

AAIC 2024-From the Perspective of a Person with Dementia

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EDITORIAL

My name is Michael Ellenbogen and I am an International Dementia Advocate who is living with dementia. I had the opportunity to attend my first AAIC conference. I was so excited to be there with some of the smartest folks in the world. While I was so impressed by the latest discoveries, I was also amazed by some of the challenges we still face. In some ways it was just depressing. I will try to explain these to you below.

Major advances have been made in detecting blood-based biomarkers. One of the new tests had an accuracy rate of 91% in diagnosing Alzheimer's. This is great news. It will make it much easier for people to get a partial diagnosis. However, there are many other companies now in this space and some do not have a good track record, which could possibly lead to some organizations to get discouraged in their use. We need to weed them out through the FDA. They also have Tau blood tests, but this Tau is associated with the presence of Amyloid. Most insurance companies will not cover these yet.

Cognitive testing is really improving using technology. Some of them can be completed within two minutes with very good accuracy in showing cognitive impairment. What's even better you can use these tests right in your own home. These tests have taken out some of the earlier discrepancies of socioeconomics. While all of this is great there are also many newcomers to this field. It will take others to determine which ones are great and eliminate the use of the ones that are not.

The amyloid clearing drug, Leqembi, by Eisai has now slowed disease progression by three years. I think this will be even longer as these trials continue. I feel this was some of the greatest news I learned at AAIC. I actually came across one of my fellow dementia advocates who was on one of these drugs and he has now even seen improvements in his cognitive function. His care partner even saw the changes. This brought tears to my eyes because we now have hope. While this requires an infusion every two weeks, they are waiting approval from the FDA to administer by injection, which will make it easier and less costly. I hope they end up with auto injectors so people can do it from their home.

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I was really impressed by the Brainshuttle technology developed by Roche. This helps transport of medications across the Blood-Brain Barrier. It seems that they finally found a way to get the drugs there much more efficiently, but it is still early in its uses.

In one session I attended, they were discussing person-centered care. I cannot begin to tell you how frustrated I was listening to them. I worked on committee of people living with dementia in 2012. We developed a white paper outlining what person-centered care meant to us. It seemed to become more of a marketing term. These speakers were now saying how they have been talking about this for 30 years and they feel they will have a model in the next 5 years. That is completely a failure in my opinion. They need to get some business minded individuals involved to help make this happen in a timely manner. It should not take more than two years, starting from scratch. They also just realized they should be including people with dementia which was extremely upsetting considering the Alzheimer's Association was greatly involved.

While it was great that Centers for Medicare and Medicaid Services (CMS) launched a new program called the GUIDE Model, it continues to fail on educating hospital staff around dementia care and finding a way to identify those with cognitive issues who may not have a formal diagnosis. This will help people navigate the health system and allow them to live longer in their home. This will also save money for CMS.

I made sure to do a lot of networking. I came across two attending neurologists that specialized in dementia. I don't remember exactly how they said it but I will share with you what they told me.

1st comment – *I do not recommend or see value in giving Cholinesterase inhibitors, such as Aricept, or Namenda because they only work for about 3 months, if they do work. They also have such a small impact on improving cognitive function.*

I find this statement shocking as these drugs have been proven to work more than the 18 months originally tested in the clinical trials, for those that they help. Those that can benefit from the boost that these medications provide can see a huge impact on their cognition, like it did for me and my other friends who live with dementia.

2nd comment – *There is no reason to give anxiety & depression medication as when they progress they will no longer remember about having dementia.*

I myself have greatly benefitted from anti-anxiety/anti-depression medications. They help decrease apathy and make it easier to tolerate offending noise.

I found it very upsetting that there were not more advocates there living with dementia. Most organizations and companies fail to include these individuals, which is very sad. Those living with dementia must be part of the process from the beginning.

While I really enjoyed AAIC 2024 and am thankful to the Alzheimer's Association for having me there, I believe they need to find a way to clearly identify their staff. There were some "helpers" wearing black shirts that could direct you here or there, but I feel all that are part of the association should have some identifying symbol so one can easily locate them if one has a question or needs help.

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CONFLICTS OF INTEREST

Author declares there are no conflicts of interest.