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In This Issue

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Erratic Behavior and Memory Loss: Help Your Clients Find Alternatives to Antipsychotic Medications

By John L. Roberts, CELA

Erratic behavior among people with dementia poses a challenge for caregivers. Nursing homes often resort to powerful antipsychotic medications to control the behavior of residents with memory loss, dementia, and Alzheimer's. A national survey found that in 2004 about one-quarter of residents were being administered these drugs, and data collected by the Centers for Medicare and Medicaid Services in 2010 shows that up to 20 percent of the nursing residents who are given antipsychotic medications do not have a psychotic condition. Nursing homes that have frequently employed antipsychotic drugs in the past are more likely to administer them to newly admitted residents, according to a 2010 University of Massachusetts Medical School study.

The use of antipsychotic drugs (such as Abilify, Haldol, Risperdal, Seroquel, and Zyprexa) to quell dementia's behavioral symptoms can cause serious side effects beyond the chemical "fog" they often induce. In 2005 the U.S. Food and Drug Administration began requiring manufacturers of "atypical" antipsychotics (including Risperdal, Seroquel, and Zyprexa) to include black box warnings of increased mortality risk for older patients with dementia, and in 2008 the agency extended the requirement to conventional antipsychotic drugs. Since then, doctors who treat elderly patients outside of nursing homes have cut back on prescribing antipsychotic drugs for dementia patients, but the practice persists in nursing homes.

Nursing home administrators are becoming aware of the problem. For example, in November 2010, the Massachusetts Bureau of Health Care Safety and Quality launched a campaign to educate administrators about non-pharmacological strategies to address erratic behavior in dementia and Alzheimer's patients.

A similar educational effort is needed for elder law attorneys, for financial planners who influence long-term care planning decisions, and for the family members of elders with memory loss and dementia. Elder law attorneys must be knowledgeable about the progressing needs of memory loss patients and the available non-chemical alternatives to help protect each client's quality of life. Without this perspective, Medicaid planning and efforts to protect or set aside assets will be, at best, incomplete. At worst, asset-protection advice acted on without a sound understanding of the needs of a memory loss patient who is still able to live at home or in assisted living may cause the family to withhold or hoard financial resources that would otherwise have prevented a nursing home admission and reliance on antipsychotics.

Safer and less intrusive alternatives to antipsychotic medication are available to families and caregivers who want to do everything possible to prevent the erratic behavior that causes a crisis nursing home admission, and to avert the use of chemical restraints in a nursing home. This article describes some of those alternatives and urges elder law practitioners to make their clients aware of them before behavior becomes erratic and unmanageable.

The Law Covering Chemical Restraints

Federal law guarantees nursing home residents the least restrictive living environment. Residents have the right to be free from “any physical or chemical restraints imposed for purposes of discipline or convenience that are not required to treat medical symptoms. Restraints may only be imposed (I) to ensure the physical safety of the resident or other residents, and (II) only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used.” 42 U.S.C. § 1395i-3(c)(1)(A)(ii) and 42 U.S.C. §1396r(c)(1)(A)(ii).

The regulations implementing the Nursing Home Reform Law explicitly limit the use of antipsychotic drugs. 42 C.F.R. §483.25(l)(2) states that any use of antipsychotic drugs must be based on a comprehensive assessment of a resident to ensure that:

i. Residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record; and

ii. Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs.

Guidance issued to Surveyors for Long-Term Care Facilities by the Centers for Medicare & Medicaid Services lists inadequate indications for administering antipsychotic medications:

> They should *not* be used if the only indication is one or more of the following: 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.

State Operations Manual, Appendix PP at 387 (emphasis added). “When antipsychotics are used without monitoring they may be considered unnecessary medications.” Id. at 389.

Do you have clients who, under their authority as health care agents, have authorized the use of antipsychotic medications to address erratic behavior? Does the health care agent understand the rules, their responsibility to monitor the situation, and the rights that they may have abdicated on their loved one’s behalf?

Identifying the Underlying Causes of Erratic Behavior

Dementia can be accompanied by a number of problematic behaviors, including aggression, yelling, wandering, and resisting assistance. However, these difficult behaviors often can be traced to an underlying disease or to the memory loss patient’s environment.

At the 2009 American Association for Geriatric Psychiatry program on “Evaluating and Managing Aggressive Behaviors in Geropsychiatric Patients,” Dr. Helen Kyomen, an associate psychiatrist with McLean Hospital in Belmont, Massachusetts, discussed 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. Dr. Kyoman stressed that consistent care and understanding of these medical conditions can prevent escalation of behaviors.

A recent *New York Times* article illustrates her point. The article tells the story of a Minnesota nursing

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Tax Act Brings Changes to SSI/Medicaid Treatment of Refunds, Tax Credits

The Tax Relief, Unemployment Insurance Reauthorization and Job Creation Act of 2010 is best known as the law that extended the Bush-era tax cuts. It includes several little-noticed provisions that fundamentally alter how the Supplemental Security Income (SSI) and Medicaid programs treat tax refunds and other tax credits, making it easier for elders and people with special needs to maintain their benefits.

Pursuant to Section 728 of the new law, tax refunds are not considered countable income for SSI or Medicaid purposes. Furthermore, any money received through a tax refund will not be a countable resource for 12 months following receipt of the funds, and SSI and Medicaid recipients will be under no obligation to segregate the funds from their other resources. The same rule applies to tax refunds received prior to an application for SSI or Medicaid, which means that so long as an applicant can point to funds in his account that are traceable to a tax refund during the previous year, those funds will not be a countable resource until the year has passed.

The new law also changes the treatment of several other important tax credits. Under previous rules, Making Work Pay, Earned Income, Advanced Earned Income, and Child Tax Credits were all excluded as countable income for SSI and Medicaid purposes, but if the income was retained, it had to be spent within nine months of receipt. Now, the 12-month rule applies to all of these tax credits. In addition, First-Time Homebuyer Tax Credits that were previously countable as income and as a resource are now exempt and subject to the same countability rules as the other tax credits.

CMS's Informational Bulletin also addresses what happens when an applicant seeking Medicaid long-term care benefits places her tax refund into a trust. According to the bulletin, the law "effectively precludes applying penalties under section 1917(c) of the Social Security Act to individuals who, in applying for long term care benefits under the Medicaid program during the period in which tax refunds or advance payments are not countable either as income or resources . . . dispose of part or all of the refunds or advance payments in a manner that normally would be considered a transfer of assets for less than fair market value."

In one more piece of good news, the law applies to any refunds or credits received after December 31, 2009, which means that, in limited cases, applicants who were initially denied SSI or Medicaid benefits because of receipt of a tax refund or credit may actually be retroactively eligible for benefits.

For the Social Security Administration's Emergency Message regarding the changes, go to: http://bit.ly/gkTH4J; for CMS's Informational Bulletin, go to: http://bit.ly/ii4qd1

home patient, a woman in her 90s, who would frequently cry out and was given a "potent cocktail" of three psychotropic drugs, including the antipsychotic Risperdal. Then the nursing home began a program to employ behavioral solutions in an effort to wean its residents off antipsychotic medications. After the woman's medications had been reduced she was able to communicate, and it was discovered that pain from a nerve condition was the cause of her earlier wordless cries. After the nerve condition was treated, the nursing home was able to stop her psychotropic medications completely. (See "Clearing the Fog in Nursing Homes," Feb. 15, 2011.)

Alternatively, the memory loss patient's environment may be to blame for behavioral problems. If the patient is engaging in erratic behavior, Dr. Kyomen has a checklist of questions for physicians and caregivers, including:

Is there overstimulation? 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?

Is there understimulation? 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? Are the programming activities and structure appropriate to the patient's functional capabilities?

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? Is the patient troubled by a roll belt or other safety restraint?

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?

The lack of consistent daily relationship may be the most common cause of erratic behavior. Lack of relationship and resulting boredom creates a poor quality

State Laws Create Obstacles to End-of-Life Planning, Study Finds

A new study of advance directive laws nationwide finds that all states erect barriers that make it difficult or impossible for individuals—particularly the isolated elderly and terminally ill—to complete advance directives.

For example, researchers found that the advance directive documents in use in all the states are written above a 12th-grade reading level, when 40 percent of Americans can read no higher than an 8th-grade level. In addition, 35 states do not allow oral advance directives and 48 states require witness signatures, a notary public, or both. Both restrictions effectively guarantee that many isolated elderly individuals will not let their end-of-life wishes be known, the researchers note. Often the only people terminally ill patients trust are health providers and social workers, but state laws ban such individuals from serving as health care proxies. Forty states do not allow same-sex or domestic partners to be the default health care proxy if an individual hasn't chosen one, as would be the case for heterosexual spouses.

The researchers' recommendations include improving document readability, allowing oral advance directives, eliminating witness or notary requirements, and removing bans on certain individuals serving as proxies.

The study is reported in the January 17, 2011, issue of the *Annals of Internal Medicine* and is titled "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care." Among the study's authors is Charles P. Sabatino, director of the American Bar Association Commission on Law and Aging.

of life for the memory loss patient, just as it does for you and me.

No one would consider it reasonable to leave a child alone in an apartment every day, especially a child diagnosed with a disorder such as autism or schizophrenia. However, how many elderly memory loss patients are left alone in assisted living apartments for hours each day, and then evicted when they exhibit erratic behavior? Psychologist Paul Raia, Ph.D., Director of Clinical Services for the Alzheimer's Association, MA/NH Chapter, has observed that "people 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 a meaningful activity." (See *Enhancing the Quality of Life in Advanced Dementia,* Brunner/Mazel, 1998.)

Dr. Raia explains how "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."

The Alzheimer's Association offers an easily understood pamphlet explaining activities to engage the memory loss patient ("Activities at Home"). The pamphlet counsels that activities must be realistic and relaxed: "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."

Often, embarrassment over declining or lost capabilities may initially prevent a memory loss patient from responding or accepting activities and interactions. Time, patience, and love are indispensible when approaching erratic behavior if the family wants to avoid antipsychotic intervention.

Companion Services

Providing "failure free" activities requires companionship, a solution that takes the memory loss patient off the otherwise certain path toward chemical restraints and a nursing home admission. Paid companions, also known as "sitters," can serve many functions that benefit a memory loss patient. In addition to assisting the patient with activities such as eating and dressing, the very presence of the companion is comforting, preserves a personal daily routine, and is significant on an emotional and psychological level.

Family members who grasp how companion services can support the memory loss patient at home or in assisted living will play a significant role in postponing a nursing home admission or sparing their loved one from being subjected to psychotropic medication and physical restraints once in a nursing home.

Families who are unable to grasp the concepts of compassion and quality of life for the memory loss patient may be persuaded to invest in supplemental services for financial reasons in order to protect a five-year Medicaid look-back period.

Family members who are still unwilling to see the increasing needs of the memory loss patient, and decide to withhold resources from the patient, will miss important opportunities to prevent the need for antipsychotic medications. There is little that an elder law attorney can do in these situations. Can you ethically assist with Medicaid planning or probate proceedings if you know that a family member is likely to use a power of attorney to deny the elder access to services

Keep in Touch – *The ElderLaw Report* welcomes letters in response to articles. Letters can be sent to: *ken@elderlawanswers.com* that could prevent a nursing home admission and use of antipsychotic medication?

Changing the Culture of Nursing Homes

If a nursing home admission does become necessary, companions can still play a role in reducing the need for physical and chemical restraints. As memory loss and dementia progress, the patient may experience panic, terror, or confusion, and these strong emotions can drive an individual to express a need to fight or escape. The familiar and friendly face of a companion who is devoted to the patient can help the individual get through periods that would otherwise escalate to unmanageable behavior.

Companions, though, cost money. If a supplemental needs trust has been established, a Medicaid patient can be provided a level of companionship that a busy nursing home staff cannot provide. When no financial resources are available, family members who visit regularly can encourage interaction with nursing home staff and help relieve the loneliness and boredom that can escalate to erratic behavior.

Susan Wehry, M.D., the recently named Commissioner of Vermont's Department of Disabilities, Aging and Independent Living, told an audience of Massachusetts nursing home administrators in November 2010 that when it comes to changing behavior, it is "easier to change ours." Dr. Wehry advised nursing staffs to make their care more about building a relationship with the patient rather than simply carrying out tasks. She explained how genuine relationships with nursing home residents require that staff members be curious about the backgrounds, personalities, and needs of their residents. When erratic behavior crops up, staff members should ask themselves, "What is this person trying to tell me?" If genuine relationships are established, the staff is better able to figure out what is causing the behavior without quickly turning to antipsychotic drugs.

In short, there is no substitute for time spent with the memory loss patient. Dr. Raia in his book offers the example of an Alzheimer's patient who would occasionally get up from his chair, walk across the room, and hit another nursing home 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."

To relieve confusion and distress, the environment of the nursing home must have common quiet spaces and staff members who speak in normal conversational tones.

The family member who hoards resources, visits infrequently, and places a memory loss patient in a noisy nursing home room shared with three other medically needy residents can expect the facility to rely on antipsychotic medications to manage the loved one's confusion and resulting behavior.

Conclusion

When family members understand how a memory loss patient's unmet needs can drive behavior, they have taken the first step toward solutions that may prevent a nursing home admission or the unnecessary use of antipsychotic medications.

Antipsychotic medications are far less expensive than hiring staff or providing a companion to sit and engage the memory loss patient in appropriate activities and conversation. Anyone with progressive dementia and

Elderly Woman Can Sue Law Firm for Unfair Debt Collection

An 85-year-old New Jersey woman who missed her final mortgage payment because she was hospitalized can sue a law firm for unlawful debt collection, even though the firm contacted her lawyer about the debt and did not contact her directly, a federal court has ruled.

Dorothy Rhue Allen missed her final mortgage payment of $432 on the house she had owned since 1976 because she was in the hospital. The mortgage company began foreclosure proceedings against Ms. Allen through a law firm. When Ms. Allen's lawyer asked how much she would have to pay to resolve the problem, the bank and law firm told her the total charges would be $5,797, including nearly $2,400 in legal fees.

Ms. Allen sued in federal court, alleging these charges were much higher than allowed under the Fair Debt Collection Practices Act. A district court judge dismissed the case, finding that the charges were not covered by consumer protection law because they were sent to Ms. Allen's lawyers. However, a federal appeals court found that the communication to Ms. Allen's attorney was an indirect communication to Ms. Allen and sent the case back to the district court to revisit. Other appeals courts have been divided on this question.

Ms. Allen's attorney has asked the court to certify the case as a class action.

memory loss—even the client with plenty of money and the means to pay for a good quality of life without heavy medication and restraints—is at risk of being drawn into a nursing home legal system that routinely approves antipsychotic medication as an inexpensive substitute for individual care.

Unless there is a family member who is educated and able to ask about the alternatives, the path of least resistance too often leads to antipsychotic drugs under the current system.

When providing your clients with the technical legal information they need to make long-term care decisions, also help them understand the alternatives to antipsychotic medication that are necessary to protect quality of life and give their long-term care plans the best chance of success.

John L. Roberts, CELA, is an elder law attorney in Longmeadow, Massachusetts. A former judicial law clerk for the U.S. District Court in Springfield, he has served clients with probate, estate settlement, real estate, Medicaid, and estate planning in Hampden County since 1991. A bibliography of resources on alternatives to antipsychotic drugs is available at: http://MassHealthHelp.com/html/antipsychotic_bibliography.html