My Journey with Lewy Body Dementia

By Robert Bowles

Several weeks ago I found myself reflecting on my journey with Lewy body dementia (LBD). I became intrigued as I followed my journey in my mind. I had read that “LBD is a progressive disease, meaning symptoms start slowly and worsen over time.” The question came to me, “How can someone be doing so poorly at the time of diagnosis and be doing as well as I am now?”

Reflecting on this question I concluded that this reversal in well-being related to finding purpose in life. After selling my pharmacy I had owned for 38 years, I felt my life was over. I lost my purpose in life. No longer did I have my patients to love and care for. Over the next 18 months, I visited eight physicians. My original diagnosis was depression. I was placed on an antidepressant. Not responding to that antidepressant, a second one was added. After taking this new medication for only 11 days, my body would hardly move. The medication was stopped. I was referred to a cardiologist who diagnosed me with orthostatic hypotension. Ultimately, I was taking seven pills a day to raise my blood pressure and two a day to lower it. Not improving, the cardiologist referred me to a neurologist. On my first visit I was diagnosed with Parkinson’s. I returned in one month, and the diagnosis was changed to likely being frontal temporal dementia. This neurologist referred me to a memory and cognitive center. On my first visit, I was given a diagnosis of LBD.

Initially, my reaction was ‘it is what it is and everything will be OK.’ I had no idea what path my journey would take. Within two months of diagnosis, I was hallucinating and acting out. I was sleeping 16-to-20 hours a day. The only time I would wake up was for my wife to tell me it was time to eat. I would immediately go back to sleep.

My neurologist made several medication changes, and I started improving. I improved so much I drove myself to the airport, flew to Orlando, and attended a conference. I continued to improve and even hosted a Lewy Body Dementia Association (LBDA) event 16 months after diagnosis. I planned it one night in just 4 hours. It was through this event that I found my new purpose in life.

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I began to realize there was life after a diagnosis of LBD or any dementia. I realized that I did not need to read the final chapter. I became intrigued with advocacy when I served on the executive committee of the Georgia Pharmacy Association. I decided to pour my efforts into advocacy. I wanted others to know dementia was a disease, and there was no stigma in it. I wanted others to know, yes, there is life after diagnosis.

Doors began to open as I followed my new purpose. One door opened I did not like. Eighteen months after my diagnosis, my colon ruptured. After 10 weeks, the ileostomy ruptured and the surgeon reconnected my colon. Two major surgeries in the span of 10 weeks was a lot for anyone and especially someone with LBD. I refused to be discouraged, but then it was determined I would need cervical disc surgery. This surgery, being the third in just 6 months, was even more difficult to recover from. My desire for advocacy exceeded the setbacks.

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Enjoying Dementia Mentors, I was ready to add another opportunity. I was asked to administrate a Facebook page for the Forget Me Not dementia support group. This page is specifically for LBD. We share our experiences, strength and hope, while offering love, care and compassion to others.

https://www.facebook.com/groups/1466664356939288

Getting involved in advocacy has opened many other doors. I am a guest on Lori Le Bay’s Alzheimer’s Speaks – Dementia Chats each 2nd and 4th Tuesdays at http://www.alzheimersspeaks.com/. And, we have also recently started the Thomaston Memory Café in my hometown which meets twice a month. Socialization and engagement are an integral part of doing well with dementia. I want those living with dementia in my community to do well. Early in 2015 Gary Joseph LeBlanc will be providing a seminar for first responder’s right here in my hometown. Next on the horizon will be helping businesses become dementia friendly to persons living with any form of dementia in our communities.

I am fortunate to have received an early diagnosis and to have excellent medical care of my LBD. Most likely, many will read this article and say there is no way (continued on page 3)
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this person could have LBD. I even questioned my diagnosis up until eight months ago. Now, I realize there is no doubt I have LBD. It now takes me longer for memory recall, my Parkinsonism symptoms have increased, my fluctuations in thinking abilities are more frequent, and I have less notice that it is about to occur. I dream for better methods of diagnosis so that early diagnosis may occur when appropriate. Early diagnosis has allowed me to do the things that I am doing.

Even with the changes that have occurred in my life and the increased symptoms, I refuse to be discouraged. For me, a positive attitude is everything. It sets the stage for how I will live with LBD. I know that as I have become socially active and engaged, I have done better. Finding purpose in my life was the catalyst that made all of this possible. Dementia Mentors has an online memory café in the US twice each week and once each week in Europe. This provides social interaction which is the lifeblood of living with dementia.

Sometimes, I think about the persons who have sacrificed their life for this great country. I think about the wounded warriors and how they have returned to this country with things like post traumatic stress disorder (PTSD), amputations, broken families, and other things. When I think about this, it greatly diminishes my thoughts of what I am experiencing. As I think about the wounded warriors, it causes me to forge ahead and live with LBD well.

Editor’s note: Robert Bowles is a retired pharmacist who resides with his wife in Thomaston, Georgia. When he is not involved in advocacy, he enjoys watching football and baseball games and spending time with his family. He has started writing his reflections on living with LBD at: https://www.facebook.com/LBDlivingbeyonddiagnosis

Getting to Know LBDA

“Dementia” is a general category for over 70 different medical reasons for abnormal changes in cognitive (thinking) and functional abilities. Although Alzheimer’s disease is the most common form of dementia, Lewy Body Dementia (LBD) affects over 1 million older adults in the US and accounts for up to 20 percent of people with dementia worldwide.

Lewy Body Dementia can be difficult to diagnose and usually involves changes in thinking as well as physical symptoms consistent with Parkinson’s disease such as tremor, slowed movements, and sleep disturbance (physically acting out one’s dreams). People with LBD can also hallucinate or have fluctuations in their thinking abilities, and it may be difficult to find support for these unique experiences.

The Lewy Body Dementia Association (LBDA) is dedicated to raising awareness of LBD and to providing support to people with LBD and their families, as well as professionals involved in LBD research or care. The Association was formed by a group of caregivers who met in an online LBD caregiver support group. The Board of Directors of LBDA are located throughout the United States, and LBDA volunteers are from the United States, Canada, and the United Kingdom, thus providing international outreach and collaboration. The organization’s website provides a wealth of educational and support opportunities and can be explored at: http://www.lbda.org/
Mind & Body: 
A Chance to Connect

by Kerianne Marston, MA

The New York City Chapter of the Alzheimer’s Association is incredibly proud of our Harry and Jeanette Weinberg Early Stage Center. The Center offers many different types of groups for people with early-stage memory disorders. In February 2014, we began to offer Mind & Body, a weekly yoga and relaxation group. This program allows participants to take time to care for themselves and focus on their overall well-being. For one hour, we are able to drop any worries or to-do lists, and spend time together just to breathe and feel.

Living with an early-stage memory disorder has unique challenges and stresses and it is important to take time out to relax. During our sessions, group participants utilize many breathing, meditation, and movement techniques to calm their nervous systems and de-stress, as well as to lengthen and strengthen their bodies.

The exercises we do often focus on symptoms or issues that are common to the group and to seniors in general. For instance, we do many exercises to improve balance and coordination, in an effort to reduce the risk of falling. We also try to focus on digestive health, which many people struggle with due to side effects of their medications. Reducing stress can affect a person’s mood and improve his or her overall health and well-being. This can be very helpful in managing other dementia symptoms.

The main goal of our sessions is to feel better when we leave than we did when we came in. We especially focus on doing what feels good in our bodies today. For each participant, each pose will feel different and will look different, too. We usually begin the session with a few moments of seated meditation, checking in with how our bodies feel. We then begin to bring our awareness to our breath. For the full hour, we concentrate on our breathing. Focusing on the breath means that we are paying attention to what is happening in the moment, and not to anything else going on in our lives. This attention to the breath has the added benefit of keeping us safe; if we go into a pose too far and lose our deep breathing, it alerts us to take a step back.

We then begin to link the breath to our movement in a very mindful way. Some of our favorite sequences and poses include sun salutations, the eight movements of the spine, self-acupressure massage, tree pose, and victory pose. All of our poses

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are done either seated in a chair or standing. There are many versions of each pose, which means each person can participate in a way that feels comfortable.

Often at the beginning or end of the session, we will read an inspirational passage from a book or magazine, a poem, or some other written word. One of our very favorite readings is from Perspectives. It is from the Summer 2013 issue, and is titled “Gratitude is the One Pill Everyone Should be Prescribed.” We highly recommend this piece!

As one Mind & Body participant shared, “No matter what is going on in my week, I know I have this group. It’s the highlight of my week!” Mind & Body is a very special time for all of us who come together for a chance to connect to our bodies, our breath, and most importantly, each other.

To learn more about the New York City Chapter’s Early Stage Services, including the Harry and Jeanette Weinberg Early Stage Center, call our 24-hour Helpline at 800-272-3900 or visit our website at: [http://www.alz.org/nyc/index.asp](http://www.alz.org/nyc/index.asp) and click onto Early Stage Services.

The Chapter is grateful to all of the generous donors of our Early Stage Services and in particular, Jeffrey N. Jones and The Warner Foundation, Inc.

Editor’s note: The author refers to an article from a past issue of Perspectives newsletter. To read “Gratitude is the One Pill Everyone Should be Prescribed” see our website below. Click onto newsletters and scroll down to Perspectives Volume 18, Number 4. [http://adrc.ucsd.edu/](http://adrc.ucsd.edu/)

A WINTER RESOURCE

In many regions of the world, winter months pose challenges for staying warm and healthy. The National Institute on Aging (NIA) has an informative 15-page publication called *Stay Safe in Cold Weather* that offers older adults tips on staying warm and avoiding a dangerous condition called “hypothermia.”

Hypothermia occurs when a person’s body temperature drops dangerously low because of exposure to cold. Low body temperature can contribute to a number of serious health conditions that can be fatal, including heart attack, kidney problems, or liver damage. People with memory loss must take extra precautions to avoid circumstances that could lead to hypothermia. Becoming lost or disoriented while outdoors alone in very cold weather could lead to hypothermia. Also, some people may forget to dress warmly enough or forget to turn up the home thermostat to a comfortable temperature and become dangerously cold without realizing it.

*Stay Safe in Cold Weather* discusses hypothermia and its warning signs, how to prevent the condition in the home or outdoors, and case examples of people at risk. Read this important and helpful booklet on the National Institute of Aging website at:

Reading About Research: Things to Keep In Mind

It seems as though almost every week we hear about a new study that reports exciting progress in dementia research. There is so much work happening in this field and research is crucial to finding treatments and a cure. However, sometimes these studies have conflicting results and they can be hard to interpret. One study might tell you that a particular food or beverage is good for the brain, while another study might show a different result. How do you know what to believe? It is important to stay objective when you read or hear about new research and there are several factors to keep in mind when thinking about how reliable and relevant a study may be. The following information can help you understand and interpret the results of research studies:

What is the source?
Is it a book, a scientific magazine, a popular magazine, a newspaper article, a government web page or a web page from someone with no relevant credentials? Anyone with an opinion can write an article on a web page, but only serious research is published in scientific magazines or peer-reviewed journals (publications reviewed by professionals working in the same field).

Who did the research?
Legitimate research articles always state the name of the researchers, their credentials, the organization where they work, when the research was done, and where the research study was originally published.

How was the study designed?
When reading a study, check the methodology (how the study was designed and conducted) to put the findings in perspective. If the methodology is not explained, it is hard to form an opinion on how valid it is. Here are some other things to consider about the methodology:

Animal or human? Some studies may be conducted on animals rather than humans. However, testing something using animals does not mean that the same results will be found when the same test is conducted with humans.

How many subjects? The higher the number of participants, the more likely the results will be representative of the population being studied. For example, a study with only 10 participants cannot claim to represent a large segment of the population, although it may indicate a potential direction for future research.

The type of population
Do the participants in the study represent the population at large? For example, if the subjects are all experiencing the early stages of Alzheimer’s disease, are the findings applicable to everyone with Alzheimer’s disease? What about other kinds of dementia?

Was there a control group?
Did the study include a group of participants (a control group) who did not receive treatment or participate in the activity that was studied? If so, did this group score worse, better or the same as participants who received the intervention?

Beware of bias
Who funded the study? If the funding agency has something to gain or lose by...
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the results (such as having a product or medication approved or rejected), there is more potential for bias. If it sounds too good to be true, it probably is. Research funded by independent agencies and reviewed by other researchers who didn’t assist with the study is less likely to be biased. Reputable journals require authors to declare any conflicts of interest.

Are the conclusions in line with the results?
Conclusions from the findings of a study should stay within the parameters of the research areas that were studied. Be wary of vague and sweeping generalizations, such as “everyone should take gingko biloba.” Did the study effectively demonstrate a “cause and effect” relationship between the findings and the conclusions? Things can be associated with each other without one causing the other. For example, the presence of aluminum in the brains of people with Alzheimer’s disease does not necessarily mean that aluminum causes Alzheimer’s disease. One possibility might be that aluminum is a by-product of the disease.

How many studies have been done in this area?
One experiment is never definitive. While multiple studies can come to different conclusions, there must be several studies done in an area to know we can trust the results. When enough research has been done on a topic, researchers examine and combine all of these results to look for patterns.

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BRAINSTORMING

We asked participants of the weekly memory loss support group at UC San Diego’s Shiley-Marcos Alzheimer’s Disease Research Center: “WHY DO YOU PARTICIPATE IN RESEARCH?”

Here are a few of their replies:

“My doctor recommended it. What did I have to lose? The doctor gave me a chance for something that could help me, I think it has worked to slow down the progression, and it was worth a shot.”

“I’m the third generation in my family with Alzheimer’s. I participate in research partly because I want to be cured and I feel good about it.”

“The Neurologist told me to and that got me to this Alzheimer’s Research Center and that got me to this support group which is the highlight of my week!”

“I have the problem and I worry about my kids. Both of my parents had Alzheimer’s. I’m doing all I can to fight it.”

“If you didn’t have volunteers for research we wouldn’t have anything!”

“I want to be a part of the future. I want to take part in the cure.”

To learn more about research opportunities in your area, call your local chapter of the Alzheimer’s Association or look for a national research center near you at:

http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers
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