

**NAPA -- FACA 2012 Public Comments**  
*(July Comments Only)*  
February 7, 2013

**JULY 2012 COMMENTS**

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## JULY 2012 COMMENTS

**DATE:** July 21, 2012

**SUBJECT:** Suggestions for dealing with patients with Dementia

I want to thank you for allowing me to participate in this NAPA meeting. In this document, and those attached, I write of issues I feel are important to be shared with the committee. When I have the opportunity to speak during the live meeting, I may follow this format, or I may have additional comments or suggestions.

Attached are a few documents that I hope will benefit many dealing with Alzheimer's disease or other dementia. The first document "Hospitals Dealing with Dementia Patients (1)" is based on my experience in staying in the hospital. I would like to think that what happened to me will apply to most hospitals and they all need to be educated.

When I have brought this to the attention of Doylestown Hospital the people were very receptive and realized that further education was needed. They are now discussing how to best approach/take advantage of my skills and the use of the Alzheimer's Association to better educate their personnel in this facility. My hope is that this hospital can become a model for other hospitals dealing with dementia patients.

Attached is also "Alzheimer's Initiatives - International Association of Chiefs of Police" document. I worked with the Alzheimer's Initiatives Project Manager for the International Association of Chiefs of Police. Some of these issues are being addressed while others are not. It also seems to be open to the local police chiefs to determine if this is something they will need or benefit from. While the Project Manager feels they should all be implemented, there is no way to get all the Chiefs involved. This is all being done voluntarily. While I know the township next to mine is involved, I cannot say that for the police in my township. Multiple calls went unanswered. My suggestions and many others should become mandatory for not only the safety of the patient and the public, but also for the officer.

Since diagnosed with Alzheimer's, I have had the fear that I will suffer in many ways as I die slowly from this disease. How will I suffer? One way, which I recently realized, is from pain that my doctor might not recognize or treat once I am no longer able to effectively communicate my needs. Recently I found a way that makes it easy for people to do two things: To learn how people can suffer from Advanced Dementia and to then make decisions that are legal and moral. Basically, I do not want to continue any treatment that will ONLY prolong my dying and increase the chance of my suffering.

This tool is a set of illustrated cards. It creates a Natural Dying Living Will. The name is thus "Natural Dying Living Will Cards." Each of the four dozen cards describes a single aspect of Advanced Dementia in plain language. Each card also has a line drawing, to explain the text. What I did when I "sorted the cards" is to make a decision about what I wanted for each item: Treat and Feed, or Natural Dying? A video is being created in which I can explain my choices, which my loved ones can view when the time comes. I am glad I have the opportunity to say now what I will want later. I can have confidence that I will not have to suffer a prolonged dying with emotional or physical pain. I do not think this system covers all of my concerns, but it's the best available that I am aware of today. This should be considered for all others.

One of the manifestations of dementia is wandering. Patients rely upon familiarity and can get lost easily. This can create panic for the patient and their loved ones and may sometimes result in injury or death. Today there are many state-of-the-art location based products and services that offer safety and peace-of-mind to families and loved ones. People need to be educated about these products and directed to the ones that are best fit for their application. The medical field needs to embrace these products as they do drugs. These products can lead to the person safely staying at home longer. Therefore these products should be a must for all patients and should be covered by health plans and government plans. We also need to figure out how to bring down the cost so that everyone can take advantage of them.

As a dementia patient living in the spotlight, I am often contacted by people trying to sell or convince me to use a product they have that will either reverse or cure my disease. We all have this hope factor in us and are very willing to do some very stupid things to see if they work. There needs to be a single unbiased source of all proven technology that people can rely on. There should be information on what is known to help and what has been known to fail. Too many people are being scammed by the quacks and we need to help people understand what really works. Now I say this with caution, because we also need to remain open-minded. Some real solutions may come from non-traditional methods. As long as respectable people have done a true trial, following the stringent protocols established, that can also be backed up by the medical field, then it should be added to the list.

And my last and final point and question. What assurances do families have that what you are doing will get us a means of prevention and treatment by 2020 or 2025? I am already concerned by the lack of funding being appropriated for this cause.

Please do not hesitate to reach out to me should you have any questions. I welcome the opportunity to become more involved in this committee and to be able to give my viewpoints as an Alzheimer's/dementia person. I also volunteer to be utilized by this committee and HSS to be a voice for other AD patients.

Thanks and have a great weekend.

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

ATTACHMENT: Hospitals dealing with Dementia Patients (1).doc  
Alzheimer's Initiatives - International Association of Chiefs of Policy.docx

<b>Available as separate links:</b>	
Hospitals Dealing with Dementia Patients	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach162.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach162.pdf</a>
Alzheimer's Initiatives	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach163.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach163.pdf</a>

**DATE:** July 4, 2012

**SUBJECT:** nutrition focus for ALZ

Taking care of a loved one during the progressive stages of ALZ includes specialized meal items and feeding techniques that we practice in long term care. Would it be possible to include some information and allow funding for increased needs for nutrition education to minimize malnutrition risks for ALZ patients or is this already considered?

Best regards,

Janet Shufelt, MS RD LD  
CMDA Nominating Chair/Past President  
Clinical Dietitian LMCEC