



Guardianship/Conservatorship Section

Bulletin

CHAIR CATHERINE ANNE SEAL, CELA • FALL 2011

Message from the Chair

Catherine Anne Seal, CELA

Thank you for allowing me to serve as your Chair for 2011-2012 committee year. Serving along with me is **Wendy Cappelletto**, who is your Co-Chair. The Steering Committee generally meets bi-monthly by telephone conference call. Any Section member may participate in the call. Please let Meredith Hansen (mhansen@naela.org) know if you are interested.

The following Section members currently serve on the steering committee:

- **Wendy Shparago Cappelletto**, Chicago, Ill.
- **K.T. Whitehead**, San Antonio, Texas
- **Donna Bashaw, CELA, CAP**, Laguna Hills, Calif.
- **Sharon Rivenson Mark, CELA**, Jersey City, N.J.
- **Shirley Berger Whitenack**, Florham Park, N.J.
- **Patrice Icardi**, Anchorage, Alaska
- **Kim Trigoboff**, Forest Hills, N.Y.
- **Amy Landers May**, Columbia, S.C.
- **Ed Zetlin**, Arlington, Va.
- **Frank Johns, CELA, CAP**, Greensboro, N.C.
- **Marta Williger, CELA**, Munroe Falls, Ohio

As a Section, we work on guardianship and conservatorship issues, including advocacy and education. The Section is always interested in new projects, so if you have something you would like us to consider, please contact either Wendy or me.

The Section is now working on the preparation of an Elder Law handbook for clients and consumers. We have invited other Sections to work with us on this project, and our goal is to prepare a handbook for electronic delivery to our members, which they could print and distribute to

clients and to their community. If you are interested in the handbook, please contact Wendy Cappelletto (wendy.cappelletto@cookcountyil.gov).

The most significant issue for the Section this year is the Third National Guardianship Summit. For more information see the event website at www.guardianshipsummit.org.

NAELA's Section Community pages are now functional. Please log in to the NAELA website and select the "Communities" tab. This will bring up all of the Communities

to which you belong. The Guardianship/Conservatorship Community contains articles, minutes of past Steering Committee meetings, and a dedicated Listserv. Please take a few minutes to complete your profile information as this will help your fellow Section members learn a little more about you. Consider uploading a photo as well. There are a number of Section members who have not signed in to the Section community yet. If you are having difficulties, please contact naela@naela.org. ■

Contents

- | | |
|--|---|
| 1 MESSAGE FROM THE CHAIR
By Catherine Anne Seal, CELA, Chair | 6 MORE THAN HALFWAY THERE:
FALL 2011 UPDATE ON THE
ADOPTION OF THE UNIFORM ADULT
GUARDIANSHIP AND PROTECTIVE
PROCEEDINGS JURISDICTION ACT
(UAGPPJA)
By Kim F. Trigoboff, Esq. |
| 2 GUARDIANSHIP/CONSERVATORSHIP
SECTION STEERING COMMITTEE
2011-2012 | 7 ADULT GUARDIANSHIPS: A "BEST
GUESS" NATIONAL ESTIMATE AND
THE MOMENTUM FOR REFORM
By Brenda K. Uekert and Richard
Van Duizend |
| 2 HIGHLIGHTS OF THE JANUARY
NAELA UNPROGRAM IN DALLAS
By Catherine Anne Seal, CELA | 10 DINNER WITH MORE
UNDERSTANDING: CONTEMPORARY
DRAMA WITH EIGHT QUESTIONS
TO HELP YOUR CLIENTS AVOID
ANTIPSYCHOTIC MEDICATIONS
By John L. Roberts, CELA |
| 3 USE OF COLLABORATIVE LAW IN
GUARDIANSHIP/CONSERVATORSHIP
MATTERS
By Donna Bashaw, CELA, CAP | |
| 4 A NATIONAL STUDY OF
GUARDIANSHIP/CONSERVATORSHIP
MODELS
By Joelle M. Shabat | |

Dinner with More Understanding: Contemporary Drama With Eight Questions to Help Your Clients Avoid Antipsychotic Medications

By John L. Roberts, CELA

Painting Churches is a two act play that illustrates the emotional strain that progressive dementia puts on the spouse and child of a memory-loss patient. As the memory loss of Mr. Church becomes undeniable, Mrs. Church decides the couple has to downsize and move out of their Beacon Hill townhouse.

A FAMILIAR SCRIPT

At the outset, the decision to downsize makes sense. But as Act One unfolds, we learn that the plan to save money on living expenses means moving to Cape Cod, where the couple will live year round, at their isolated vacation cottage.

Painting Churches is about the love, acceptance, and understanding that the couple, and their middle-age daughter, find for each other. Watching them revisit the events that shaped their relationships, we get fascinating insights into our own lives, and relationships with our own parents.

The play was way ahead of its time. When it was first produced Off-Broadway in 1976, who knew about the spectrum of dementia-related diseases? The portrayal of memory loss and frailty in *Painting Churches*, and our own interpersonal struggles with these realities, is portrayed with great care and affection. The human emotions we see on stage are timeless.

The script doesn't get bogged down in technical discussions of care planning or aging in place. The job description of Geriatric Care Manager had yet to be written in 1982 when the play won a Pulitzer Prize for

Drama. GCM's and Elder Law attorneys sitting in the audience today will likely imagine Mr. and Mrs. Church heading off to elder care problems: frail Mrs. Church assigned to manage the memory loss of Mr. Church, alone, in an isolated cottage, hundreds of miles from their only adult child.

Thirty five years later, we have a much improved understanding of elder care planning, and how to explain the options to our clients and their families. Today, clients like Mr. and Mrs. Church would be better advised on how to make their transition plan work. But we can still do better at bridging the information gap that separates clients and families from full understand of proactive steps that can be taken to protect the quality of life of a memory-loss patient.

When family members do grasp the cause and effect patterns that psychologists and social workers have identified in our systems of care, they can ease the dramatic crisis that would otherwise escalate when a memory-loss patient exhibits erratic behavior: aggression, yelling, wandering, and resisting assistance. We can help. 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.

AN UPDATED SCRIPT, TO REDUCE THE DRAMA AND HEARTBREAK OF CARE TRANSITIONS

If we were to dramatize ways to bridge the gaps between public policy, professional practice, and court procedures, we might produce a play about a seasoned GCM who sits down to dinner with a newly admitted Elder Law attorney.

The script could play off a series of questions, posed across the table, designed to offer more understanding about alternatives to antipsychotic medications.

1. HAVE YOU READ THE PUBLIC EDUCATION MATERIALS THAT EXPLAIN PROGRESSIVE DEMENTIA AND WAYS THAT FAMILY MEMBERS CAN RESPOND TO ERRATIC BEHAVIOR?

The Alzheimer's Association offers a pamphlet that explains Activities at Home for the 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."

At first, embarrassment over declining or lost capabilities may prevent a memory-loss patient from responding 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 a meaningful activity." *Habilitation Therapy: A New Starscape*, originally published in *Enhancing the Quality of Life in Advanced Dementia*, Brunner/Mazel, 1998. "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. 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.

John L. Roberts is an Elder Law attorney certified by the National Elder Law Foundation. A former judicial law clerk for the U.S. District Court in Springfield, Mass., he provides clients in Hampden County with probate, estate settlement, real estate, Medicaid planning and estate planning services. A bibliography of resources on the alternatives to antipsychotic drugs is available at: MassHealthHELP.com/html/antipsychotic_bibliography.html

No one would consider it reasonable to leave a disabled child alone in an apartment every day, especially a child diagnosed with a disorder like autism. 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, also known as “sitters,” 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 the companion is comforting, preserves a personal daily routine, and is significant on an emotional and psychological level.

Family members who understand how companion services support the memory-loss patient at home or in assisted living can play a role in postponing a nursing home admission.

Families who don't understand the concepts of compassion and quality of life for the memory-loss patient might still be convinced to invest resources in supplemental services, based on financial reasons: protecting assets during a five-year Medicaid look-back period.

Family members who still refuse to recognize the increasing needs of the memory-loss patient, and decide instead to withhold resources from the patient, are forfeiting important opportunities to prevent the need for antipsychotic medications. There is little that a geriatric care manager or an Elder Law attorney can do in these situations. You might ask yourself whether you can ethically assist with Medicaid planning or probate proceedings, knowing that a family member is using a power of attorney or health care proxy to deny access to services that could prevent a nursing home admission and use of antipsychotic medication.

3. ARE YOU AWARE 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.”

Habilitation Therapy: A New Starscape, supra.

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

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?

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 behaviors.

If physical pain, such as back pain, goes uncared for, erratic behavior is a frequent result. A February 15, 2011 *New York Times* article tells how a Minnesota nursing home patient was given psychotropic drugs, including Risperdal, to manage her loud outbursts. The nursing home started a program called Awakenings to find behavioral solutions as alternatives to using antipsychotic medications. After the woman's medications were reduced, she was able to communicate. It was discovered that pain from a nerve condition caused her wordless cries. After the nerve condition was treated, the nursing home was able to discontinue her psychotropic medications.

In a recent Massachusetts case, a memory-loss patient who was able to walk independently complained of back pain for several weeks, and then began behaving erratically in his secure assisted living residence. He was sent to a psychiatric hospital, chemically and physically restrained, and then discharged to a nursing home where antipsychotic medications and physical restraints were continued. After several weeks in the nursing home he became unable to walk.

4. DO YOU REALIZE HOW MUCH MONEY MEDICARE SPENDS TO DRUG DEMENTIA PATIENTS WHO BEHAVE ERRATICALLY?

Alternative responses to erratic behavior cannot be monetized as easily as a pill or an injection. The U.S. Government has filed suit against the makers of Risperdal for allegedly “paying millions of dollars in kickbacks” for dispensing drugs to nursing home patients. The *Boston Globe* reported in March 2010 that Massachusetts joined the lawsuit. The manufacturer defended the rebates it dispenses to Risperdal 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. 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 \$161 million in waste during a six month period in 2007.

5. IS THERE A DIFFERENCE BETWEEN LAW AND PRACTICE IN YOUR STATE?

Nursing homes use psychotropic medications 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 residents who are on antipsychotic

meds have *not* been diagnosed with a psychotic condition.¹ This has been recognized by nursing home administrators.² 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.

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.

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

Guidance issued to Surveyors for Long Term Care Facilities by the Centers for Medicare & Medicaid Services lists the conditions that allow for antipsychotic use, as well as the 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.

Guidance issued by the Centers for Medicare & Medicaid Services, State Operations Manual, Appendix PP at 387

When antipsychotics are used without monitoring they may be considered unnecessary medications. *Id.* at 389. How many memory-loss patients are placed on antipsychotic medications in your state, without ever experiencing the benefits of alternative responses to their first signs of erratic behavior?

6. ARE JUDGES IN YOUR STATE AWARE OF THE ALTERNATIVES?

If antipsychotic medication monitoring is part of your state's Probate or Surrogate's

1 Statistics for April-June 2010 at MDS Quality Measure/Indicator Report on Psychotropic Drug Use Nursing home drug use puts many at risk. Boston Globe, March 8, 2010

2 State regulators, nursing home industry launch campaign to reduce inappropriate use of antipsychotic medications for residents with dementia. Boston Globe, Nov. 18, 2010.

Court system, the authority to administer the drugs may be routinely allowed by the court 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 the alternatives to medication are suggested to the Court by a Petitioner who understands the alternatives. 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 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 ADLs. In one recent Massachusetts case, the judge ruled it is *not* neglect to withhold companionship services from a dementia patient who lives alone in an assisted living apartment with daily incontinence care and occasional visits from family.

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 POA/Health Care Agent. 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 POA/Agent to protect the quality of life of a person who becomes lost at the center of the swirling legal controversy.

Tactical delays and confusion sown by an adverse party, the emotional toll of litigation, and the prohibitive costs of expert witnesses can prevent well meaning family members from explaining how companionship services and activities will avert the

need for a nursing home admission, even in cases where the elder has plenty of money to pay for those services.

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. HAVE MEDICATION MONITORS AND COURT-APPOINTED ATTORNEYS IN YOUR STATE BEEN TRAINED TO UNDERSTAND THE DIFFERENCE BETWEEN MEMORY LOSS AND PSYCHOSIS?

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 meds? Does training for these advocates adequately distinguish the memory-loss client from younger patients with psychosis and severe mental illness?

In a recent Massachusetts Probate Court case involving an elderly memory-loss patient who was being physically and chemically restrained, a Guardian ad Litem drew on his experience with monitoring medication and supervision of the criminally insane. The GAL testified that a criminally insane patient had been assigned a permanent companion to restrain aggressive behavior, inferring that an individual companion to assist the frail 90-year-old nursing home resident with eating, conversation, and ambulation would be restrictive.

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. The examples provided by Dr. Raia, and the questions posed by Dr. Kyomen can help explain the possibilities.

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 care giving 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 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?”

An editorial in the February, 2009 *Lancet* 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.” ■

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