



# THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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## What is social work and what can it do for you?

The role of a social worker is to listen to your needs and provide helpful resources.

**What social workers can help with:** Social workers are devoted to helping you cope with your non-medical problems. They can be found in many settings, like in a school or medical facility. Social workers at the Fixel Institute are able to help you find care and resources in your area. They are also able to assess if you would benefit from social support and can share support group information.

**What to expect from a social worker:** You can expect social workers to be empathetic, organized and patient. Supporting you is their #1 priority so they have excellent listening and communication skills. Since each person has a unique set of needs, social workers are equipped to solve problems in creative ways.

**How to connect with a social worker:** If you are a patient at the Fixel Institute, you are able to make an appointment with one of our two social workers. Jana Unislowski and Alana McKay are excellent in what they do. They are familiar with community and state-wide resources. They are also familiar with the effects of neurological diseases and are able to offer relevant assistance. Connect with your doctor for a referral.

If you are not a patient at the Fixel Institute, connect with our team at [dlb-support@neurology.ufl.edu](mailto:dlb-support@neurology.ufl.edu) for assistance.

## 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](mailto: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](mailto: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://www.dropbox.com/s/zw6ss8ff5p2199d/FLUX-LBD\\_Flyer.pdf?dl=0](https://www.dropbox.com/s/zw6ss8ff5p2199d/FLUX-LBD_Flyer.pdf?dl=0). Call 352-448-8111 or email [Tracy.Tholanikunnel@neurology.ufl.edu](mailto:Tracy.Tholanikunnel@neurology.ufl.edu) for more information.

## Meet Our Team:

### Nikolaus McFarland, MD, PhD



Dr. McFarland is an Associate Professor of Neurology and current Division Chief of Movement Disorders at the University of Florida, College of Medicine. He holds The Wright/Falls/Simmons Professorship in PSP/Atypical Parkinson's. He joined the UF Department of Neurology and the Center for Movement Disorders & Neurorestoration in 2010 (recently renamed, the [Norman Fixel Institute for Neurological Diseases](#)). He is also a member of the Center for Translational Research in Neurodegenerative Disease ([CTRND](#)) that aims to bring the bench closer to the bedside. He completed his medical and graduate training at the University of Rochester School of Medicine & Dentistry and neurology residency at the University of Virginia. At the Massachusetts General Hospital he pursued fellowship training in Movement Disorders and research in

Parkinson disease and related disorders, and served as an Instructor at MGH/Harvard. He has received support from the NIH-NINDS, American Parkinson Disease Association, Parkinson Foundation, and Michael J. Fox Foundation. Dr. McFarland directs a comprehensive multidisciplinary clinical-research program for Atypical Parkinson disorders including dementia with Lewy bodies (DLB), multiple system atrophy (MSA), progressive supranuclear palsy (PSP) and corticobasal syndrome. He is actively involved in multiple clinical trials for Parkinson disease, Atypical Parkinsonism's, and Huntington disease. He is also Director of the UF Huntington Disease Society of America ([HDSA](#)) Center of Excellence, CurePSP Center of Care, and the Fixel Institute Biomarker laboratory.

### 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](mailto:DLB-support@neurology.ufl.edu).



### Are you a caregiver in need of support?

Join our monthly Virtual Lewy Body Dementia Caregiver Support Group!

- Every 4<sup>th</sup> 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>

