NAPA -- FACA 2012 Public Comments

(August Comments Only)

February 7, 2013

AUGUST 2012 COMMENTS

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DATE: August 29, 2012
SUBJECT: We need a bold plan to stop Alzheimer’s!

Although the official comment period has closed for the NAPA draft plan, I'm writing today to urge you to go bolder with the final plan to be released by HHS later this month.

Alzheimer's is a cruel disease. It slowly steals one's intellect, ability to communicate, independence, and dignity, even control over basic bodily functions like eating and caring for personal hygiene. It also places an overwhelming burden on caregivers -- emotionally, physically, and financially.

The commitment to a 2025 deadline in the draft NAPA plan represents a major step forward in the fight against Alzheimer's. I am pleased that the plan recognizes the need for increasing enrollment in clinical trials, compressing the drug development process, accelerating targeted research, and better coordinating activities with other countries.

However, I am one of many concerned Alzheimer's advocates who believe that this first draft fails to present a strategy aggressive enough to achieve the goal of preventing and treating Alzheimer's within 13 years. It lacks specificity in terms of timelines and deadlines, provides no path to providing significantly greater resources, and does not hold a single high-level office or individual accountable for the overall plan.

I hope that HHS will address these issues so that the next version of the plan will be bolder.

With the number of Alzheimer's patients expected to triple in the coming decades, we must embrace a plan that eschews a "business-as-usual" approach and tackles Alzheimer's with the urgency and aggressiveness it requires. If not, we stand to lose millions more lives -- and trillions of dollars -- to this disease.

Thank you.

Georgia Koenig
Corona, CA

DATE: August 28, 2012
SUBJECT: NAPA - Objection to Recommendation

Thank you for your outstanding efforts on NAPA and the May 2012 Alzheimer's Disease Summit.

Below you will find a brief response to a proposal on the use of NAPA funding which has disturbed me sufficiently to immediately respond to both the Alzheimer's Organization and NIH. Specifically, NIA's goal to reduce use of antipsychotics by 15% in the first year and to expand training programs on behavioral intervention.

This is outrageous.

The FDA specifically proscribes the use of antipsychotic drugs other than for their specified purpose and has issued unequivocal warnings of danger up to and including stroke or death to the elderly on misadministration. Medicare specifically proscribes the use of chemical or physical restraints.

The United States Attorney is handling hundreds if not thousands of False Claims Act matters with severe economic penalty against pharmaceutical firms. Local prosecutors are filing criminal complaints against nurses and doctors for the use of anti-psychotics not only in SNF's but, as to children in juvenile detention facilities.

37% of the AD population in Florida is on psychotropic drugs.

First, the act of using a pill or injection in this manner for behavioral control has been characterized by prosecutors as a criminal battery.

Medicare, through Plan D has intimate knowledge of the extent of use by date, duration, dosage and location. If there is extensive use of antipsychotics in a particular facility, the matter should be referred to the United States attorney's office for investigation and appropriate action. Absent referral yet with knowledge, obstruction of justice issues arise.

Individuals don't have the ability to do this. They can only act as to a particular patient in what is essentially a disenfranchised population. Health care surrogates, if any, may or may not be informed of the offensive conduct or attentive to the needs of AD patients who are being abused in this manner.

It is inevitable with an increasingly litigious baby boomer generation that such obstruction of justice charges, conspiracy, RICO and other criminal complaints will be made against the federal government employees, agencies, nursing home operators, nurses and doctors and pharmacies as well as civil actions for damages from injury or wrongful death. It has already started.

Treating this inhuman torture of elderly as an administrative efficiency issue is an abuse as vicious, criminal and sadistic as the act of administering the injection or forcing the pill. I don't know if you have ever sat next to a SNF frail elderly AD with a hip fracture, shaking and crying after administration of an antipsychotic. It will haunt you. One more day is too much.

In one Medicare 5 star facility, an attempt was made in the first week to give a new AD patient an anti seizure drug because the patient was "acting out". The surrogate declined. In this facility,

AD were separated from the general population. A friend/aide covering the new patient for an afternoon was a nurse and a former nun from Ireland. She took her to a SNF music recital and was shocked because the rest of the patients were virtually comatose. The surrogate showed up at the facility the next day to find the patient's arms covered with a large hematoma and bruises from wrist to elbow as well as split skin on the forehead. No one had alerted the surrogate to the injury. No staff member would address the injury. The AD patient was pulled out of the facility.

The only way to stop this abuse is to aggressively act. The United States Attorney in Boston took action against J&J and Omnicare under the False Claims Act. It is incumbent upon Medicare and NIH/NIA and AD advocacy organizations to treat this with the same seriousness of purpose and dispense with pharma and nursing home owner/operator handholding. If you as individuals and as a representative of your agency or organization do not have the courage, the talent, the knowledge and the integrity to immediately save these patients from needless continued suffering, don't work in this field.

One doctor advised me that the section of the brain controlling the creative was the last to be destroyed in AD. After months of fruitless research for activities which benefitted AD, I found myself reading the Jerusalem Post on August 5 to find a care center in Israel with a program which made their days enjoyable.

How embarrassing for us that I had to go so far.

Training of Staff

The recommendation to utilize NAPA money on manpower to train nurses and aides in behavioral intervention techniques is a waste of time and an inefficient, inappropriate use of manpower and resources. I don't understand the continuing tolerance of the medical profession feeding itself from subsidies. What is next? Gerontology certification training for attorneys who are not up to speed?

Administrators, nurses and aides are licensed by the state. Prior to licensure, they have to complete training through state approved contractors to insure that they are qualified to perform the function of the profession they have elected to join. If the state, by and through its contractors has not met its responsibility to properly set forth statutory and regulatory qualifications for certification and/or contractors have not met those guidelines in training programs (for which they are compensated), to qualify licensees to meet the needs of the population they service (AD) despite clear demonstrable need, it is incumbent upon the state and its contractors to immediately remedy any training deficiencies.

The professional associations or the Alzheimer's organizations can prepare AD Behavioral Intervention Training materials by disc or online/video cam for sale to state training approved contractors. The state training contractors should incorporate these materials into certification training. If the individual is already licensed, state facility and professional license renewal should be contingent on licensee completion of such continuing professional education.

Tapes are valuable because they can be viewed repeatedly by staff, caretakers and home health care aides at leisure. With all respect to dedicated trainers, sometimes the level of sophistication is not very high and the quality of instruction questionable. Further and often, recommended techniques which fail to address the individual do not work. For example, one newly trained MSW put a group of AD in a room overlooking the garden with peaceful music.

One lady was quiet but when they moved her out, she burst out crying. She said they kept her in room next to a desk listening to that “horrible music” because the bill had not been paid and they would not let her go to the bathroom until her family showed up and paid it. She was quiet because she was embarrassed.

Second, agitation and “acting out” are based on inability to communicate physical distress, pain or discomfort, infection, medication side effect or misadministration, fear, frustration, or confusion. Hallucination occurs in the late stages. Behavioral intervention will not be effective if the problem is physical because the underlying cause is not abated. This should be the first step in evaluation.

As experienced nurses will tell you, successful behavioral intervention involves an intimate knowledge of the patient and time consuming one on one attention. Unless and until there is increased staffing in the facility so more than medication administration, dressing, bathing, changing and feeding can be accomplished, no more than lip service will be paid to training efforts. Nurses are furious that, because of budgetary staffing constraints, they may be professionally hurt and their patient’s needs are not addressed. Other nurses are so beaten down they are numb and operate on autopilot. Some doctors are clueless. They defer to nurses and pharma in prescription and rarely visit the patient. Yet Medicare pays for their time.

The Florida legislature has declined to increase minimum staffing. Consideration should be given to a mandatory national standard.

Represented decline in the use of antipsychotics is not based on facility compliance with Medicare proscriptions. It is based on the fact that reputable SNF’s and AL’s refuse to take patients with AD. If a patient develops AD while in the facility and doping is not used, the facility demands 24/7 private care in addition to the facility charges which is paid for by the family as a condition of retention. This is why AD are taken home for private care and lives of caretakers are destroyed.

I have reviewed the financial representations of SNF’s and AL’s which are on the market throughout the nation. A substantial majority represent a net profit to owners of 35 to 50% of gross income. If a SNF or AL is doping to increase or preserve owner profit, it is time for closure with possible criminal prosecution. Alternatively, federal or state takeover or placement in a form of receivership until compliance is accomplished would be recommended.

I will address specific recommendations including programs and services which actually benefit AD afflicted under separate cover including sources of additional funding for the Alzheimer’s Organization.

We had a triple dose of AD in our family. I was responsible for one highly agitated elderly with multiple physical issues for fifteen years, nine 24/7 as well as one late stage dementia. I have used the resources of your site and NIH since it was first accessible on the internet as well as every other medical information site available. I have read deficiency reports for probably 70% of SNF’s in Florida, visited facilities, spoken to nurses and other caretakers on a regular and continuous basis and had a front row seat to institutional neglect of elderly AD including a few direct hits.

By way of my qualifications, I am attorney, with a BA University of Notre Dame in government/economics, an MPA NYU, and experience representing the legislative interests of a State Department including Aging, Local Government Services, Housing and Human Services

with floor privileges in the Senate and House; in a corporate construction/development operation in a new and heavily regulated industry conforming operations and employment with statutory and regulatory directives; law firm experience including pharma product liability defense; and extensive experience as a mediator.

Thank you for your time.

Patricia A. Murphy, Esq.

DATE: August 24, 2012
SUBJECT: We need a bold plan to stop Alzheimers!

Although the official comment period has closed for the NAPA draft plan, I'm writing today to urge you to go bolder with the final plan to be released by HHS later this month.

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Thank you.

Hannah Dickinson
Memphis, TN