

## Non-drug Approaches for Care Partners to Use When a Loved One Living with LBD has Behavioral Changes

Rosemary Dawson Ed.D; Helen Buell Whitworth, MS, BSN; and James Whitworth, LBDA Co-founder

### **Rosemary Dawson**

After a career in higher education and research, Dr. Dawson retired completely to devote her full attention to caring for her husband who had Lewy body dementia (LBD). When he passed, raising awareness and educating people about LBD, supporting people with LBD and their care partners, and advocating for funding and research became her passion as a way to honor her husband's life and memory and to make the journey gentler for others.

- Advocate - for funding, research, and other support (government agencies, pharmaceutical organizations, researchers, and clinicians)
- Moderator/owner - LBD Caring Spouses online support group composed of approximately 800 spouses of people living with LBD
- Moderator/owner – Life after Lewy online support group for people whose spouses have died of LBD
- Author - articles and guides for LBD care partners
  - *Care Partners' Role in Medications for Loved Ones with Dementia with Lewy Bodies*
  - *Being an Engaged Care Partner: A Guide for Spouses of People with Lewy Body Dementia* (with P. Snyder & J. Maruna)
  - Care Briefs for the Lewy Body Dementia Association (LBDA); seven on Behavioral Changes in LBD; Be Aware of Polypharmacy; and Sleep Disorders in LBD.
- Lewy Buddy - Lewy Body Dementia Association (LBDA) communicating one-on-one with people living with LBD and their care partners via telephone and email
- Member – LBDA Living with Lewy Advisory Council
- Volunteer of the Year (2017) for the Lewy Body Dementia Association
- Member -LBDA - Volunteer, Programs, and Services Committee
- Member and resource - Northern Virginia (NOVA) LBD Support Group
- Moderator – two LBDA-sponsored Facebook groups; Member – three other LBD Facebook Support groups
- Presenter and participant: International Conference on Dementia with Lewy Bodies, Ft. Lauderdale, FL (December 2015) - Two poster presentations
- Volunteer consultant to pharmaceutical company clinically testing drugs to treat LBD
- Presenter and participant: Patient-Centered Clinical Trials, Philadelphia, PA, Eyeforpharma (October, 2016)

## James and Helen Buell Whitworth

An electronics engineer, James Whitworth retired to care for his wife, Annie, who had Lewy body dementia (LBD). After she passed in 2003, spreading the word about Lewy body dementia became his mission. As such, he:

- Co-founded the Lewy Body Dementia Association (LBDA)
- Served on the LBDA Board of Directors for a six year term, the first two years as President.
- Was the first LBDA telephone support person (now called Lewy Buddies)
- Was an LBD caregiver support group facilitator for several years; monitors several online LBD caregiver support groups; was a moderator of the LBD Caring Spouses group, and is a charter member of the After LBD Group.

When her sister who already had Parkinson's developed terminal cancer, Helen Buell Whitworth retired from her nursing and counseling career to be her caregiver. This was Helen's first personal experience with a Lewy body disease, although it wasn't until she met James that she knew this.

After Helen and James married in 2005, they combined forces. Together they:

- Wrote three award-winning books about LBD and dementia:
  - *A Caregiver's Guide to Lewy Body Dementia* (winner of the 2012 Caregiver Friendly award with over 130 five-star Amazon reviews)
  - *Managing Cognitive Issues in Parkinson's & Lewy Body Dementia* (a 2015 Gold eLit award winner)
  - *Responsive Dementia Care: Fewer Behaviors, Fewer Drugs* (a finalist in the ongoing international Wishing Shelf awards)
- Presented about LBD at the 2014 Global Conference on Parkinson's Disease in Colorado.
- Did staff training and family member workshops in care facilities and hospitals in Arizona, California, Oregon, Idaho, Washington and Alaska.
- Spoke at LBD and Parkinson's caregiver support groups, senior centers, churches, and senior living communities in the above western states.
- Develop and sell LBD training workshop materials to care facilities.
- Have had an LBD- related website, LBDtools.com since 2008
- Are members of LBD caregiver support groups in Mesa and Phoenix, AZ

In addition Helen:

- Was the LBDA Volunteer Coordinator from 2006 to 2008
- Was the 2007 LBDA Volunteer of the Year
- Has maintained a weekly blog, the Lewy Body Roller Coaster, since 2011