I am a doctor who specializes in the care of frail older people. I have spent the last quarter century trying to learn about older people and improve their care through clinical practice, research, and education. I have treated many thousands of patients with dementia in many different care settings.

Although my remarks today are quite personal, I also represent AMDA—Dedicated to Long Term Care Medicine, the professional association for long term care physicians, an organization whose stated mission is to improve the quality of care through education. AMDA has worked hard to educate physicians in the principles and practice of medicine in long term care settings, to promote awareness of and compliance with federal regulation of nursing homes among physicians, to train and certify nursing home medical directors, and to promote and improve interdisciplinary patient-centered care.

My personal story is this: I practice mostly in nursing homes and other long term care settings. I am Medical Director of two skilled nursing facilities. I have been well educated by AMDA about federal regulations pertaining to physicians practicing in nursing homes, and I am quite conscious of those regulations when I provide care to patients as well as when I review the care provided by others. I do use antipsychotic drugs for ongoing treatment of patients with schizophrenia and bipolar disease living in nursing homes, many of whom previously lived in state mental hospitals that no longer exist, and who have little or no access to mental health services in the community. I do not prescribe antipsychotic drugs for treatment of agitation or other behaviors in patients with dementia and I know that the leadership of AMDA acknowledges the use of these medications in patients with dementia only as a last resort, and only when all else has been tried and failed, which is rare.

Nevertheless, I and other like-minded physicians feel tremendous pressure in all care settings to prescribe medication to make patients with dementia behave. Most of the time, this equates to chemically restraining the patient. This pressure most often comes from frustrated caregivers but also from family members who have been led by other healthcare professionals to believe that these drugs are essential. My desire to avoid or eliminate antipsychotic drug prescription for treatment of behavior in patients with dementia has at times put me at odds with facility staff, patient’s families, and other healthcare professionals.
In approximately 20 years of providing geriatric consultation at some of the most prestigious American medical centers, my recommendations to reduce and eliminate antipsychotic and other medications in hospitalized patients whom I believed were experiencing adverse drug consequences were frequently ignored.

Moreover, in a number of instances over the last decade, psychiatrists providing consultation in nursing homes and assisted living facilities where I work have ordered antipsychotic drugs on my patients without my knowledge, and without the knowledge and consent of my patients and their family members.

As a consequence, I have chosen to focus my practice in facilities where I feel most comfortable. Even so, I routinely receive urgent requests from nursing and administrative staff and family members to prescribe antipsychotic medications including specific drugs by name. Studies have show that the use of antipsychotic drugs in patients with dementia varies several fold from facility to facility, and that higher prescribing rates are based upon the ‘culture’ of the facility, and not based upon patient characteristics such as the severity of their illness or their symptoms.

In taking on the care of new nursing home patients transferred from the hospital, many of whom receive a dozen or more prescription medications, I discontinue or reduce the dosage of some medication in almost every instance because of concerns about safety. The information that accompanies these patients from the hospital is often of extremely limited utility.

I also routinely discontinue antipsychotic drugs in elderly patients that have been admitted to my care, even though doing so may put me at odds with the doctor that prescribed them. These medications have often been started in the hospital for reasons that are unknown to me, my patients, and their families. I have seen antipsychotic drugs prescribed in hospitalized patients for use as sleeping pills.

Federal regulations regarding antipsychotic drugs, unnecessary medications, and chemical restraints do not apply to hospitals and assisted living facilities, nor do they apply to nursing facilities that do not accept Medicare or Medicaid payment.

In fairness to nursing homes, the problem of overprescribing of antipsychotic drugs in elderly patients with dementia is by no means limited to nursing homes. In fact, according to Medicare claims data the majority of antipsychotic drug prescribing for elderly Medicare beneficiaries occurs outside of nursing home setting. Moreover, the quality of care by a number of measures is higher in nursing homes than in hospitals and other care settings where federal regulations do not apply. For example, you are far more likely to develop a pressure ulcer or be physically restrained in the hospital than in a nursing home. I do not believe that hospitals and the doctors who work there should be held to a lower standard.

Moreover, I do not believe that dementia, or even undesirable behavior in dementia in most instances is a drug deficiency (requires a medication or prescription).
There is a firm, fixed belief among many healthcare professionals that difficult or disruptive behaviors such as hitting, wandering, yelling, and agitation, are cause for medication and that medication is likely to be beneficial for that purpose. Very few people working in health care, including physicians, receive any training in understanding and responding to challenging behaviors by any means other than medication. In fact, few physicians practicing in this country today received any meaningful training in nursing homes and other long-term care settings during medical school or residency training.

Most doctors treat unwelcome behavior in hospitals, nursing homes, and other care settings as a disease that requires a medication to modify the symptoms. These drugs are used as chemical restraints. Consequently, if the use of antipsychotic drug is restricted, other sedating drugs with other adverse consequences will quickly take their place, as is already beginning to happen. In that regard, the concern should not be for the use of antipsychotic drugs alone, rather the concern should be to avoid any medication that affects brain function if its intended use is as a chemical restraint. Likewise, and even more importantly, the concern should be for improved dementia care in all settings that focuses on understanding behavior and its meaning, in order to meet the patient’s own needs and goals. The use of medications to treat behavior creates unrealistic expectations and distracts caregivers from solving the underlying problems associated with undesirable behaviors.

I believe that behavior itself is not a disease. Simply put, behavior is communication. In people whose ability to communicate with words is limited (such as patients with dementia), communication tends to be more nonverbal (i.e. behavioral). Our challenge is to figure out what they are trying to say, and if they are in distress, to identify the underlying causes and precipitants. Many of the behaviors that are commonly observed in patients with dementia and that are often labeled as difficult, challenging, or bad, such as agitation, wandering, yelling, inappropriate urination, and hitting are typically reactive, almost reflexive behaviors that occur in response to a perceived threat or other misunderstanding among patients who by the definition of their underlying illness have an impaired ability to understand.

Moreover, all of the challenging behaviors exhibited by confused elderly patients in every health care setting across the country every day are identical to those behaviors observed among normal, healthy, very young children every day in day care centers and preschools across the country. While the behaviors are often the same, the expectations, and responses are often quite different, particularly in health care settings. What is necessary for caregivers is to try to figure out the meaning of the behavior- what are they trying to say? What are they responding to? And what is our behavior telling them?

Identifying underlying factors, such as pain, anxiety, a search for a familiar object, person or place may be invaluable in developing an appropriate response. Difficult behaviors in dementia typically represent a conflict between an individual and their environment- often the human environment. Health care environments are on the whole quite restrictive and generally inflexible. All patients seeking health care are expected to conform to the
environment. Patients with dementia often have trouble comprehending their environment, resulting in misperceptions that are often perceived as threats. In most instances, the key to behavior management in dementia is environmental modification, especially the human environment, which may be as simple as changing our approach and our response in order to prevent and minimize distress. The fundamental basis of health care is caring for others. The fundamental basis of caring is love, acceptance, and respect for persons.

AMDA believes in and promotes a multidisciplinary team approach to patient centered-care and is working with the Centers for Medicare & Medicaid Services (CMS) and the Pioneer Network to change the culture of health care in the United States. A minimum requirement of patient-centered care is informed consent. We strongly believe that patients and their families should be afforded sufficient information and dialogue to make appropriate treatment decisions regarding potentially harmful medications. Likewise we respect and agree with existing federal regulations regarding the avoidance of chemical restraints and unnecessary drugs.

We are developing core competencies for physicians in long term care. We believe in raising the bar for dementia care and helping dedicated and caring individuals to leap over that bar. We are working to educate and empower physician medical directors in long term care, to educate attending physicians, to develop strong relationships with patients and their advocates, and to support caregivers in long term care. We believe that these efforts will lead to the kind of health care quality we all want without increasing cost. We believe there is no substitute for good doctors spending the time their patients and families need to solve problems and relieve suffering. Doctors who are more often present and engaged in nursing facility care use fewer health care resources. Physician training does work to reduce antipsychotic drug prescribing. AMDA provides physician training on good dementia care at its annual symposium and other events and is working to provide more education and training to the entire interdisciplinary team. AMDA has had a representative working with CMS for the development of a training program for nurses aides in areas of care for persons with dementia and prevention of abuse.

We acknowledge that virtually every dollar of health care spending at some point occurred as a result of a physician’s order. We also recognize that many worthy causes deserve funding that currently does not exist. Being a good physician therefore requires being a good steward of scarce resources and focusing on what works. What the money is spent on should be a reflection of what we value most as a society. What my colleagues and I value most is loving care.

Jonathan M. Evans, MD, MPH, FACP, CMD
Vice President, AMDA—Dedicated to Long Term Care Medicine