Eight Questions to Help Clients Avoid Antipsychotic Medications

By John L. Roberts, CELA

Elder Law attorneys can help bridge the information gap that separates clients and families from a full understanding of steps they can take to protect quality of life for memory-loss patients.

When family members grasp the cause and effect behavior patterns of memory loss, they can ease the dramatic crisis that would otherwise escalate when a memory-loss patient exhibits erratic behavior: aggression, yelling, wandering, and resisting assistance. More people can be spared from the antipsychotic medications that have been too commonly used to manage care during the final months and years of life. Elder Law attorneys can help.

John L. Roberts, CELA

The following eight questions and answers can help you understand alternatives to behavior modification medications.

John L. Roberts, CELA, serves clients in Hampden County, Mass. A bibliography of resources on the alternatives to antipsychotic drugs is available at: http://MassHealthHELP.com/html/antipsychotic_bibliography.html. This article was previously published in the NAELA Guardianship/Conservatorship Section Newsletter. To join this Section or to learn more about NAELA Sections, visit www.NAELA.org > Membership > Member Resources > Sections.

1. Have you read about how families can respond to memory loss?

"Failure-free" activities at home can help a memory-loss patient:

> Find activities that build on remaining skills and talents. A professional artist might become frustrated over the declining quality of work, but an amateur might enjoy a new opportunity for self-expression.[1]

At first, embarrassment over declining or lost capabilities may prevent a memory-loss patient from responding to or accepting activities and interaction. Time, patience, and love are the ingredients that allow family members to manage erratic behavior in a way that can help avoid antipsychotic intervention.

Psychologist Paul Raia, Director of Clinical Services for the Alzheimer's Association, MA/NH Chapter, explains the most obvious problem for the memory-loss patient:

> [P]eople with Alzheimer's disease who spend significant amounts of time doing nothing experience more psychiatric symptoms, such as depression, anxiety, paranoia, delusions, and hallucinations, than people who are occupied by

1 Alzheimer's Association, *Activities at Home: Planning the Day for a Person With Dementia*, www.alz.org (accessed Sept. 14, 2012).

a meaningful activity. The increased amounts of leisure time with which these people find themselves can be addressed successfully through enriching activities that promote feelings of purpose and accomplishment.[2]

2. Are you aware of the alternatives to antipsychotic medication?

Lack of consistent daily relationships may be the most common cause of erratic behavior. The resulting boredom creates a poor quality of life for the memory-loss patient, just as it would for you and me.

No one would consider it reasonable to leave a child with a disability alone in an apartment every day. But how many elderly memory-loss patients are left alone in assisted living apartments for hours every day, and then evicted when they exhibit erratic behavior?

Appropriate activities provide an alternative to the boredom and frustration that lead to acting out. These activities require companionship, a solution that can take the memory-loss patient off the path toward chemical restraints and a nursing home admission. Paid companions can serve many functions that benefit a memory-loss patient. In addition to assisting the patient with activities like eating and dressing, the very presence of a companion is comforting, preserves a personal daily routine, and is significant on an emotional and psychological level.

3. Did you know that environment and physical health can trigger erratic behavior?

Dr. Raia offers the example of an Alzheimer's patient who would occasionally get up from his chair, walk across the room, and hit another resident:

> By keeping a log, we began to see that he would only hit someone if he was in the activities room, but not every time he was in that room. There did not appear to be any pattern to whom he hit. Later, we saw that he would only hit people on sunny days, but not on every sunny day on which he was in the activities room. Then, we saw that he only hit people on sunny days if he was sitting on one side of the room. With the log we were able to eventually determine that he would hit people if he sat in the activities room and the sun was shining in his eyes. The intervention was simply to make sure that the blinds were closed on sunny days if this particular man was in the activities room. Thus, with patience and careful analysis of the situation we were able to avoid the use of a psychoactive medication.[3]

Dr. Helen Kyomen, an associate psychiatrist with McLean Hospital in Belmont, Mass., has published an article, "Agitation in Older Adults," that has questions to prompt physicians and caregivers to search for alternatives to medication:

> **Is there over stimulation?** Does the patient have a roommate who intrudes into the patient's personal space excessively? Is the patient's space overly noisy because of equipment (such as oxygen concentrators or ventilators) or individuals who call out incessantly? Are staff members rushing in and out of the patient's area as they change shifts?
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> **Is there under stimulation?** Is the patient occupied with appropriately challenging tasks that encourage interest and a sense of mastery? Is the patient exposed to adequate amounts of sensorimotor stimulation?
>
> **Do people or objects trigger stressful memories, drives, or feelings?** Does the patient believe that a family member is responsible for the patient's placement in an extended-care facility? Does the patient think that a friend who comes to visit at the hospital is able to take him or her home? Does a roll belt or other safety restraint trouble the patient?
>
> **Are there unmet needs?** Is the patient hungry or thirsty? Does the patient need to be oriented to the facility or be toileted? Does the patient need glasses, hearing aids, or similar sensory enhancers?[4]

Dr. Kyomen also lists some of the physical ailments that can trigger erratic behavior: arthritis, constipation, diarrhea, urinary tract infections, vaginal yeast, decubitus ulcer infections, tinea (ringworm), gastroesophageal reflux disease, headaches, muscle aches, dental problems, podiatric conditions, low vision, and hearing loss. Care and understanding of the medical conditions can prevent escalation of erratic behaviors.

4. Do you realize how much Medicare spends drugging dementia patients?

Alternative responses to erratic behavior cannot be monetized as easily as a pill or an injection. The U.S. Department of Justice has filed suit against the makers of Risperdol[5] for

2 Paul Raia, *Habilitation Therapy: A New Starscape*, Enhancing the Quality of Life in Advanced Dementia, (Brunner/Mazel, 1998).

3 *Id.*

4 Helen Kyomen & Theodore H. Whitfield, *Agitation in Older Adults*, 25 Psychiatric Times (No. 8, 2008).

5 Dept. of Justice, *U.S. Files Suit Against Johnson & Johnson for Paying Kickbacks to Nation's Largest Nursing Home Pharmacy*, www.justice.gov/opa/pr/2010/January/10-civ-042.html (Jan. 15, 2010).

allegedly paying millions of dollars in "kickbacks" for dispensing drugs to nursing home patients. The manufacturer defended the rebates it dispenses to Risperdol prescribers.

The Center for Medicare Advocacy estimates that substantial savings could be achieved if Medicare did not enable the inappropriate use of these powerful drugs.[6] The Office of Inspector General found that more than half of Medicare claims for atypical antipsychotic drugs given to nursing home patients were erroneous, amounting to $116 million in waste during a six-month period in 2007.[7]

5. Do law and practice conflict in your state?

Nursing homes use psychotropic medicines to modify the behavior of residents who suffer from Alzheimer's disease, memory loss, and dementia. Medicare surveys show that in many states, 20 percent of nursing home residents who are on antipsychotic medications have not been diagnosed with a psychotic condition (see map on page 15).[8] Nursing home administrators have recognized this.[9] But the courts in your state may not be aware of the problem.

Under federal law, patients have the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms.[10] Restraints may only be imposed: 1) to ensure the physical safety of the resident or other residents, and 2) only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used.[11]

Indications that allow for antipsychotic drug use are listed in the State Operations Manual published by the Centers for Medicare & Medicaid Services.[12] It also lists indications when administering antipsychotic medications is prohibited:

> If the only indication is one or more of the following, the drugs should not be used: 1) wandering; 2) poor self-care; 3) restlessness; 4) impaired memory; 5) mild anxiety; 6) insomnia; 7) unsociability; 8) inattention or indifference to surroundings; 9) fidgeting; 10) nervousness; 11) uncooperativeness; or 12) verbal expressions or behavior that are not due to the conditions listed under "Indications" and do not represent a danger to the resident or others.[13]

6. Are judges in your state aware of alternatives?

If antipsychotic medication monitoring is part of your state's Probate or Surrogate's Court system, court authority to administer the drugs may be routinely allowed based on paper filings. If judges have not been educated about alternative approaches to managing erratic behaviors, frail elders who have memory loss and dementia may be mixed into a case flow of patients of all ages who have psychosis and severe mental illness. If the court appoints a monitor who is not trained to raise the issue of alternatives, or to explore potential options, another chance for a higher quality of life for the memory-loss patient is forfeited.

Next, consider the case where a Petitioner who understands the alternatives suggests the alternatives to medication to the Court. Awareness of these alternatives is absolutely essential for a judge who is asked to decide a contested Guardianship. A judge who understands the alternatives will be able to understand the family member who asks the Court to order a Health Care Agent or the holder of a Power of Attorney (POA) to provide companionship services, appropriate activities, and other services to an elder who is in the early or mid-stages of dementia.

If the Health Care Agent/POA refuses to provide the services, a judge who is unfamiliar with alternatives may simply dismiss the petition, as long as the elder is receiving basic care and assistance with activities of daily living.

6 Center for Medicare Advocacy, Inc., *Reducing Antipsychotic Drug Use in Nursing Homes: Save Residents' Live, Save Medicare Billions of Dollars*, http://www.medicareadvocacy.org/2011/03/17/reducing-antipsychotic-drug-use-in-nursing-homes-save-residents-lives-save-medicare-billions-of-dollars/ (Sept. 24, 2012).

7 U.S. Dept. of Health & Human Servs., Off. of Inspector Gen., *Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents*, ii, http://oig.hhs.gov/oei/reports/oei-07-08-00150.pdf (May 4, 2011).

8 The Centers for Medicare and Medicaid Servs., *MDS Quality Measure/Indicator Report*, https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MDSPubQIandResRep/qmreport.html (Apr.-June 2010).

9 Kay Lazar, *Mass. aims to cut drug overuse for dementia*, Boston Globe (Nov. 18, 2010), http://www.boston.com/news/health/articles/2010/11/18/mass_aims_to_cut_drug_overuse_for_dementia/.

10 42 U.S.C. § 1395i-3(c)(1)(A)(ii); 42 U.S.C. § 1396r(c)(1)(A)(ii).

11 *Id.*

12 Centers for Medicare & Medicaid Servs., State Operations Manual, Appendix PP — Guidance to Surveyors for Long Term Care Facilities, at 383 (Jan. 7, 2011).

13 *Id.* at 387.

Many Probate Court judges have a background in family law and divorce practice. The judge may view a contested guardianship case through a similar lens, seeing the Petitioners as disagreeable family members who want to wrest control from the Health Care Agent/POA. Seen through tiny windows of pretrial motion hearings, the view becomes further narrowed at trial by vigorous application of evidence and procedural rules. The case ends up being less about the needs of the elder, and more about a struggle for power among parties. The judge may forfeit many opportunities to motivate the recalcitrant Health Care Agent/POA to protect the quality of life of a person who becomes lost at the center of the swirling legal controversy.

If the judges in your state *do* understand the alternatives that prevent the need for antipsychotic medications, the recalcitrant Health Care Agent/POA can be more readily encouraged to listen to requests for services, at a time in the journey when those services will do the most good.

7. Are medication monitors and court-appointed attorneys in your state trained to understand the difference between memory loss and psychosis?

Understanding Clients Who Have Dementia

By John L. Roberts, CELA

In July 2012, I took a 10-minute Virtual Dementia Tour that opened my mind and heart to the emotions that might be experienced by a person who has diminished capacity. The tour was provided by the staff at Keystone Woods Assisted Living in Springfield, Mass.

Have you ever taken a guided tour that provides a recording or a live tour guide who directs your attention and helps you understand a new or unfamiliar place? The dementia tour is just the opposite.

The following artificial impairments set me up for the indignity of dementia and the very serious emotions that a person with diminished capacity has to deal with every day:

- Headphones over my ears simulate the hearing experienced by a person with diminished capacity. The headphones play distracting bits of conversations, sirens, and noises, to simulate the mental confusion that goes with the inability to process and sort out sounds and voices.
- My eyes are covered by yellow tinted goggles with solid black focal points that obscure the center of my field of vision to simulate macular degeneration and loss of vision.
- Plastic sheets with prickly spikes are inserted in my shoes to simulate neuropathy and loss of feeling in my feet.
- Thick plastic gloves with bumpy spikes on both of my hands take away my sense of touch, and any dexterity.

Constant irritation: I feel annoyed that my hearing and vision is being interfered with. Why can't I see the full field of vision? What little I can see is obscured through a yellow filmy haze.

Anger: The tour guide gives me quick instructions of what I'm supposed to do next: fold up a pair of socks, brush my teeth, and several other tasks that I can't hear through the cacophony that's pouring into my head from the earphones.

Fear: I can only imagine the panic I would be feeling if this demonstration were the real thing. Someone who should know and understand my needs just took 10 seconds to tell me what to do, and pushed me away.

Frustration: I fumble with the pair of socks, and try to remember the other tasks the tour guide told me to do. How am I supposed to get through this if no one will help me?

Sadness: I know I could do some of the tasks, if only someone would prompt me or give me just a little bit of time or attention. But no one does.

After several minutes of futility, the tour is over and I have a small understanding of the emotions experienced by the person with dementia. I also have a much greater understanding of the importance of our responses to the need for care.

Antipsychotic drugs may be avoidable, if reasons for erratic behavior are understood.

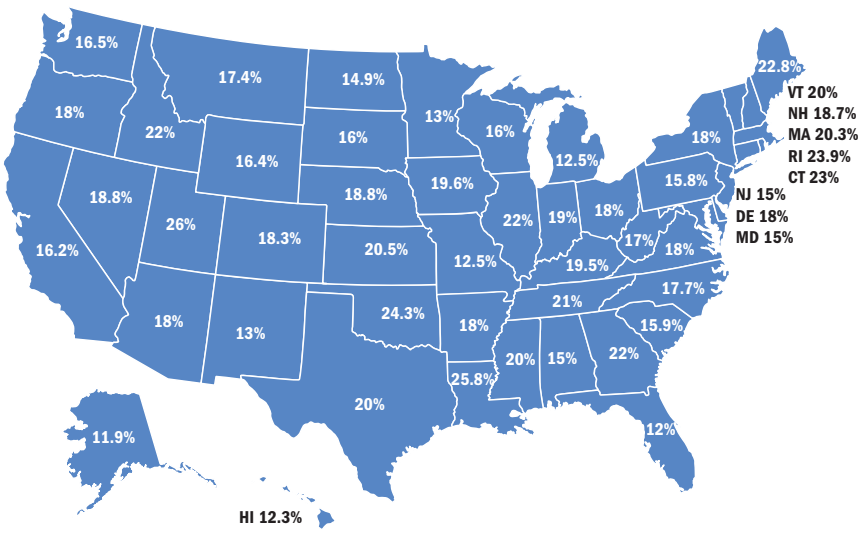
The first line of defense for people who don't have a knowledgeable Health Care Agent are the court-appointed attorneys and monitors who are responsible to protect the patient's interests. Do these court-appointed advocates understand the proactive approaches to erratic behavior that can prevent or reduce the need for antipsychotic medications? Does training for these advocates adequately distinguish the memory-loss client from younger patients with psychosis and severe mental illness?

Advocates and attorneys who can distinguish each case of progressive memory loss are better able to help clients and families protect the quality of life for the memory-loss patient.

8. Are nursing homes in your state aware of the alternatives?

If a nursing home admission does become necessary, the memory-loss patient can still be spared the intrusion of antipsychotic medications. Dr. Susan Wehry, Commissioner of the Department of Disabilities, Aging and Independent Living in Vermont, told Massachusetts nursing home administrators in November 2010 that when it comes to changing behavior, it's "easier to change ours." Dr. Wehry advises nursing home staff to think of their caregiving as more about building a relationship with the patient, as opposed to simply carrying out tasks.

Genuine relationships with nursing home residents require that staff members be curious about residents' backgrounds, personalities, and needs. When erratic behavior crops up, staff members should ask themselves: "What is this person trying to tell me?"



Nursing homes use psychotropic medicines to modify behavior of residents who suffer from Alzheimer's disease, memory loss, and dementia. In some states, 20 percent of nursing home residents who are on antipsychotic medications have *not* been diagnosed with a psychotic condition. (Source: See footnote 8.)

Conclusion

An editorial in the February 2009 Lancet[14] concludes that: "The risks and benefits of prescribing antipsychotics to patients with dementia need to be carefully balanced and these drugs should be used only if alternative strategies do not work. To protect the health and dignity of people with dementia and reduce the use of antipsychotic drugs, approaches that make the needs of patients central to decisions about care should be promoted." ■

14 *Antipsychotic Drugs for Dementia: A Balancing Act*, 8 The Lancet, 125 (Issue 2, Jan. 2009), http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(09)70001-8/fulltext.