

NAPA -- FACA 2012 Public Comments
(October Comments Only)
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OCTOBER 2012 COMMENTS

DATE: October 14, 2012
SUBJECT: What it's like to be in my shoes

I would also like to share with your team a modified article that I had originally written for the World Alzheimer Report 2012. Since that time I had the opportunity to take a 3 week vacation which I truly loved. At the same time it pointed out new weakness in my skills and I realize I have declined a bit more. There was a time that I can follow a map and could easily get from point A to B. Unfortunately this time was different. I had to continuously rely on my wife who was not quite used to taking on this challenge. When I look at the map, I just cannot focus on an area and I just keep seeing all of the streets. You also need to keep into memory where you are coming from and what was the last cross streets, which again I cannot retain. Unfortunately my frustration was passed on to her because I expected her to perform at the level I once could. It's not easy living with a dementia person.

Then there was looking at the menus, I just could not seem to look at menus and make sense because I was being confused by it being into different languages even though one was English. For one reason or another I just could not process that information and had to rely on my wife to know what I like to help me make a choice.

Then there was the train stations. I looked at the boards completely confused and not understanding what my wife was seeing on how and where to get our next train. I just went along for the ride and thank god she knew what she was doing. These are all things I have never had to rely on anyone. In fact I was the one being the leader in my business and personal life when it came to those types of things.

I also use to have a great sense of direction without a map and almost never got lost. But I realized that in order to do that you need to be able to retain when and where you turn so you can keep track of direction. It seems that I lost that because I had to tell my wife to figure out where we were many times. She was not use to that which placed a lot more stress on her. It seems that more and more things are starting to fall on her shoulders and that is a very big burden to have to carry. In fact I realized to late that I had over burden her with even making this trip, which I was once very cable of doing or at least sharing the load. There was so much planning involved and it all fell one her because I cannot even be a bouncing board to check for accuracy anymore.

I always walked around with this fear that I might get lost in a crowd from my wife. But that's why I always made sure to have the business card for the hotel I was staying at. I am telling you all this and sharing the article below because we all hear all the medical terms around dementia issue, but I really believe most people are clueless when it comes to truly understanding what dementia people really have to deal with. I learned this first hand dealing with the supposedly expert health reporters. I want people to become educated and realize that while our disability is not visible, it is by far a very true disability. I hope this will be useful to your team. As always I am willing to speak about this openly and be completely honest no matter how embarrassing it may be.

"The Realities of Alzheimer's and Overcoming Stigma"

Alzheimer's disease and other forms of dementia affect more than 35 million people worldwide today. An astonishing fact that today someone in the world develops dementia every 4 seconds. By the middle of the century more than 115 million people will be affected by the disease if we do nothing.

My name is Michael Ellenbogen, and I am living with Alzheimer's and trying to make a difference. I was previously a high-level manager in the telecommunication industry. In 2008, I was diagnosed with younger-onset Alzheimer's disease (YOAD) after struggling to get a diagnosis since my first symptoms at age 39. Losing my job and not being able to work had a huge impact on my life as I was a workaholic. I am now an Alzheimer's advocate and a spokesperson for the Alzheimer's Association (U.S.) as a member of its national 2012 Early-Stage Advisory Group.

I am so frustrated, because no one realizes how seriously disabled I am. If I had a loss of limb or some other visual ailment, it would make people realize. I don't want them to feel sorry for me or pity me, just want to be understood. So many people say you do not seem to have Alzheimer's, and that frustrates me. Let me tell you what it's like to live with this debilitating and progressive disease.

Imagine for one minute that your friend, relative or family member has Alzheimer's and has to deal with the following issues. When I go shopping and look at items, most of them never really register in my mind, even though I see it clearly. I have trouble making decisions, because I question whether I am making the right one. I can no longer enjoy my favorite hobbies, because it requires processing skills that I no longer have. I went from being a gadget person, to now being threatened by technology that I no longer can use. This is what I deal with and so much more.

I go to a happy affair only to be tortured by the noise and surrounding conversations, because of the loudness that cannot be filtered out. If people try to speak with me in a public setting where there are many other conversations, I just don't understand what they are saying. This is because all of the people speaking come in at the same volume level. All the words run together, and it sounds like a foreign language.

I went from being extremely proactive to becoming much less active and motivated. I leave things around the house and don't put them away, because I don't know where they go or feel I may not know where to retrieve them again. One moment I am nice and another I may fly off the handle. I can no longer write or speak like I used to. My friends slowly become distant and usually speak to my wife. I do realize this.

I worry every day about the challenges ahead. Or even worse, I am losing my mind and see it happening, but I cannot do anything to change the course. People always say 'if I can do anything just let me know.' If I take them up on that offer, they back out of their commitments. I have become extremely surprised by the lack of public commitment to my pleas for support of Alzheimer's disease. While some may be sympathetic in the moment, there appears to be little follow-through. This is very upsetting, because I feel as though it affects me personally as well as the millions of others living with the disease. I was always there for others when they needed it and now I feel alone.

While many people just coast through the day, I have to use 110% of my processing skills to do most things, which increases the stress and frustration. The worst part about this disease is knowing that I am doing all these things wrong and have no way to control or stop it, and it's only getting worse as the days go by. I used to save lots of money by doing so many things around the house. Now I lost the drive, determination and skills needed to do those things. Many times I hurt myself trying or make it worse.

I cannot begin to explain how it tears me up inside to see my spouse struggling to do the things that I once was capable of doing and know I cannot do a thing to help. I realize that one day I may no longer be able to drive and this devastates me. I see my wife becoming stressed, depressed and overwhelmed, but caregivers know it will only continue to get worse. Sadly, they keep telling themselves that they can do it all even when we know they will need help. I, the patient, see it definitely. My wife is on the road to hell, and she does not even realize it yet, because she is so busy trying to block it all out. The worst part about all this is, I have not even reached the worst stage. That scares the hell out of me.

I have been so surprised by the stigma associated with this disease. It comes at you from all angles. People think they knew what Alzheimer's is, but they don't. I see this not only from people living with dementia but many media health correspondents, physicians and organizations that are geared to helping those deal with the disease. I have learned that I do not want to share my diagnosis with people I meet until they get to know me. If I was to tell them upfront, I would be treated so differently, which I have learned. I kind of see this disease like HIV use to be. The people who have it are so afraid to let others know, including family. I do not get it. We did nothing wrong to get this disease, and we need to speak up to let our voice be heard. We did nothing and no one should be ashamed of having it. I feel so much better when I share it with others than when I try to hide it.

Because of my frustration with existing environment for people with dementia, I realized change was need. I decided to use my few skills left to advocate. I have spent some of my last few years being on television, radio, newspapers, many blogs and working with many politicians. I also had an opportunity to speak at all of the public sessions to develop the first U.S. National Alzheimer's Plan, all this on my own. But that was not enough, because I ran into so many people who just did not want to get involved. I am now a volunteer for the national Alzheimer's Association Early-Stage Advisory Group. If there is something I want you to walk away with it's that you can make a difference, but it will take persistence. Write a letter to your public official or reach out to local support organizations to create needed programs and services. Your voice and your story are powerful tools. Please get involved.

The simple truth is, if you have not been touched by this devastating and debilitating disease yet, consider yourself extremely lucky. Sadly, it's just a matter of time before it touches you. It is my hope that my actions today may prevent future generations from suffering with this disease. So give yourself piece of mind and do something today. I hope that what I am doing will allow me to leave this world knowing that I did everything possible to make that next generation have a fighting chance. There are no excuses for not wanting to help. The human cost factor is too high, and we are all accountable to do something.

There are many organizations out there like ADI and the Alzheimer's Association that can help you. The Alzheimer's Association got me started in many ways with my new journey. It not only helped me, but it also had helped my wife as my caregiver. They have a website with many resources at <http://www.alz.org>. I encourage you to reach out today if you have not already. I would also encourage you to educate yourself.

Please join me and Go Purple. I wear a purple Alzheimer's bracelet every day. And for those living with Alzheimer's, stop focusing on what you cannot do and join me in the battle to advocate. We still have so much to give, and we need to use our skills at our own speed. There is nothing to be ashamed of. I, and your loved ones, are counting on all of you.

Michael Ellenbogen

Author of "The Insider's Guide To Saving Money"

<http://www.michaelellenbogen.com>

<http://www.michaelellenbogenmovement.com/>

DATE: October 5, 2012
SUBJECT: October 15 Meeting Attendance

Good afternoon -- On behalf of the Council on Social Work Education (CSWE), I am submitting the enclosed written public comment for the October 15 Advisory Council meeting.

Dr. Darla Spence Coffey, CSWE President, plans to also provide oral comment during the meeting.

Please do not hesitate to contact me with any questions.

Wendy A. Naus
Lewis-Burke Associates LLC
Washington, DC

ATTACHMENT: Alzheimers Advisory Council Written Comment Oct 2012.pdf

<i>Available as separate links:</i>	
Public Comment to the Advisory Council on Alzheimer's Research, Care, and Services	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach167.pdf