Testimony to the State Assembly:

I want to thank you for giving me this opportunity to speak on this important topic. I am a registered nurse for the last 33 years and prior to that worked as a nurse's aide through college for a total of 20 years of working in nursing homes. While going to college I worked as a nurse's aide in a nursing home on the dementia unit. At that time when I would see a resident (we called them patients back then) was agitated, I would inform the nurse and she would come with a medication in hand in response to the report. I did not know there was a better way at that point in my training. After college I went to work in hospitals for a few years and in 1985 I returned to my first love….working with the elderly. I was a staff member for a short time and then became a supervisor. It was still common practice to respond to an agitated patient with medication. Then OBRA 1987 enacted a new set of regulations that were implemented in October 1990. In 1991 I became the Director of Quality Assurance of a nursing home and it was my job to ensure that these new regulations were complied with. In regards to antipsychotic medications, in order to comply with the regulation, we formed a committee with the physician, the nurse, the pharmacist consultant, the social worker and the activity worker where we would develop comprehensive care plans to address behaviors and focus on weaning the residents off of the medications. This was done unit by unit and week after week and was an ongoing process as you would always have residents admitted on these medications or returning from the hospital on the medications or we would have emergent situations where the drugs were temporarily used. This process was effective in reducing the numbers of residents on the drugs, ensuring the residents who were taking them were taking them for the right reasons and were weaned as soon as possible and to always weigh the benefits and the risks. I took this model to other nursing homes that I worked in. Additionally, we made sure that the aides knew behavior strategies since they were the ones working closely with these residents. For the last 10 years I have worked as a legal nurse consultant reviewing nursing home negligence cases. Most cases that have come my way are pressure ulcer or falls cases. However, invariably I find that these cases involve antipsychotic drugging as well. The downfall of the resident will start with the onset of use of antipsychotics. The regulation has anticipated this possibility. It reads: 483.25 "(l) Unnecessary Drugs: Each resident's drug regimen must be free from unnecessary drugs . An unnecessary drug is any drug when used: (i) In excessive dose (including duplicate therapy)l or (ii) for excessive duration; or (iii) without adequate monitoring; or (iv) without adequate indications for use: or (v) in the presence of adverse consequences which indicate the dose should be reduced or discontinued; or (vi) Any combinations of the above." The MDS assessment has a process called the CAA (CaRE Area Assessment) which also prompts the professionals to consider this possibility. However, I do not see that the facilities look at the resident's decline and consider the possibility of the medication being the culprit of the resident's decline. I don't see behavior care plans with revisions on them. I see standardized pre-printed plans that are not living breathing documents.

You want to see all the non-drug interventions that have been tried. I don't see any behavior interventions on the CNA records. This is proof of not having an individualized plan of care. Ideally, you want to see several things that the CNA can use in their tool box to help manage the residents' behaviors. What kind of music do they like? Do they prefer male or female caregivers? What were their lifetime activities? When I do see documentation relating to the antipsychotic medication it is usually documentation to "cover" or "justify" the use of the medication in a way that does not seem authentic. For instance, a resident made it to 90 years old without a diagnosis of psychosis and they start having behaviors and a psychiatric consult is ordered and suddenly we have a diagnosis of psychosis. Instead of working on non-drug interventions and finding ways to comfort the resident, the energy is used to justify the route that is being taken. I would like to share one resident's 86 day journey towards death after the initiation of antipsychotic medication. This is a case that I reviewed because the family was seeking legal assistance due their loved one sustaining a pressure ulcer. When I reviewed the records, it was the antipsychotic medications that were administered that were the bigger outrage to me. Here is the story of Jenny:

Meet Jenny, an 80-year-old nursing home resident who suffered from dementia, hypertension, diabetes, and depression. She was hospitalized because of rectal bleeding. What happened next is a common scenario for the elderly suffering from dementia. In the hospital, Jenny became agitated, commonly seen in patients with dementia due to the foreign environment. The response to her agitated behaviors was to order Haldol (an antipsychotic) and Ativan (an anti-anxiety) medication. Jenny was already taking an antidepressant. Now she was on three psychotropic medications, which were continued when Jenny returned to the nursing home. Jenny's return marked the beginning of an 86-day, downward spiral that ended in her death.

Timeline of events upon her return:

· Day 1: Jenny was extremely agitated, screaming and crying to go home. The nursing home responded by injecting her with Haldol, 1mg intramuscularly. (*This antipsychotic medication was on top of the daily dose carried over from the hospital stay*).

· Day 3: Jenny was lethargic and had hyperextension of her neck. (*Both are known side effects of the antipsychotic medications.*) She was sent to the ER for evaluation; the Haldol dose was reduced by 0.5 mg.

· Day 13: Jenny refused to take her medications and had one episode of screaming and crying. The physician was notified. The facility's response was to change Haldol to liquid form for easier administration and to increase its dose. There are notations on this same day that Jenny's body was rigid and her appetite poor. (*Both possible side effects of the medication.*)

· Day 15: Jenny had increasing rigidity of her trunk and was unable to sit in the wheelchair, so she was placed in a reclining chair.

· Day 28: Jenny expressed that she had pain in her knees; a cream was ordered to apply to

her knees for the pain.

· Day 38: Jenny had an elevated temperature and was found to have sepsis due to a Urinary Tract Infection. She was sent to the hospital.

· Day 40: The hospital performed a swallow evaluation and concluded that Jenny's difficulty with eating was due to her decreased alertness. (*Decreased alertness is a side effect of the antipsychotic medications.*)

· Day 41: Jenny was placed on another medication, Artane, which counteracts the adverse side effects of Haldol. Yet, the physicians kept Jenny on the same dose of Haldol.

· Day 47: Jenny returns to the nursing home.

· Days 47-56: Jenny again complained of knee pain. One day, she called out for her son. She was given Ativan. She was noted to be eating poorly.

· Day 57: Haldol was increased to 1 mg 3 times per day; a second antipsychotic, Depakote, was ordered at the dose of 125mg twice daily.

· Days 58-70: Jenny cried intermittently, which some nurses recognized as a result of her knee pain. She was given Tylenol.

· Day 70: Depakote was increased to 250 mg twice daily for the episodes of crying out.

· Day 71: Jenny had difficulty swallowing and needed to have her fluids thickened to prevent choking.

· Day 75: Jenny was so constipated that she was impacted with stool and required a suppository. (*Constipation is another frequent side effect of Haldol.*)

· Day 77: Jenny developed a pressure ulcer, also known as a bedsore.

· Day 83: Jenny was dehydrated and malnourished.

· Day 85: Jenny developed pneumonia.

· Day 86: Jenny died.

The story of Jenny is sad but true, a common one in many nursing homes. Many people do not recognize that the source of Jenny's downward spiral was the use of antipsychotic medications. It is easier to give agitated, elderly residents medication/s that will calm them rather than determine the underlying cause/s of the problem, particularly in a person who may be unable to communicate her needs. However, taking the easy road by administering these medications is essentially a form of slow killing.

My recommendations:

- Education is always the start of culture change. I can tell you that when I was a nurse's aide in the seventies and I was reporting behaviors to the nurse in charge, I was expecting the nurse to come with medication because that was the accepted practice. If the practice is to call the physician looking for a magic pill, than this is what will continue to happen. Facilities have to provide the staff with a different set of tools to manage behaviors. It is only in learning that there was better ways to care for the residents, and in facilities expecting the standards to be adhered to. When I was a Director of Nursing and orienting new staff members, whenever I spoke about this subject, I would give the analogy of a child, a child who cannot talk yet. If their child was crying would they drug the child? No, they would figure out what is distressing the child. Is she hungry, tired, thirsty, in pain? Does she need to be held and sang to? A parent would do everything they could to comfort the child and when they exhausted all those avenues and the baby was still distressed they would call the doctor. Why can't we do the same for our elderly?
- Processes need to be worked into the ongoing Performance Improvement of the facility…such as a committee that meets weekly with the mission to reduce the antipsychotic medications of the facility. After a period of time, the committee can meet every 2 weeks but it is something that always needs to happen or the numbers creep up again.
- The Department of Health needs training on citing the Unnecessary Drug F-tag along with the proper scope and severity.
- CMS needs to properly supervise the DOH.