

Include us

Perspective

What is wrong with this picture? I am constantly reaching out to many who do some kind of work for the dementia world, ranging from healthcare workers, certification organizations, Pharma government agencies and technology companies. They all are working to improve the lives for those living with some form of dementia like Alzheimer's. Many share with me their ideas and give me reasons for why they have made some of their decisions. They all sound very good if you are a caregiver or an expert in neurology. To me some of the ideas sound like they are being done for the wrong reasons, or have even failed to address the real issues that people with dementia face. Most of these people are really proud when they first reach out to me. Unfortunately, many times after our first discussions things go south as I point out many negative issues with the product or policy they had created. Many fall short of the potential. They don't always get it because they seem to feel they have created something so great with the help of other caregivers who had to deal with those living with dementia. They feel very confident they were able to get it right because they received the right feedback.

They all seem to be surprised when I tell them they are wrong in their thinking. I ask them how many people living with dementia helped in the process. The look on their face or the dead silence seems to tell the story. They all say they have not. I asked them if they had even tried to find someone with dementia to help them, and they say the thought never even crossed their mind. To be very honest with you I am totally shocked that these folks never even gave it any thought. If you are going to build something or speak about a specific topic would you not first reach out to the experts in the field for their advice and thoughts?

I consider it a big problem when you have people telling us what we need when they themselves are clueless. I do not understand why they do not feel people with dementia are needed. In my opinion these people and organizations need to change their thinking if they truly want to help those living with dementia. I recommend they have at least one person involved – at minimum. But if you really want to do it right one will have 3 to 9. It is important to have diversity and know the person is still capable of contributing. I personally cannot understand why the companies would not have included people with dementia as part of a board if the organization was geared to dementia certifications. Would you not think it would be important to get the view from a person that would be directly impacted by the decisions being made?

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I believe part of the problem is because they are biased and also because of the stigma surrounding people like me. They all think that the minute one gets diagnosed a switch turns on and they no longer can function. They think about some person who is laying in some institution no longer capable of thinking or doing things. Well I have good news. We may be like that in our last year but many of us have many good years left where we could still be productive just not as good as we once were. In fact, with the proper help from society we could be able to lead a fairly normal life. This thinking on others needs to and must stop. Don't send us to the grave sooner than our disease calls for.

We need to put our crazy thinking aside and figure out a way to tap into all of these folks living with dementia to truly help the future. As a person who was a very high-level manager and very successful I could have never understood some of the things I see in myself today. In fact as I write this I still cannot understand it. But I bet sharp people like doctors could ask so many questions of me now which would lead to a tremendous value in creating new text books of what it really means to have dementia. Sadly, most are a failure because it was written by someone who did not understand the thoughts of one with dementia. I can assure you that your interpretation is different from mine and others based on previous discussions with others. So let's bring the right change by including the real experts – those living with dementia. The best example I could give for this is an organization DAA in the US which has created a board of 9 people with dementia. Now that is progress.