



## ***Tracking Dementia Symptoms Along the Journey***

***William “Barney” Nelson***

*From an interview conducted by Jamie Lett, Indiana University*

***When Barney Nelson received his diagnosis, he was not surprised. Based on his own research, he knew his symptoms already pointed toward Lewy Body Dementia. He rejected the tragedy narrative and looked forward to a life of trying new things and doing things in a different way.***

**Jamie:** Why don't we talk about the diagnostic journey?

**Barney:** It's one of my favorite things to talk about.

**Jamie:** When did you receive your diagnosis, if you don't mind me asking?

**Barney:** January 2019, but frankly, six or seven months before then, I already had pretty well figured out what I had, because my symptoms just lined up very well with Lewy Body. I was starting to have hallucinations at night. My tremors were getting worse, my cognitive capability was getting worse. I'd had REM sleep disorder for many years, which has increasingly become a key indicator from a diagnostic standpoint, sort of a precursor to dementia.

**Jamie:** How did you feel after receiving the diagnosis?

**Barney:** I wasn't surprised, obviously, and I wasn't really scared. One of the first things out of my mouth was, "I'm not afraid to die." You know, dementias are fatal: there is no cure and there's really not a lot you can do, medicine-wise or whatever, to change the trajectory. I don't believe it to be a tragedy narrative, so to speak. You may have to pivot, you may have to do some things differently, you may no longer be able to do things you used to do, you may want to try new things. I knew what the end game was going to be, but I felt like I still could live a lot of my life.

***Barney's diagnosis journey was smoother than many living with dementia. The log of symptoms that he had kept for many months had been a very useful tool for his health care team. To help others along their journey, Barney created Dementia Symptoms Tracking Tools. [www.dementiasymptomstrackingtools.com](http://www.dementiasymptomstrackingtools.com).***

**Barney:** When we talk about the diagnostic process, I very much got into that, understanding the process, because it worked so well for me. I'd hear so many stories from other people who would go four or five years with doctors, trying to get a diagnosis—a really horrible scenario. I mentioned I kept a log of my symptoms. By the time I saw the dementia specialist doctor, showed her my log and described what I'd been experiencing, we were well down the diagnostic road. She actually told me the log helped her understand in an empirical way what was going on with me. It made a big difference, you know?

I went ahead and put together a couple of log sheets and built a website and put them on there. It's called *Dementia Symptoms Tracking Tools*. There are PDF documents, you can download them for free, and you'll see the log and a list of all these different symptoms. You just keep track of what your symptoms are, the time frame they started, frequency, and all that. It's helpful information you can share with your doctor or just keep for yourself, as you track how things are going for you, how symptoms are progressing.

**Jamie:** When did you set that up?

**Barney:** Shortly after I was diagnosed, because I saw a real need for something like that. I saw the whole diagnostic process was a mess. Dementia is a very difficult disease to diagnose accurately, particularly Lewy Body. I saw a real need there, as I heard horror stories about people who, again, were going four or five years talking to three or four different doctors, getting three or four or five different diagnoses and not making any progress, living with fear and uncertainty. It was creating a really difficult burden for them and their families. I wanted to help; I put it together, it didn't take me all that long.