evacuation plan.

Emergency kit

An emergency kit should be protected from rain. Store all of your items in a watertight container and in a location with easy access. Use waterproof bags to help protect any medications, documents or device chargers. Other items included are up to you but consider packing a few outfits, shoes, toiletries, copies of important documents, physician information, water and non-perishable goods.

Evacuation plan

People living with LBD sometimes do not do well with changes in their routine or environment. In Florida, there are special needs shelters that some may qualify for. You are able to connect with your local Office of Emergency Management to see if you qualify and register in advance. Your local office may help you complete a basic disaster plan and provide you with helpful information on what an evacuation would look like.

If you are interested in connecting with your local emergency management office either visit floridadisaster.org/counties or call 850-815-4000 for assistance. The Alzheimer's Association and the University of South Florida have also created a helpful guide for dementia caregivers available at <https://www.alz.org/media/flgulfcoast/Disaster-Guide.pdf>.

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>

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