

**NAPA -- FACA 2012 Public Comments**  
*(April Comments Only)*  
 February 27, 2013

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## APRIL 2012 COMMENTS

**DATE:** April 30, 2012  
**SUBJECT:** National Alzheimers Plan Recommendations

I AM A DAUGHTER,AN AMERICAN , A VOTER AND A CAREPARTNER FOR A PARENT WITH ALZHEIMERS DISEASE AND THESE ARE MY RECOMMENDATIONS FOR THE NATIONAL ALZHEIMERS PLAN:

Goal One is of vital important-To accomplish this goal, it is imperative that a subgroup is formed to accelerate and streamline efforts to isolate and identify potentially viable drugs that can effectively cross the Blood Brain Barrier and stop and preferably regress the Alzheimers disease process. This group should consist of a representative from all of the top federal and non-federal agencies that are involved in bringing a drug through the development process into human testing and beyond to becoming FDA approved. This subgroup should consists primarily of a representative from HHS,NIH,NIA,WHO,FDA, Doctors and Researchers , as well as Biotech and Pharmaceutical companies. Similar to the Therapeutics For Rare And Neglected Diseases (TRND) Program-this subgroup should stimulate drug development and research by providing an opportunity to partner with one another in a collaborative environment with the goal of moving promising drugs into human trials in a timely, efficient and highly effective manner. This subgroup should use an application and evaluation process to select collaborators. Selected investigators should provide each separate drug candidates starting points and ongoing biological disease expertise throughout the total project. Each drug composition should be studied individually and separately so that the best possible ones can be accurately identified and focused upon. Therefore each potentially valid treatment and or cure for the alzheimers disease process is regarded as a separate project or entity , within the main project; the main project's goal being to create a new and better medicine for the alzheimers disease process and or a cure.

The Alzheimers Disease Summit in May 2012 should be looked upon as a breeding group for potentially valid drug candidates. All and any information gathered and disseminated at the summit should be thoroughly analyzed for the absolute best possible viable candidates to be studied by the subgroup, in a supreme effort to accomplish goal one. A representative from each agency involved in the subgroup should be in attendance at the summit so that they can absorb information and use it accordingly.

To increase public awareness of the disease and its various components a public service announcement should be broadcast across the country on every public tv station. This announcement should show a person with the disease, throughout the various progressive stages and explain to America that alzheimers is much more than a loss of memory but instead a progressive degenerative brain disease that is fatal and desperate for public support and a new and better medicine and or a cure.

Thank you

Carla Danesi  
Gloria's Daughter "Remember Gloria,Gloria Lives"

**DATE:** April 25, 2012  
**SUBJECT:** Alzheimer's Comment

My name is James Alfano. I am a physical therapy student at Thomas Jefferson University in Philadelphia, PA. I was recently doing some research on Alzheimer's legislation for my "Geriatrics" course when I came across the National Alzheimer's Project Act. After reading more about NAPA online, I was pleased to see that the Advisory Council welcomes public comments. While I understand that the April 17<sup>th</sup> Advisory Council meeting just passed, if it is at all possible, I would like to include the following comment for consideration at the next meeting.

Having a grandmother with Alzheimer's disease, I understand how emotionally difficult, physically taxing and financially burdensome this disease can be for a family. As my grandfather has become older and less able to take care of her, my mother and aunts have stepped up and given up much of their free time to care for her. However, with all of them working, a home health aide is needed.

Over the past couple of years, my grandmother has had numerous aides because the previous one decided that she could no longer make the commute or take care of my grandmother, among other reasons. While I understand there are legitimate reasons why an aide can no longer work with a particular patient, my family and I often felt that the aides were dictating terms to the home health agency in that they chose when and where they wanted to work and for how long. Their unreliability presented as a burden for my family and was traumatic for my grandmother who has difficulty adjusting to the new people due to her cognitive limitations.

I believe a system that makes the aides more accountable to the individuals they are assigned to care for would be beneficial, possibly through more education or training. I also believe the directors of home health agencies should be required to have a medical background so that they would be better able to understand a patient's needs and assign appropriate aides to the individuals requiring care, especially to those with dementia.

Thank you for your time and consideration of this matter.

James Alfano  
Philadelphia, PA

**DATE:** April 23, 2012  
**SUBJECT:** National Council of Certified Dementia Practitioners Comments regarding Long-Term Services and Supports Subcommittee Recommendations Document April 2012 Handouts

In reading number 6 we wanted to add our comments. We have four recommendations:

Our first recommendation is that the committee should be aware of which states are requiring dementia education and how many hours are required. The regulations are different in every state and for each industry, such as Adult Day Care, Hospice, Home Care, Nursing Homes, Assisted Living, Hospitals, Rehab Centers, Psychiatric Facilities and Locked Dementia Units. Some states require more dementia education such as 20 hours and other states and depending on which industry require less dementia education while others do not have a specific number of hours. Some states may require more than 10 hours of dementia education. So at minimum before your recommendation is passed, you should be aware of what each state is requiring for dementia education and for each industry. At minimum the national standard should be more than 10 hours. We are recommending at minimum 12 hours of Live dementia education for all front line staff and health care professionals.

We recommend live training by a certified Alzheimer's and dementia trainer. In some states the education is permitted per the state regulation via Weimar and video training. We stand against this way of initial Alzheimer's and dementia training because you can not be sure that the person attending the Webinar or video training is in fact that person. Nor can you insure when the material is presented by Webinar or video training that the employee understood the material. "Live Training" is critical in preventing abuse and neglect of our most vulnerable elders by the front line staff and health care professional.

In addition, we recommend ongoing training through out the year to keep the staff up to date on regulatory changes and new advances in all aspects of care. Each year for NCCDP Alzheimer's and dementia Staff Education Week February 14 to 21 and we provide free staff in-services for educators to download from our site which includes the power point, hand outs, pre tests and post tests. This is a free services and is available from November till May. We add many new topics every year. Your recommendations should let the public know of this free service.

Secondly, the wording you have for the education piece is "reliable source". We feel it should be spelled out to specifically state, universities, associations, nationally recognized companies and nationally recognized organizations. such as the National Council of Certified Dementia Practitioner's, National Alzheimer's Association, National Alzheimer's Foundation, Office on Aging, etc. The public should be aware by your office of all of the organizations and companies providing dementia education and not just a select few who are serving on your committee. The institution than can make a choice as to which organization to use for staff training.

Our third recommendation should be that the words "Paraprofessional Caregiver" come out and replace with all Health Care Professionals and Front line staff including Nursing Assistants, Home Health Aides, Personal Care Assistants, Activity and TR professionals, Nurses, Social Workers, Dietary Workers, PT, OT, Speech, Housekeeping, Bus Drivers, Administrators, Assistant Administrators, Pharmacists, Physicians and all other staff who interact with the patient. We feel this needs to be very detailed and specific and not in any way target one specific profession as all professions who interact with the geriatric patient be included in the Alzheimer's and dementia training.

Our fourth recommendation is that Alzheimer's and dementia education be mandated in all colleges, universities, trade schools that provide a medical profession trade or certification or license for any health care related profession regardless if they are entering the geriatric field.

Sandra Stimson, CALA ADC CDP CDCM  
National Council of Certified Dementia Practitioners  
<http://www.nccdp.org>

**DATE:** April 20, 2012  
**SUBJECT:** RE: Why Physician-Assisted Dying is NOT for dementia patients; (response to Mr. Ellenbogen by Stanley A. Terman, PhD, MD, who wrote a NAPA public comment on March 26 2012)

While I agree with some of your statements and there is a flaw. The flaw is not thought my ideas, but the system we created. Many of us think they are god and have the right to make decision for everyone else and they do not look past the religion aspect of things. The perfect world would be based on having doctors put me out based on taken a certain score on the 30 question MMI test (or whatever you call it) they always give you. I am not sure what the number would be, but probably about 15 - 20. That of course would require much more involvement from my doctors so I could truly understand what that all means. It should also be based at taking that test 3 separate times at different times of the day, with at least a week in between. That would all be based by my original request when I was still capable of making a sound decision. I would be happy to discuss it with anyone interested in speaking about it.

Michael Ellenbogen

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From: Stanley Terman  
Sent: Friday, April 20, 2012 1:30 PM  
Subject: Re: Why Physician-Assisted Dying is NOT for dementia patients; (response to Mr. Ellenbogen by Stanley A. Terman, PhD, MD, who wrote a NAPA public comment on March 26 2012)

### **Why physician-assisted suicide/dying cannot help patients who have dementia**

Mr. Ellenbogen brings up an important point, one that concerns many people who worry about dementia: Briefly: Is there a way for them to exit in a dignified way that is also timely?

Mr. Ellenbogen expressed this fear well, and I feel compassion for him. His stated problem begs for an effective solution. Yet the one he proposed is seriously flawed from several points of view: the clinical, practical, ethical, moral, and psychological, as well as legal.

The points of agreement and the one point of disagreement that I have with Michael Ellenbogen is within his key paragraph that I copied below and then respond to, point-by-point, by adding my specific comments:

Mr. Ellenbogen wrote: "You need to make plans when you are still able to think clearly. You must figure out a method so you know what to do when the time comes. The scary part for me is knowing when the right time may be. You do not want to go earlier then you have to, but you do not want to wait until the point where you may not be able to decide to do it, or remember how to do it. **That is why I am a true believer in assisted suicide.** It would be nice to let someone know my wishes far in advance, and when we get to that point they would instruct me on what I had to do. This way, my family and I could get the most out of my life without question."

First a general comment: Mr. Ellenbogen expresses what I have been calling the "**Dementia Fear**," when he writes: "You do not want to wait until the point where you may not be able to

decide to do it, or remember how to do it," since by the word, "IT," he really means suicide. More typical is this blunter statement: "If I don't kill myself now (**when I can**), I won't be able to kill myself later (**when I want to**)." The consequence of acting on this fear is "premature dying," which violates the principle of the sanctity/preciousness of life. This is the problem for which Mr. Ellenbogen is searching for a solution.

Now, point-by-point:

Yes, I agree: "You need to make plans while you still have the mental capacity to make end of life treatment decision." Let me add: One way to do this is to create a clear and specific Living Will and to appoint a proxy/agent whom you trust to make sure that others will honor the wishes you previously expressed in your Living Will. The document designates your proxy/agent must give the appointed individuals sufficient power to facilitate your last wishes.

Yes, I agree: "You need to figure out a method so you know what to do." To respond: My personal choice, and what I advise my patients to consider is to forgo the continuation of another person's hand to assist oral feeding and drinking. This is what I have been calling "Natural Dying." Important: food and fluid are always placed near enough to reach so that if you regained the ability to eat independently, you could. Forgoing treatment that has become extraordinary or disproportionate is both legal and moral.

Yes, I agree: "The scary part is knowing when the right time may be." Appreciating that you will lose the ability to decide on that time later means you must make this decision while you still can. The goal of TIMELY DYING is possible if you can trust your proxy/agent and your future physician to engage in the process of "shared decision-making." Then, someday, they will compare your future condition with the decisions you expressed in your clear and specific Living Will to decide if it is time for "Natural Dying."

Important: Assisted suicide is not legal for patients who have dementia, even in Oregon, Washington, or Switzerland. While legal in theory, it is very rarely practiced in Holland because physicians do not feel comfortable killing a patient who cannot *contemporaneously* express the wish to die. Dutch physicians also do not feel comfortable killing a patient whose major issue is their anticipatory fear of greater suffering and burdens *in the future*; they insist that patients have unbearable suffering which cannot be relieved in any way other than by dying--which is NOT the case for patients in the early or middle stages of dementia. Even for patients who had such terminal diseases as cancer or neurological diseases (which comprise the majority of patients who used Oregon's "Death With Dignity Act"), only 600 people died this way since 1997. Compare this number to the one to two million people who currently are suffering in the advanced stage of dementia--a number that will triple by mid-century. Thus, physician-assisted dying cannot be a practical, legal, or ethical answer for a prolonged dying with much suffering for patients who reach the stage of advanced dementia.

Yes, I agree: "It would be nice to let someone know my wishes far in advance..." and "This way, my family and I could get the most out of my life without question." This laudable goal can be accomplished by effective Advance Care Planning.

But now, a resounding NO, I do NOT agree: "When we get to that point they would instruct me on what I had to do" (e.g., how to commit suicide). Your family members would risk being indicted for a serious crime with severe penalties. They are also likely to suffer from greater moral angst and grief, if they actively helped you die when they were not sure about--as you put it "when the right time... when [I] get to that point." The best way to reduce the emotional

burdens on families is to create your gift of a clear, specific Living Will and to make it clear that you are responsible for the ultimate existential decision, not them.

Let me end with a personal note to Michael Ellenbogen: I am sorry you have the diagnosis of dementia. I am glad that you are still functioning at such a high level. Unfortunately, you cannot be sure, just because each dementia patient is different, just how long you will retain your ability to exercise good judgment about end-of-life medical decisions. Now, you do. Someday... unless you die of another disease first, the irreversible, progressive disease of dementia will likely deprive you of that good judgment. (Perhaps an exception is a very well controlled vascular dementia that remains stable.) This is the reason why it is so important that you make your decisions, memorialize them, and appoint surrogates to facilitate them NOW. It would be an enormous shame and waste of your good life, if you were to commit suicide prematurely, just because you still possessed the mental capacity to make medical decisions. I hope you live as long and as well as possible.

Conflict of interest statement: Stanley A. Terman, PhD, MD, has written three books on this subject and created a deck of illustrated cards that people, even those in early dementia, can use to generate a clear and specific Living Will if they want to attain the goal of a timely and peaceful dying. (The books are "The BEST WAY to Say Goodbye: A Legal Peaceful Choice at the End of Life," "Peaceful Transitions: Stories of Success and Compassion," and "Peaceful Transitions: Plan Now, Die Later--Ironclad Strategy"; the cards are "My Way Cards for Natural Dying" or "Natural Dying Living Will Cards." Dr. Terman is the founder and Medical Director of Caring Advocates, a non-profit organization.)

Stanley A. Terman, PhD, MD  
Board Certified in Psychiatry  
Medical Director and CEO of Caring Advocates  
Carlsbad, CA  
<http://www.CaringAdvocates.org>  
<http://www.MyWayCards.org>  
<http://www.MyLastWishes.org>

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From: Michael Ellenbogen  
Sent: Fri, Apr 20, 2012 at 7:38 AM  
Subject: Response to letter from Stanley A. Terman, PhD, MD, dated, March 26 2012 in the NAPA public comments about Michael Ellenbogen

I am writing to you out of frustration to the letter of Stanley A. Terman, PhD, MD, dated, March 26 2012. While I do not know what his credentials are, I can assure you 100% without doubt that he does not have any understanding of what Alzheimer's patients are capable of doing or not doing. While I have heard from all the smart doctors make the statement that if you know one Alzheimer's patient, you only know one as for their symptoms go.

While I may have trouble writing, speaking, do financing and many of the other things I so dearly miss, I am very capable of making very good judgments. In fact I still help many people who do not have dementia to help them with decisions they are unable to make.



Some people like to be in the public spot light for the wrong reasons, which is the case for this individual. If you are going to make statements, you should understand all sides, not just a one side point of view, maybe perhaps poor judgment on his part.

My wife feels that she would have no problem taking care of me all the way to the end. Since she happens to be an RN she feels she could take off for a year to become my private nurse, if and when I became bad. But I have many fears of reaching that point in my life. First of all, I do not want to be remembered as the person who could no longer talk or take care of himself. I want to leave this world with dignity and not make others feel better about themselves because they kept me around to the end. I do not want to frustrate and burden their lives any more than I have. While we have had a great life, those are the thoughts I want to leave my wife with. I also hope that she finds someone new in her life so she can move on. My daughter lives in another state and I do not want her to feel obligated to move back, close to home, just to help her mother. I do not think my wife realizes what a major undertaking this is. While she may be good at what she does, she cannot handle this type of pressure.

Then of course, I do not want to suffer and be tortured for the rest of my life. There are many times, on a daily basis, when I am not always clear on what I need to do to make myself more comfortable or not suffer from pain. In the middle of the night, while sleeping, I become uncomfortable because I'm hot, so I flip the covers off my feet and feel so much better. A few hours go by, and now my feet are cold, so I replace the blanket. Now imagine that you are hot, and there is no way to remove that blanket. I would go crazy because I could not do that and would suffer. That is exactly what would happen if I could no longer do or think for myself.

My wife seems to think that those types of issues would not bother me. Who really knows? However, I do not want to be the one to find out and suffer. Sure, she can want to think it will not happen, for her peace of mind, but what about me?

Let me give you another example. I have major allergy problems and I constantly have a postnasal drip. Its major impact to me is at night and I frequently wake up gagging and coughing in an effort to clear my nose and throat. Sometimes I can waste 45 minutes before I finally resolve the issue. I actually suffer today and feel tortured at times. Can you imagine if that happens to me and I cannot let someone know what's bothering me and cannot do anything for myself. That frightens me to no end. My allergist has run out of options with me. This problem has really become much worse this year.

One last example. I am particular about how my pillow feels when I go to sleep. I like it to be very fluffed up. Usually once during the night I tend to flip it so that I get the fluffed end again, and it feels so much better when I do that.

People may tell you to wait until it gets worse, but they are wrong. You need to make plans when you are still able to think clearly. You must figure out a method so you know what to do when the time comes. The scary part for me is knowing when the right time may be. You do not want to go earlier then you have to, but you do not want to wait until the point where you may not be able to decide to do it, or remember how to do it. That is why I am a true believer in assisted suicide. It would be nice to let someone know my wishes far in advance, and when we get to that point they would instruct me on what I had to do. This way, my family and I could get the most out of my life without question.

There are many other reasons I can go into, but I need to go to a funeral for a family member who final passed away after years of torture. He finally passed from Parkinson Disease the

other day. He was zombie and scared and had no life. He had living will that was over ridden because some family member was going to have a wedding and they decide to put feeding tube in when he would have probably died in another day or two. Now that is poor judgment from people like you.

Please see Stanley A. Terman letter below.

Regards,

Michael Ellenbogen  
Author of "The Insider's Guide To Saving Money"  
<http://www.michaelellenbogen.com>  
<http://www.michaelellenbogenmovement.com/>

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DATE: March 26, 2012

SUBJECT: Submitting my COMMENT based on my telephonic statement of March 14, 2012 to the Advisory Council

*This letter is very similar to my oral testimony (a few corrected typos and better words)--except for my adding a new paragraph at the beginning--to respond more fully to a public comment that preceded mine:*

A person (Michael Ellenbogen?) who currently suffers from mild Alzheimer's dementia concluded his comments by recommending the Advisory Council on Alzheimer's Research, Care, and Services consider the "right-to-die" option. He thus implied that Physician-Assisted Dying could be an option for patients who suffer from dementia. Because of time limitations, I could only disagree briefly by saying that Physician-Assisted Dying will neither help nor is needed. I now explain more: (1) Why would Physician-Assisted Dying NOT help? Where Physician-Assisted Dying is legal, the law requires patients be of "sound mind" when they ask their physician to write a prescription for a lethal dose of medication. Yet dementia patients lose the mental capacity to make medical decisions early in the course of this progressive disease. Thus for dementia patients, Physician-Assisted Dying would compound their tragedy with **premature dying**. This is because dementia patients can have much good life after they lose capacity--and they can expect more, with further research--so I and many others consider **premature dying** an act that violates the **principle that life is precious**. (2) Why is Physician-Assisted Dying NOT needed? Because Living Will forms and the discussions they provoke can be both moral and effective. Combined with other clinical and strategic forms, diligent Advance Care Planning can give people peace of mind, whether they are still well or in the early stage of dementia. They need not worry about being forced to linger for months to years by enduring the huge burdens and suffering that characterize Advanced Dementia. Instead, they can feel confident that others **will honor their Known Wishes** after they lose the ability to speak for themselves.

Sincerely,

Stanley A. Terman, PhD, MD  
Medical Director and CEO of Caring Advocates  
Carlsbad, CA

**DATE:** April 20, 2012

**SUBJECT:** Why Physician-Assisted Dying is NOT for dementia patients; (response to Mr. Ellenbogen by Stanley A. Terman, PhD, MD, who wrote a NAPA public comment on March 26 2012)

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Let me end with a personal note to Michael Ellenbogen: I am sorry you have the diagnosis of dementia. I am glad that you are still functioning at such a high level. Unfortunately, you cannot be sure, just because each dementia patient is different, just how long you will retain your ability to exercise good judgment about end-of-life medical decisions. Now, you do. Someday... unless you die of another disease first, the irreversible, progressive disease of dementia will likely deprive you of that good judgment. (Perhaps an exception is a very well controlled vascular dementia that remains stable.) This is the reason why it is so important that you make your decisions, memorialize them, and appoint surrogates to facilitate them NOW. It would be an enormous shame and waste of your good life, if you were to commit suicide prematurely, just because you still possessed the mental capacity to make medical decisions. I hope you live as long and as well as possible.

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Carlsbad, CA

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From: Michael Ellenbogen

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My wife feels that she would have no problem taking care of me all the way to the end. Since she happens to be an RN she feels she could take off for a year to become my private nurse, if and when I became bad. But I have many fears of reaching that point in my life. First of all, I do not want to be remembered as the person who could no longer talk or take care of himself. I want to leave this world with dignity and not make others feel better about themselves because they kept me around to the end. I do not want to frustrate and burden their lives any more than I have. While we have had a great life, those are the thoughts I want to leave my wife with. I also hope that she finds someone new in her life so she can move on. My daughter lives in another state and I do not want her to feel obligated to move back, close to home, just to help her mother. I do not think my wife realizes what a major undertaking this is. While she may be good at what she does, she cannot handle this type of pressure.

Then of course, I do not want to suffer and be tortured for the rest of my life. There are many times, on a daily basis, when I am not always clear on what I need to do to make myself more comfortable or not suffer from pain. In the middle of the night, while sleeping, I become uncomfortable because I’m hot, so I flip the covers off my feet and feel so much better. A few hours go by, and now my feet are cold, so I replace the blanket. Now imagine that you are hot, and there is no way to remove that blanket. I would go crazy because I could not do that and would suffer. That is exactly what would happen if I could no longer do or think for myself.

My wife seems to think that those types of issues would not bother me. Who really knows? However, I do not want to be the one to find out and suffer. Sure, she can want to think it will not happen, for her peace of mind, but what about me?

Let me give you another example. I have major allergy problems and I constantly have a postnasal drip. Its major impact to me is at night and I frequently wake up gagging and coughing in an effort to clear my nose and throat. Sometimes I can waste 45 minutes before I finally resolve the issue. I actually suffer today and feel tortured at times. Can you imagine if that happens to me and I cannot let someone know what's bothering me and cannot do anything for myself. That frightens me to no end. My allergist has run out of options with me. This problem has really become much worse this year.

One last example. I am particular about how my pillow feels when I go to sleep. I like it to be very fluffed up. Usually once during the night I tend to flip it so that I get the fluffed end again, and it feels so much better when I do that.

People may tell you to wait until it gets worse, but they are wrong. You need to make plans when you are still able to think clearly. You must figure out a method so you know what to do when the time comes. The scary part for me is knowing when the right time may be. You do not want to go earlier then you have to, but you do not want to wait until the point where you may not be able to decide to do it, or remember how to do it. That is why I am a true believer in assisted suicide. It would be nice to let someone know my wishes far in advance, and when we get to that point they would instruct me on what I had to do. This way, my family and I could get the most out of my life without question.

There are many other reasons I can go into, but I need to go to a funeral for a family member who final passed away after years of torture. He finally passed from Parkinson Disease the other day. He was zombie and scared and had no life. He had living will that was over ridden because some family member was going to have a wedding and they decide to put feeding tube in when he would have probably died in another day or two. Now that is poor judgment from people like you.

Please see Stanley A. Terman letter below.

Regards,

Michael Ellenbogen  
Author of "The Insider's Guide To Saving Money"  
<http://www.michaelellenbogen.com>  
<http://www.michaelellenbogenmovement.com/>

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DATE: March 26, 2012  
SUBJECT: Submitting my COMMENT based on my telephonic statement of March 14, 2012 to the Advisory Council

*This letter is very similar to my oral testimony (a few corrected typos and better words)--except for my adding a new paragraph at the beginning--to respond more fully to a public comment that preceded mine:*

A person (Michael Ellenbogen?) who currently suffers from mild Alzheimer's dementia concluded his comments by recommending the Advisory Council on Alzheimer's Research, Care, and Services consider the "right-to-die" option. He thus implied that Physician-Assisted Dying could be an option for patients who suffer from dementia. Because of time limitations, I could only disagree briefly by saying that Physician-Assisted Dying will neither help nor is needed. I now explain more: (1) Why would Physician-Assisted Dying NOT help? Where Physician-Assisted Dying is legal, the law requires patients be of "sound mind" when they ask their physician to write a prescription for a lethal dose of medication. Yet dementia patients lose the mental capacity to make medical decisions early in the course of this progressive disease. Thus for dementia patients, Physician-Assisted Dying would compound their tragedy with **premature dying**. This is because dementia patients can have much good life after they lose capacity--and they can expect more, with further research--so I and many others consider **premature dying** an act that violates the **principle that life is precious**. (2) Why is Physician-Assisted Dying NOT needed? Because Living Will forms and the discussions they provoke can be both moral and effective. Combined with other clinical and strategic forms, diligent Advance Care Planning can give people peace of mind, whether they are still well or in the early stage of dementia. They need not worry about being forced to linger for months to years by enduring the huge burdens and suffering that characterize Advanced Dementia. Instead, they can feel confident that others **will honor their Known Wishes** after they lose the ability to speak for themselves.

Sincerely,

Stanley A. Terman, PhD, MD  
Medical Director and CEO of Caring Advocates  
Carlsbad, CA

**DATE:** April 20, 2012  
**SUBJECT:** Question

How do I reach out to Dr. William Shrank, MD at the CMMI?

Dr. Ling sent me his email but no response as of yet. I wish to apply for a demonstration project to improve the quality of care for patient with AD using a “wrap around” at risk approach which was outlined in m letter to you a few weeks back (see attached).

Thank you,

Dr. Joel Ross

ATTACHMENT: NAPA testimony april 17 2012.docx

<b><i>Available as separate links:</i></b>	
Comments on the NAPA Plan	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach158.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach158.pdf</a>



**DATE:** April 20, 2012

**SUBJECT:** Response to letter from Stanley A. Terman, PhD, MD, dated, March 26 2012 in the NAPA public comments about Michael Ellenbogen

I am writing to you out of frustration to the letter of Stanley A. Terman, PhD, MD, dated, March 26 2012. While I do not know what his credentials are, I can assure you 100% without doubt that he does not have any understanding of what Alzheimer's patients are capable of doing or not doing. While I have heard from all the smart doctors make the statement that if you know one Alzheimer's patient, you only know one as for their symptoms go.

While I may have trouble writing, speaking, do financing and many of the other things I so dearly miss, I am very capable of making very good judgments. In fact I still help many people who do not have dementia to help them with decisions they are unable to make.

Some people like to be in the public spot light for the wrong reasons, which is the case for this individual. If you are going to make statements, you should understand all sides, not just a one side point of view, maybe perhaps poor judgment on his part.

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Please see Stanley A. Terman letter below.

Regards,

Michael Ellenbogen  
Author of "The Insider's Guide To Saving Money"  
<http://www.michaelellenbogen.com>  
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DATE: March 26, 2012

SUBJECT: Submitting my COMMENT based on my telephonic statement of March 14, 2012 to the Advisory Council

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A person (Michael Ellenbogen?) who currently suffers from mild Alzheimer's dementia concluded his comments by recommending the Advisory Council on Alzheimer's Research, Care, and Services consider the "right-to-die" option. He thus implied that Physician-Assisted Dying could be an option for patients who suffer from dementia. Because of time limitations, I could only disagree briefly by saying that Physician-Assisted Dying will neither help nor is needed. I now explain more: (1) Why would Physician-Assisted Dying NOT help? Where Physician-Assisted Dying is legal, the law requires patients be of "sound mind" when they ask their physician to write a prescription for a lethal dose of medication. Yet dementia patients lose the mental capacity to make medical decisions early in the course of this progressive disease. Thus for dementia patients, Physician-Assisted Dying would compound their tragedy with **premature dying**. This is because dementia patients can have much good life after they lose capacity--and they can expect more, with further research--so I and many others consider

**premature dying** an act that violates the **principle that life is precious**. (2) Why is Physician-Assisted Dying NOT needed? Because Living Will forms and the discussions they provoke can be both moral and effective. Combined with other clinical and strategic forms, diligent Advance Care Planning can give people peace of mind, whether they are still well or in the early stage of dementia. They need not worry about being forced to linger for months to years by enduring the huge burdens and suffering that characterize Advanced Dementia. Instead, they can feel confident that others **will honor their Known Wishes** after they lose the ability to speak for themselves.

Sincerely,

Stanley A. Terman, PhD, MD  
Medical Director and CEO of Caring Advocates  
Carlsbad, CA

**DATE:** April 19, 2012

**SUBJECT:** Eldercare Workforce Alliance NAPA Comments

Thank you for the opportunity to provide comments at the meeting of the Advisory Council on Alzheimer's Research, Care, and Services on Tuesday. A hard copy of the oral comments we shared is attached as well as a copy of the written comments we submitted previously.

Gail MacInnes  
Policy Advisor & Analyst  
Eldercare Workforce Alliance

ATTACHMENT: EWA Comments on Draft Plan- 033012 - FINAL.pdf  
EWA NAPA Comments 4-17-12 FINAL.docx

***Available as separate links:***

Comments on the Draft National Plan	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach140.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach140.pdf</a>
Eldercare Workforce Alliance Comments for the Advisory Council on Alzheimer's Research, Care, and Services	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach157.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach157.pdf</a>

**DATE:** April 18, 2012  
**SUBJECT:** Follow up RE: Comments on Draft National Plan to Address Alzheimer's Disease;  
Down syndrome

I am writing to follow up on my previous email below that included attached comments concerning the Draft National Alzheimer's Plan, to make sure that you did receive my email & comments (I have also attached another copy to this email). I understand that the next NA Plan Advisory Council meeting is scheduled for tomorrow, April 17, and also wanted to be sure the copy of my comments was submitted to the Advisory Council for consideration and appropriate discussion.

Could you confirm?

I understand the Advisory Council meeting tomorrow will be available for live streaming via the internet; am I correct that there will be no teleconference of the meeting or opportunities for external input?

Are there other recipients (or postings) relevant to the development of the Plan to which it would be appropriate to provide these comments?

Thank you very much,

Michael M. Harpold, Ph.D.  
Chief Scientific Officer  
Chair, Scientific Advisory Board  
Down Syndrome Research and Treatment Foundation

=====

From: Michael Harpold  
Sent: Thursday, March 29, 2012 7:08 AM  
Subject: Comments on Draft National Plan to Address Alzheimer's Disease; Down syndrome

I am uncertain whether my comments on the Draft National Plan to Address Alzheimer's Disease (see attached) are most appropriate to be sent to you, as liaison with the Advisory Council, and/or napa@hhs.gov (representing address for public comments), as I am unclear whether there is a distinction. I believe my comments may be most appropriate and relevant for the Advisory Council and their considerations, and therefore sending to you. Please let me know if I should also send directly to napa@hhs.gov.

I appreciate the opportunity to participate in the March 14 Advisory Council teleconference as well as the opportunity to submit my comments on the Draft National Plan to Address Alzheimer's Disease and its importance for the more than 400,000 individuals with Down syndrome in the US and their families and caregivers as well as associated stakeholders. More explicit inclusion of Down syndrome as integral to the Plan, particular concerning fundamental, translational and clinical research, will be important for accelerating progress and success not only for individuals with Down syndrome, and associated very high Alzheimer's disease neuropathology and dementia, but also for the entire population that will develop or currently have Alzheimer's disease.

Should you have any additional questions etc., please do not hesitate to contact me.

Thank you,

Michael M. Harpold, Ph.D.  
Chief Scientific Officer  
Chair, Scientific Advisory Board  
Down Syndrome Research and Treatment Foundation

ATTACHMENT: Harpold\_DSRTF\_Comments on NAPA Draft Natl Alzheimers Plan 03.12.doc

***Available as separate links:***

Comments Regarding Draft National Plan To <http://aspe.hhs.gov/daltcp/napa/Comments/cmtach156.pdf>  
Address Alzheimer's Disease

**DATE:** April 17, 2012  
**SUBJECT:** Family Caregiver Alliance Input on Today's Meeting

Family Caregiver Alliance would like to submit the attached comments into the official record for today.

Thank you,

Sean Coffey, MPA  
Policy Specialist  
National Center on Caregiving  
on behalf of Kathy Kelly, Executive Director of Family Caregiver Alliance  
<http://www.caregiver.org>

ATTACHMENT: Family Caregiver Alliance Input on Advisory Council Meeting #4  
(4.17.2012).pdf

***Available as separate links:***

Comments on Meeting #4 Presentation Handouts	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach155.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach155.pdf</a>
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**DATE:** April 17, 2012  
**SUBJECT:** Comments

Attached, please find comments relating to the National Plan to Address Alzheimer's Disease from national public health organizations. These comments address the public health elements of the Plan. A paper copy of the comments were also sent on April 6, 2012.

Thank you.

Catherine Morrison

ATTACHMENT: April 6 NAPA Comments - National Public Health Organizations.pdf

<b><i>Available as separate links:</i></b>	
NAPA Comments	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach154.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach154.pdf</a>



**DATE:** April 17, 2012

**SUBJECT:** Comments for Research Subcommittee Recommendations for Points 7 and 12

I would like to include the following comments for discussion at the **Research Subcommittee Recommendations**, Points 7 and 12.

I'm very concern about **point 7**, specifically sub-points (A & B), recommending HHS use existing authority to reduce drug development and taking immediate steps by HHS to go after patents and intellectual property. If the goal of this committee is to spur innovation and drug development then why attack businesses incentive to invest in the disease? If this point is passed, it may have a chilling effect for small pharmaceutical and private research organizations who's members demand a "return on investment".

And again for **Point 12**, the aspect of industry being made to share intellectual property because this committee votes on a process or mechanism to side step inventors patent rights or industries trade secrets will again send a chilling signal to the investment community by making investors think twice about investing in Alzheimer's Disease research and thereby creating the opposite effect this committee is trying to accomplish.

Overall, this committee needs to be pragmatic in the understanding that a cure will be discovered when a group of factors is satisfied not because of a lofty marketing idea of a cure by 2020. These factors include, advancement in medical technology, better understanding of human genetics, and overall better medical training.

Thank you,

Brian Sexton

**DATE:** April 15, 2012  
**SUBJECT:** RE: April 17 meeting attendance

Attached is my letter to be read at the NAPA April 17 meeting. I tried to keep it as short as possible, but I was afraid I would lose part of the message I was trying to convey. I would have liked to focus on only one or two points, but I felt they were all very important. Maybe some were in the middle of reading you can slam a book down to get everyone's attention to refocus at my request since I am not there to get their attention. I'll be watching.

Is there a way I can send you an email to a blackberry or something if I hear something that I would like to bring up last minute as I attend the meeting from home?

Thank you again for all this. You have no idea what it means to me to be able to be a participant in this project.

Michael Ellenbogen  
<http://www.michaellenbogenmovement.com/>

ATTACHMENT: NAPA Response 4-17-12.doc

<b><i>Available as separate links:</i></b>	
Public Comments for April 17 Meeting	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach166.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach166.pdf</a>

**DATE:** April 14, 2012  
**SUBJECT:** new medicare policy

I was asked to comment on the NAPA which I did. However, a more serious situation has arisen where Medicare has placed an unsurmountable hurdle in the treatment of and research with early Alzheimer's patients. I would hope you could direct my information to the appropriate groups.

I would like to inform you that National Government Services, the large carrier for Medicare in the Northeast and Midwest, has reversed their previous position and now DO NOT allow treatment of Alzheimer's patients with cognitive rehabilitation services including memory training. Despite the NIH report and AA recommendations as well as the National Alzheimer's Project Act calling for the dropping of hurdles in Medicare, NGS has removed cognitive rehabilitation as an acceptable treatment for memory loss **IF** it is due to a chronic disease such as Alzheimer's. If the brain disease is due to injury it is still allowed. The clear purpose of this change in the Rehabilitation LCD is to exclude Medicare recipients who suffer with AD from the services they require

I would greatly appreciate it if you could post this on a blog or other vehicle that can be read by Alzheimer advocates

Thank you

Peter

**DATE:** April 12, 2012  
**SUBJECT:** FYI

Maybe you could share this article with your people. I knew a new person gets Alzheimer's in the US every 68 seconds, but this report that just came out yesterday blew me away. I have attached it for your viewing and sharing. This was copied from an article.

Have a great day?

I know realize my mission is even more important than ever. Please, please help me.

Michael Ellenbogen  
Author of "The Insider's Guide To Saving Money"  
<http://www.michaelellenbogen.com>  
<http://www.michaelellenbogenmovement.com/>

ATTACHMENT: World Health Organization 4-11-12.docx

<b>Available as separate links:</b>	
Alzheimer's News Article	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach153.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach153.pdf</a>

**DATE:** April 10, 2012

**SUBJECT:** We need a bold plan to stop Alzheimer's!

I am writing to you because of a request from USAgainstAlzheimer's, however, I'd like to make you aware of a book that has been written by Mary T. Newport, MD titled "Alzheimer's Disease, What if There Was A Cure?". She has done research on Coconut Oil which has shown significant change in her husband's Alzheimer's. In her book, she mentions that she attempted to attend an International Conference on Alzheimer's Disease.

They would not let her speak at the conference or allow her to pass out information on her research.

I find that inexcusable.

I lost my eldest sister in 2008 of the disease. It was one of the worst things I have ever been through after losing another older sister of ALS in 1996.

Thank you for your attention to this matter.

Sincerely

Michael A. Durocher  
Covington, LA

**DATE:** April 10, 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.

There now appears to be evidence that Alzheimer's is related in part to silver filling i.e. mercury. Please see below reference;  
[http://articles.mercola.com/sites/articles/archive/2012/04/07/dangers-of-mercury-contamination.aspx?e\\_cid=20120407\\_DNL\\_art\\_1](http://articles.mercola.com/sites/articles/archive/2012/04/07/dangers-of-mercury-contamination.aspx?e_cid=20120407_DNL_art_1)

#### Story at-a-glance

Studies show that mercury is the MOST toxic heavy metal to your body; this excellent new documentary film, Mercury Undercover, exposes the dangers of mercury contamination to human health and to the environment

The number one source of mercury pollution is coal-fired power plants. Second position is held by dental practices due to amalgam fillings, which are 50 percent mercury

Dental amalgams, used for more than 150 years, continue to be used by half of the dentists in North America despite a mountain of evidence they slowly leak toxic mercury into your body, and are particularly dangerous for children and pregnant women

Mercury becomes a "biochemical train wreck in your body," causing your cell membranes to leak, and inhibit key enzymes your body needs for energy production and removal of toxins.

Mercury toxicity can lead to major inflammation and chronic illnesses such as Alzheimer's disease and Parkinson's disease

The FDA, in partnership with the ADA, have been successful for many years in concealing the dangers of amalgam from the public, but organizations such as the Consumers for Dental Choice are making inroads toward getting mercury banned from dentistry worldwide-- but they need your help

By Dr. Mercola

I strongly encourage you to watch the new documentary film Mercury Undercover, which exposes just how far those in power will go to prevent you from learning the truth about mercury contamination from dental amalgam--all in the name of money.

Dental amalgam is a primitive, pre-Civil War product that is 50 percent mercury, still commonly used in dental fillings.

Angeleah Dolfay  
Seattle, WA

**DATE:** April 9, 2012

**SUBJECT:** National Plan to Address Alzheimer's

I am pleased to see that Alzheimer's and other dementias are on the minds of our elected officials. As an adult protection worker and daughter of a mother with dementia I have seen what these diseases/illnesses can do to individuals and to their families. What is needed, especially in rural areas, is funding for more support programs/providers and education of families and providers to better understand the individual and to serve them with dignity. Each individual is unique in their deterioration, their needs, and how they should be served. Please keep the focus on Alzheimer's and other dementias in the forefront, it WILL affect you or someone you know.

Catherine C. Martin  
Social Worker  
Pierce County, WI



**DATE:** April 6, 2012  
**SUBJECT:** April 17th meeting attendance

I am Joel S Ross MD. I have provided medical care for over 10,000 victims of Alzheimer's Disease since starting my comprehensive geriatric and Alzheimer's Disease practice in 1986. I would like to present my comments on the NAPA plan. I am a member of the advisory panel of NAPA and through my organization, The Memory Enhancement of America we provide an unprecedented level of care and treatment to all those afflicted with memory loss/mild cognitive impairment and dementia due to Alzheimer's Disease.

I would desire to discuss the urgent need to open a demonstration project in our 6<sup>th</sup> congressional district. This Memory Evaluation and Treatment Center (METC) will provide complete and comprehensive management for mild, moderate and severe stages of Alzheimer's Disease. Funded in part by the a portion of the 83 million dollars signed into law by President Obama it shall include but not limit itself to providing medical/nursing/social/psychological care of AD patients as well as offer physical and occupational therapy; address the many ethical, financial and legal challenges this deadly disease poses to patients, caregivers and society in general. This METC will show cost effectiveness by reducing unnecessary hospitalization, reducing need for emergency room visits, delay nursing home if not eliminate the need for such placement as well as be a center of excellence for all other 434 Congressional districts in our wonderful nation. Pharmaceutical research of the highest caliber testing safety and efficacy of the latest medications in development will be a further extension of METC.

All at no cost to the patient. I propose that Medicare/Medicaid and a portion of NAPA money be used to test this METC concept and in a randomized study using a group of 200 AD patients assigned to traditional (fragmented and inefficient, standard of care) and comparing them to a similarly matched group of 200 AD patients assigned to METC care.

I and my many colleagues and other professional associates and organizations believe quite strongly and will prove a METC is the only place for AD patients to receive comprehensive, compassionate and welcomed care.

My bio is attached for your review.

I welcome the opportunity to speak at the April 17<sup>th</sup> meeting on behalf of the nearly 5.5 million victims of AD as well as for those who have died from this dreadful 100% fatal disorder.

Thank you for the time to consider my suggestions,

Dr Ross  
President, Memory Enhancement Centers of America Inc.  
Eatontown, NJ  
<http://www.memorycenternj.com>  
Clinical Associate Professor of Medicine, Mount Sinai Medical Center  
New York, NY

ATTACHMENT: Biographical\_SketchJoelRoss Feb 20 2012.doc

<b>Available as separate links:</b>	
Joel S. Ross, Biographical Sketch	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach165.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach165.pdf</a>

**DATE:** April 6, 2012  
**SUBJECT:** National Plan to Address Alzheimer's Disease

As national public health organizations representing state and local public health practitioners, educators, providers, agency officials, and academicians, we are writing to urge you to ensure that the National Plan to Address Alzheimer's Disease includes public health as a key feature of its structure and implementation.

We applaud the department's effort to utilize the resources of the aging network traditionally drawn upon in dealing with Alzheimer's disease. However, the Plan does not fully engage the public health community at federal, state, and local levels. This risks overlooking the work of the Centers for Disease Control and Prevention (CDC) and specifically the Healthy Aging Program's work. Additionally, states have begun to use their public health networks to confront Alzheimer's as broadly as possible. We believe the most successful implementation of the Plan will be through a population based, public health approach.

Therefore, as your agency develops the final version of the Plan, we urge you to include these critical elements:

**(1) A clear statement of Alzheimer's disease as a public health crisis and its burden.**

Alzheimer's and other dementias are a major public health issue and will increasingly affect the health and well-being of the population until effective interventions are available. In the United States, 5.4 million Americans are living with Alzheimer's disease, costing society an estimated \$200 billion this year. In addition, more than 15 million friends and family members provide unpaid care to those with Alzheimer's and other dementias -- care valued at over \$210 billion. Public health takes a broad view of health care and seeks to achieve lasting change in the health of entire populations, extending far beyond the medical treatment of individual people. The tools and techniques of public health are expansive in scope and required for successful implementation of the Plan.

**(2) Addressing the connection between Alzheimer's and other multiple chronic conditions from a public health perspective.** At least three-quarters of people with Alzheimer's and other dementias have one or more other chronic conditions. Yet, the National Plan to Address Alzheimer's Disease does not mention chronic disease or multiple chronic conditions from a public health perspective. Additionally, the Plan does not mention the HHS Initiative on Multiple Chronic Conditions, which includes both individuals with cognitive impairment and their caregivers as important considerations. The role of state and local health departments in coordinating efforts to reduce disabilities, improve functioning, and enhance quality of life for individuals with multiple chronic conditions is vital to the implementation of the Plan. Examples of these programs include Chronic Disease Self-Management and Falls Prevention programs. The importance of recognizing, effectively treating, and minimizing the impact of multiple chronic conditions, including the impact that Alzheimer's has on managing other chronic conditions, could be highlighted in Goals 2 and 4.

**(3) Surveillance.** The Plan rightly includes Goal 5 to improve data to track progress, but it omits important surveillance and data collection work by the CDC and its state level partners. Work conducted through the Behavioral Risk Factor Surveillance Survey (BRFSS), the world's largest telephone-based health interview survey, now allows states to conduct surveillance on cognitive impairment (CI) and caregiving. These data are essential to understand the burden and impact of Alzheimer's, cognitive impairment, and caregiving at state and local levels -- data that does not currently exist. With similar data in the areas of obesity, diabetes, and arthritis, state and

local leaders have been able to make impressive gains in public health programs and policies using BRFSS information. The CDC has been a leader in the development and implementation of these questions, with a majority of states now having used or currently using the CI module. The CDC Healthy Aging Program is working with partners, including the states, to ensure that all 50 states have used the module at least once by 2013. An additional action should be included in Strategy 5.A to support the important surveillance work being conducted by the CDC and its partners.

**(4) A rigorous, public health-driven awareness campaign.** As written, the Plan either relies on the aging network or does not comment on available public health resources to disseminate and educate the public on early diagnosis, reducing stigma around Alzheimer's, and caregiver services. For example, the CDC Healthy Aging Program has studied diverse groups of older adults to understand communication strategies. State public health officials are skilled in working with aging adults and caregivers, efforts that could inform the Plan. Consideration of the role of public health should be included in Action 3.C.1 and Strategy 4.A.

We appreciate your commitment thus far on the issue of Alzheimer's and on the development of a strong National Plan to Address Alzheimer's Disease. The public health community at the local, state, and federal level is vital to the successful implementation of the Plan and to improving the lives of individuals affected by Alzheimer's disease and their caregivers.

Sincerely,

National Association of Local Boards of Health  
The Association of State and Territorial Directors of Nursing  
The Center for Technology and Aging  
FASGI Community Wellness Center  
National Association of Chronic Disease Directors  
National Association of County and City Health Officials  
Public Health Foundation  
Public Health Institute  
Society for Public Health Education

**DATE:** April 5, 2012  
**SUBJECT:** Comments

Attached are my comments on the draft HHS plan for the National Alzheimer's Project Act. My contact information is in the attached comments should you have any questions.

Thank you for the opportunity to comment on HHS's draft plan.

Bob Southworth

ATTACHMENT: NAPAccomments.doc

***Available as separate links:***

Comments on the Undated Draft National Plan to Address Alzheimer's Disease	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach152.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach152.pdf</a>
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**DATE:** April 2, 2012

**SUBJECT:** FasterCures' comments on the National Plan to Address Alzheimer's Disease

Thank you for the opportunity to comment on the draft National Plan to Address Alzheimer's Disease. Attached are *FasterCures'* comments for your consideration. Please confirm that you have received this submission.

Please let me know if you have any questions.

Sincerely,

Cecilia O. Arradaza  
Director, Communications & Marketing  
FasterCures  
Washington, DC  
<http://www.fastercures.org>

ATTACHMENT: FasterCures\_Comments\_NatlAlzPlan.docx

<b><i>Available as separate links:</i></b>	
National Plan to Address Alzheimer's Disease	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach151.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach151.pdf</a>

**DATE:** April 2, 2012

**SUBJECT:** Comments from an Alzheimer's Caregiver and Research Scientist

I am very impressed by the Draft National Plan to Address Alzheimer's Disease (and Related Dementias). It is well written and quite comprehensive from my perspective. But I do have some concerns and suggestions.

My wife was diagnosed with Alzheimer's Disease in February 2010. I am her primary caregiver and health advocate. Fortunately, long-term care insurance has afforded us the opportunity to have two very good caregivers thus providing me the ability to work part time as a research scientist at CNA, a Federally Funded Research and Development Center (FFRDC). My wife and I have experienced both the classical, traditional clinical medical approach and, more recently, the alternative complementary medical approach. In addition, I am a member of two caregiver support groups: one offered by a Ministry to the Aging at my church, and the second offered by the Alzheimer's Family Day Center of Fairfax, VA.

From this base of experience and education, I offer my observations and suggestions:

1. The plan seems to lack a sense of urgency. While the goal "to prevent and effectively treat AD by 2025" is laudable, the selection of 2025 along with the general tone of the plan does not convey the urgency I believe is necessary. Selecting either 2020, because it's sooner and a nice round number, or 2022, as it comes 10-years after the release of the National Plan and is akin to President Kennedy's announcement in 1960 of manned flight to the moon by the end of that decade, would be better. Both years signal a message of boldness and ambition more so than does 2025. I believe caregivers and family members would be encouraged by such ambitious goals.
2. The plan appears to display certain biases that may restrict the search for alternative solutions.
  - a) First, there seems to be an emphasis on searching for "pharmacological" solutions. Certainly, the plan recognizes other approaches, e.g. "While research on AD has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the disease" and "non-pharmacological management of physical, cognitive, and behavioral symptoms." But it does not clearly state what such "other, non-pharmacological" approaches might be. This suggests to me a bias toward pharmaceutical solutions and therefore a favoring of the pharmaceutical industry, which seems to be more motivated by profits than solutions. I encourage that these other approaches be specified. The effectiveness of public health communications necessitates clear, plain-English language.
  - b) There also seems to be a bias toward the time-consuming approach of clinical trials. The plan clearly recognizes the need to the pharmaceutical bias, I think.
  - c) The plan rightly includes "related dementias" in defining Alzheimer's Disease. But it identifies only Lewy body, frontotemporal, and vascular dementias as examples. Unless recognized but not stated by the drafters, I suggest including other neurological diseases such as Parkinson's, Huntington's, ALS/Lew Gehrig, and MS. Such an expansion might introduce synergies and efficiencies and potentially a considerably more significant effect.

Admittedly, my own personal research into AD is limited. I have only recently begun to dig more deeply into the subject. Much of my motivation comes from frustration over the silence and apparent helplessness of the traditional medical community toward my wife's disease. I have recently read two books that have strongly influenced me: "Alzheimer's Disease---What If There

Was a Cure”---The Story of Ketones” by Dr. Mary Newport, and “Stop Alzheimer’s Now! How to Prevent and Reverse Dementia, Parkinson’s, ALS, Multiple Sclerosis and Other Neurodegenerative Disorders” by Dr. Bruce Fife. These books introduced me to the “Type 3 Diabetes” aspect of AD, which I find most intriguing and compelling. If what they say is true about insulin-deficiency and insulin-resistance in the brain and the resultant “starvation” of neurons, and that nutritional substitutes in the form of ketone bodies from medium-chain triglyceride fatty acids already exist on the shelves of health food stores in the forms of coconut oil and MCT oils, THIS IS HUGE. Considering that I might be “starving” my wife’s neurons by not providing this source of fuels (already used by neonatologists, according to Dr. Newport and in pediatrics, according to my RN daughter), ignoring this evidence is morally unconscionable to me. Also if true, this nutritional approach could be a “silver bullet” of vast consequence.

Thank you for soliciting comments from the public in reaction to the draft plan. I apologize for missing the March 30 deadline. Such tardiness has become commonplace for me as an Alzheimer’s caregiver and health advocate. And thank you for your contribution to this important work.

With regards.

Gregory N. Suess, Ph.D.  
Annandale, VA

**DATE:** April 1, 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.

<b><i>Available as separate links:</i></b>	
List of the 8,267 People Who Sent this Form Letter in April 2012	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach150.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach150.pdf</a>



**DATE:** April 1, 2012

**SUBJECT:** We need a bold plan to stop Alzheimer's!

I am a retired RN. However, I now provide non-medical home care to individuals with Dementia and Alzheimer's Disease at a reasonable cost.

I also serve as their healthcare advocate, assisting the family to find good medical care for their loved one.

I think the world of you. Thank-you for attending to the needs of the aging population.

I am 66 years old. My client is also Sixty-Six, and requires constant care and attention. She is also a Registered Nurse. She responds so well to loving care. I am so fortunate to have these skills.

Your Truly,

Georgette Vianni  
Orinda, CA