

Until There's a Cure: How to Help Alzheimer's Patients and Families NOW

U.S. Senate Special Committee on Aging Forum December 8, 2010

Testimony of Patricia L. McGinnis California Advocates for Nursing Home Reform

Mr. Chairman, members of the Committee, I thank you for this opportunity to participate in today's very important forum. I'd particularly like to thank the staff of the Senate Special Committee on Aging for organizing the forum. My name is Pat McGinnis and I am the Executive Director of California Advocates for Nursing Home Reform, a nonprofit organization in San Francisco that assists and advocates for people who need long-term care.

For more than 25 years, our organization has heard first-hand the confusion, distress, and loss that is associated with the misuse of antipsychotic drugs and other psychoactive medications to chemically restrain nursing home residents who have dementia. I want to start by reading a statement about nursing home drugging:

"Excessive use of tranquilizers can quickly reduce an ambulatory patient to a zombie, confining the patient to a chair or bed, causing the patient's muscles to atrophy from inaction and causing general health to deteriorate quickly . . . it appears many doctors give blanket instructions to nursing home staffs for the use of tranquilizer drugs on patients who do not need them."

This statement sounds as if it was made very recently but it was actually made before Congress in 1970 and included in a 1975 report prepared by the Senate Special Committee on Aging titled "Drugs in Nursing Homes: Misuse, High Costs, and Kickbacks." Unbelievably, the problems have worsened in the 35 years since the Senate detailed them.

Today, the drugging problem has reached epidemic levels. Nationally, more than 350,000 nursing home residents – one of every four residents – are given antipsychotic drugs. The vast majority of these residents suffer from dementia and are receiving the drugs off-label, meaning the drugs are provided to control behavior and not to treat a diagnosed mental illness.

The way antipsychotic drugs are used in nursing homes is a form of elder abuse. Instead of providing individualized care, many homes indiscriminately use these drugs to sedate and subdue residents. Antipsychotic drugs carry black box warnings indicating that their use nearly doubles a person with dementia's risk of death, but nursing home residents and their representatives are rarely informed about these warnings. Antipsychotics don't just hasten death, they often turn elders into people their own families barely recognize by dulling their memories, sapping their personalities and crushing their spirits.

We would like to make it clear to the Committee that, while some psychoactive drugs may have positive benefits for the treatment of depression, anxiety, or even dementias, the drugs we are focusing on today are antipsychotics, such as Seroquel, Risperdal, Zyprexa and Haldol, which are designed for the treatment of those with schizophrenia.

There are many reasons that antipsychotic drugs have become the first alternative for intervention in nursing homes, particularly for residents who exhibit agitation or aggression. Drugs are cheaper than staff – at least on a short-term basis - as most of these drugs are paid for by Medicare. Additionally, many doctors who prescribe these drugs and the pharmacists who dispense them for those with dementia are ignorant of the risks and effects of the drugs prescribed and, in some cases, are intentionally misled by pharmaceutical companies. Just since 2009, over four billion dollars has been paid to the federal government by drug manufacturers to settle charges of fraudulent marketing, false claims, and kickback schemes. Finally, reimbursement for alternative therapies, particularly for therapists, psychologists and psychiatrists are limited under both Medicare and Medicaid.

It is a shameful situation, but there are some positives in this situation as well. The biggest problem with drugging, the pervasive culture that treats drugs as the first measure in behavioral control for people with dementia, is also a gateway to the inevitable solution. If we are able to shift this culture and de-emphasize drugging, we can dramatically reduce the misuse of antipsychotic drugs for people with dementia and, most importantly, improve their quality of life.

We already know what an effective campaign to shift this culture looks like: over the last 25 years there has been a pronounced effort by consumers, advocates, the government, providers and others to stop the inappropriate use of physical restraints in nursing homes. The result has been startling. Physical restraint use has dropped from more than 25% of all residents to less than 3%. The key has been concentrated, sustained education, awareness, effort, oversight and enforcement.

CANHR has initiated a campaign to stop drugging in California and we are hoping that it will take root throughout the nation. Our campaign combines practical advice for residents and their families on how to stop misuse of the drugs, along with a broad movement to raise awareness, strengthen laws and enforcement, and target offenders. This past summer we launched a first-of-its-kind website on this campaign that includes a great deal of information to help consumers learn about their rights, the risks of the drugs, and most importantly, the effective alternatives such as those highlighted today. The site includes a well-received video series and a free advocacy guide, “Toxic Medicine”, that we have distributed to the Committee.

We’ve also posted specific information on each California nursing home’s use of antipsychotic drugs to help consumers avoid facilities that are using these drugs indiscriminately. The information shows that a resident’s risk of being drugged varies tremendously by nursing home, with some facilities reporting no use of antipsychotic drugs while others drug all or nearly all of their residents.

The Campaign also has a political component, including a petition to the Governor and proposed legislation to strengthen informed consent requirements. I cannot emphasize enough the importance of

informed consent in resolving this problem. It's not just about informing people about the risks and alternatives to these drugs, it's about treating people who suffer from dementia with dignity and respect by recognizing their right to make decisions about their medical treatment. A culture of respect for victims of this disease will go a long way toward curbing the drugging problem.

We believe our campaign is a good model for a national campaign on this issue. I urge the Committee and Congress to hold hearings on this problem and to embrace the recent national recommendations made by Consumer Voice to stop the chemical restraint of nursing home residents. I will discuss a couple of the key recommendations.

First, Congress should adopt laws protecting the rights of nursing home residents to give informed consent before they are drugged. American common law and various state statutes protect the right of informed consent, but it does not appear in federal nursing home law. Codifying informed consent requirements would give national priority to the concept that people with dementia, as any other health care recipients, deserve complete information about proposed treatments and the right to ultimately decide what medications they take.

Second, we propose an education campaign to elevate the issue of antipsychotic drugs for people with dementia into the national consciousness. The campaign would focus on people with dementia, their families and advocates, as well as health care providers. For people with dementia and their families and advocates, the campaign would offer information about antipsychotic drugs - from the types of medications that are most often abused, to side effects and Black Box warnings, to the supremacy of alternative approaches that we've heard about today. As part of the education campaign, CMS should post each nursing home's drugging rate on Nursing Home Compare so that consumers can locate nursing homes that don't use antipsychotic drugs as a substitute for basic dementia care.

For health care providers, the education campaign would offer best practices for doctors, pharmacists and facilities, stressing that, if antipsychotic drugs are to be used at all, they should only be

used as a last resort after all non-pharmacological interventions have been attempted and failed. The essence of these practices should be the promotion of individualized care.

Individualized care fosters non-pharmacological interventions by placing a premium on relationships with people who have dementia and dignified care approaches such as increased exercise, formal activities, and pain management. A recent study in Vermont was able to dramatically reduce the use of antipsychotics in nursing homes by focusing on relatively simple alternatives. One alternative was learning more about a resident's past, so as to better understand the resident's needs and personality. Another alternative was giving nursing home staff more consistent schedules so they work with the same residents and learn to pick up on early signs of trouble and circumvent bad behaviors.

What is especially helpful about non-pharmacological interventions is that they are less costly than drugging. Aside from the obvious high costs of the drugs themselves is the very expensive health outcomes they often precipitate – falls, infections, strokes, and hospitalizations that add to the escalating costs of Medicare and Medicaid. Using pills to substitute for one-on-one care or for adequate staffing turns out to be, not only bad medicine, but also a poor use of resources. Reimbursement for alternative psychotherapeutic interventions, particularly psychotherapy services, should be expanded.

Congress should investigate and the U.S. Government should continue to aggressively pursue drug companies' marketing of off-label uses of antipsychotic drugs for nursing home residents.

Heightened awareness and increased information can make a major difference in the quality of lives of people with dementia. The massive reduction in physical restraint use in nursing homes is concrete evidence that federal leadership, coupled with an empowered consumer voice, can reach the far corners of the local nursing home, change the practices of health care providers and influence care in a way that dramatically improves the lives of our citizens with dementia.

Here is what we know:

- 1) The misuse and overuse of psychotropic drugs for people with dementia is at an all-time high;

- 2) There are many non-pharmacological alternatives to drugging that not only lead to better outcomes for people with dementia, but are also much less costly; and
- 3) A campaign to end over-drugging could improve the lives of perhaps millions of people with dementia.

Thirty-five years ago, the Senate Special Committee on Aging urged a “coordinated attack” on dangerous drug misuse in nursing homes, led by federal and state officials. With your help, we can finally begin that attack. Everyone here has demonstrated the sincerity of their concern for the plight of people with Alzheimer’s disease and other dementia-related illnesses. We call upon our national leaders to not only join a campaign to end over-drugging but to lead it.