Less than a decade ago, dementia with Lewy bodies was barely into the text books, although it was recognized in Europe and offered as an occasional topic for discussion in some of the professional journals. Today, it is becoming widely known by the precise nature of its symptoms and in the damage it expresses in the brain. This article addresses the unique symptoms, treatments and challenges in caring for someone diagnosed with a dementia with Lewy bodies.

By Irene Barnes

Dementia with Lewy bodies

It’s not Alzheimer’s and it’s not Parkinson’s!

Mr. Jones was an enigma to the resident care staff. At times he would demand that the nurses help him with the poisonous, green smoke he sees filling the hallways.

Then there’s the housekeeper; when she cleans and tidies his room, she’s always in trouble with Mr. Jones because she always moves his things. Mr. Jones found it necessary to pile all the moveable furniture onto his bed when he left the room. He said it was to stop the “critters” in the closet from taking his things.

Baffling behaviour

The staff were baffled by Mr. Jones. The evening shift was concerned about his confusion and hallucinations. The day staff, however, reported that he knew all their names, and although he had an unsteady walk, was alert and made perfect sense when he talked to them.

Mr. Jones would go out every morning for a walk. He didn’t like it when staff tried to detain him. He knew exactly what he wanted and demanded the freedom to do so.

While out walking, Mr. Jones fell and was returned by the police, who couldn’t understand why we allowed this very confused and unsteady man out of the facility.

The drug Sinemet (for treating the symptoms of Parkinson’s disease) was prescribed to off-set the sudden falls and “freezing” episodes experienced by Mr. Jones. Within 24-hours after taking the drug, he was shouting for everyone to evacuate the building because of the fire. When the staff told him there was no fire, he became very agitated and tried to rescue the other residents on his own.

The next morning, Mr. Jones was calm, but became very upset when reminded of the “fire” episode last evening. He denied that it happened and felt that staff were against him.

As to the care required for Mr. Jones, the staff were initially in conflict. The evening staff were very distressed by the content of his hallucinations and by the fear he experienced within. They felt that something had to be done to dampen or eliminate the hallucinating episodes and paranoia. They opted for an antipsychotic.

The day staff, on the other hand, were concerned with the adverse reactions when Mr. Jones was on antipsychotic medications. The false or accusatory ideas Mr. Jones experienced were dampened by the antipsychotics prescribed, but he was falling more, and at a higher risk for a fracture.

From his perspective, Mr. Jones felt life was hopeless: no one understood.