

April Fools Day and Night

Living with Lewy Body Disease

by Teepa Snow, MS, OTR/L, FAOTA

Of all the dementia conditions, Lewy Body Disease (LBD) is the most like playing April Fools with someone you are trying to live with. However, this roommate keeps popping up with new surprises that can be funny or simply can be scary depending on where you are in that moment, and what the SURPRISE is this time. LBD creates the greatest sense that:

- someone is deliberately lying to someone else
- someone is choosing to not do things that they can
- someone is being ridiculous about not smelling or smelling odd smells
- someone needs to sleep, and they won't versus can't
- extreme changes in abilities and behaviors can happen in moments
- evening and nights can last *forever and are scary*
- falls happen in spurts and then seem to suddenly stop, only to happen again
- medications are a crap shoot, with few winning rolls and lots of disasters
- sometimes there is nothing wrong with someone, it's all an act, and then it's not!

The condition is also one of the most frequently missed as a dementia or mis-diagnosed as either a combination of Parkinsons and Alzheimers or a mental health issue. It also has the habit of coming and going in symptom presentation and severity, making it almost impossible to get a handle on in the early stages, since everyone is seeing and experiencing something different. In an effort to better support and help people living with LBD and those who are trying to support their life, we have developed two resources.

The first is a DVD that I did with the [Pines Education and Training Institute](#). It addresses, in a workshop format, many of the symptoms that signal the possible presence of Lewy Body Disease. It also provides guidance and practice in better response and support patterns when the symptoms are present. In this video, I talk about recognizing the two very different points of view and perspectives when someone is experiencing an active phase of LBD and we are not. I try to help us recognize the value of reframing our thoughts and words about hallucinations versus visual disturbances, delusional thinking versus mis-interpreting words and actions, lying and being illogical versus confabulation, not trying to move versus not being able to initiate or reversing the desired movement by accident, and refusing to take medications or eat versus experiencing fine motor dysfunction. The goal of the video is to help people notice what might be happening and to try our different approaches to support the person who is experiencing the symptoms. [Click here](#) to view some information about the DVD and watch a trailer.

The second resource is a webinar that I conducted, one in a series of twelve on [Different Dementias](#), to provide information about LBD and to highlight the importance of advocating for the wellbeing of the person you may be trying to help, as well as yourself with health care systems that may not know much about the condition or its symptoms.

[Click here](#) to watch the video resource.

Misfire: Why You Need to Break Your Promise... Alzheimer's Disease, Parkinson's Disease Psychosis, Lewy Body Dementia

This short read was written by Dawna Cappello and Susan Heller. This book documented Dawna's experience of trying to support and care for her father-in-law on a team with her husband and mother-in-law. The entire journey was clearly devastating and incredibly distressing for her entire family. In the telling of this story, this duo offers other families insight into where mistakes were made and what might have helped. The final message of getting the right diagnosis and the right kinds of help sooner, rather than living in guilt and frustration, is one from which all individuals living with LBD and their supporters can benefit.

[Click here](#) to learn more or purchase a copy of the book.

The [Cleveland Clinic](#) has recently become one of nine centers coordinating their efforts to better understand and diagnosis people living with Lewy Body Dementia. Since LBD is probably the second most common type of dementia, this is a much-needed effort. NIH has funded a major effort to better identify the condition and develop improved treatment profiles. Hopefully, with better recognition of this very challenging condition, improved delivery of care and services will follow.

[Cleveland Clinic Receives NIH Grant To Establish National Consortium For Studying Lewy Body Dementia](#)