

## Meet the Whitworths

*by Helen Buell Whitworth and James A. Whitworth*

In our work with care partners, we attended many caregiver support groups in several states. We've heard the stories, heartbreaking and heartwarming, funny and sad and enlightening. Although group members tend to be more educated about LBD than many doctors, they still find it especially difficult to deal with LBD's hallucinations and delusions, both of which tend to show up lot earlier than Alzheimer's do.

Jim can relate. When his first wife, Annie, developed delusions and became combative, he had no idea how to deal with this and ended up taking her to a hospital emergency room. From there, she was admitted to the hospital and was not allowed to go home. Annie died without forgiving Jim for breaking his promise to her that he'd never put her into a nursing home. (Yes, with LBD, people often recognize their loved ones to the end!) If he could have known what he knows now, he might have been able to defuse Annie's irrational anger and keep her home. But that was 2003. No one knew!



We've also noticed one more thing. The more compatible the pre-LBD relationship was, the better they cope now. It isn't a matter of whether the relationship was loving or not, although love certainly helps. In fact, a friend once said, "I don't know how anyone could do this job if they didn't love their person." But some people seem to have developed a way of relating that is less stressful than others. And with LBD, decreasing stress is all important!

And so, how can we use this information to help LBD care partners? No one can go back and change the way they related, often over a period of many years. Sadly, the time is past when the person with LBD can initiate changes, but the care partner still can; and the difference is well worth the work it will take.

If care partners can learn less stressful ways to respond to their loved one's outbursts, there will be fewer outbursts--and less stress for everyone. That's where education comes in. Our books provide the knowledge so that care partners can better understand what's going on with their loved ones and Teepa has many wonderful suggestions and techniques for dealing with some of LBD's most difficult symptoms.

## **ABOUT THE AUTHORS**

The Whitworths have been working with Lewy body disorders since the 1990s, when Jim's first wife, Annie, was diagnosed with dementia. After Annie died, Jim made it his mission to spread awareness about this little known, but all too common, disorder. In 2003, he helped to start the Lewy Body Dementia Association and became its first board president. About the same time Jim was dealing with Annie's dementia, Helen retired from her nursing and counseling career to care for her sister, who had terminal cancer along with Parkinson's, another Lewy Body Disorder. After the couple met and married in 2005, Helen began using her skills to help Jim further his mission--and fulfill her own dream of traveling and teaching. The couple lives in Arizona, from where they still travel and write about Lewy Body Disorders. Their books, [blog](#) and [website](#), all show a focus on using alternative techniques and therapies to decrease the need for drugs.

## **BOOKS**

### **A Caregiver's Guide to Lewy Body Dementia**

Lewy Body Dementia (LBD) is often confused with Alzheimer's or Parkinson's. However, it has many other symptoms, such as drug sensitivities, mood disorders, and hallucinations. Families often find these more difficult to deal with than the dementia itself. A Caregiver's Guide to Lewy Body Dementia uses everyday language and personal experiences to present a comprehensive view of this disorder and how to deal with it. This easy-to-read book received a 2012 Caregiver Friendly Award from Today's Caregiver Magazine and has over 90 five-star reviews on Amazon.

### **Managing Cognitive Issues in Parkinson's and Lewy Body Dementia**

Lewy Body Dementia (LBD) can start with or without Parkinson's. Some symptoms, including those often treated with antipsychotic or anti anxiety drugs, can appear before cognitive symptoms. As the disorder advances, a sensitivity to these drugs becomes more and more likely. Fortunately, there are a multitude of alternative therapies and techniques that can help decrease the need for these drugs. *Managing Cognitive Issues* is printed in large text and easy-to-read language. It describes LBD and addresses the non-motor symptoms that are distressing to deal with and difficult to treat. A great addition to any dementia caregiver's library, it has a large chapter about drug sensitivity, a section describing a variety of alternative treatments and techniques, and a 13-page list of resources with links to several lists of most troublesome drugs.