State Guidelines for Clinical Best Practices for Early Detection, Diagnosis, Pharmaceutical and Non-Pharmaceutical Treatment of Persons With Alzheimer’s Disease:

The Texas Experience

Experts and care providers in Texas joined forces to develop guidelines that aid diagnosis and care and help elucidate the many types and causes of cognitive impairment.

BY RONALD DEVERE, MD

The fear of Alzheimer’s disease (AD) is in epidemic proportions in the United States and around the world. In many instances, this fear has overtaken the public fear of cancer, especially in individuals older than 60 years of age. It is not very hard to understand why this is happening. Many cancers are detected by early screening, and many that develop early are often very treatable and many can be “cured.” Gradual cognitive decline that robs individuals of normal communication with their family and loved ones is not a regular problem in cancer. In AD the main message by the National Alzheimer’s Association (NAA) is that individuals develop a relentless decline in cognitive impairment that eventually requires 24/7 care, which has no effective treatment, and then die—usually of the disease. Hearing this constantly, and that there are well over five million cases of Alzheimer’s in the US alone, and that the disorder has touched many families, adds more fuel to the fire of fear and worry.

I am a board certified neurologist and director of the Alzheimer’s disease and Memory Disorders Center for the last 20 years, initially in Houston and in the past 14 years in Austin, TX. Seventy percent of my practice is memory loss and dementia. My practice motto for memory loss and dementia is “the glass is half full, not half empty.” The obvious reason for this is that there are many causes or aggravating factors of cognitive decline beside AD that are treatable, and that Alzheimer’s in all its stages can be slowed down with the combination of pharmacologic and non-pharmacologic treatments. This information, however, is not known by most of the general public and many health care providers. There are numerous negative myths that abound about memory loss, dementia, and AD.

Daily, in my practice, I see people who have memory problems more often recognized by their loved ones and the only thing the family wants to know is if the individual has Alzheimer’s disease or not. I frequently see patients who have been referred by a health care provider who took a history, did a cognitive office test which scored lower than normal, ordered a CT-scan of the brain and a panel of blood tests, both of which were unremarkable, and diagnosed the patient with dementia and likely AD. The patient was given an acetylcholinesterase inhibitor (e.g. donepezil (Aricept)), often only the starting dose, and told to follow-up with the health care provider in four to six months. Many of these patients turn out to have mild cognitive impairment, which is more benign than dementia and may have a different prognosis in different individuals. (This is discussed in the new Texas guidelines.)

The National Alzheimer’s Association (NAA) has recently completed and approved a long term strategic plan to tackle AD, especially to double their revenue to support their mission: “A world without Alzheimer’s disease.” One of their strategic categories is entitled, “Increasing Concern and Awareness of the Disease.” I interpreted this to mean to inform the general public and health care providers about AD and address any public or health care provider concerns on this topic.

In 2010 the State of Texas Health department, which included members of the Texas council on AD, members of the AD program at the Texas Department of State Health Services, and many dedicated volunteers of the Texas AD partnership, decided to put together state guidelines on Disease Management Objectives for the 2010-2015 Texas State Plan on AD. The National Alzheimer’s guidelines had not been updated since 1984 and much new information had emerged since that time. It was decided to make the guidelines as user friendly as possible, so the general public and all health care providers could understand them. One year later in 2011, the National
The NAA has and continues to be an excellent source for information about AD and in raising research money to help eradicate the disease. They, however, have not done enough to help reduce the fear and worry of the disease for the general public, especially the millions of baby boomers who are now in their late 50s and 60s. I have written personal letters with suggestions of improving communication to the general public on this issue, to the national AD executive board, including the CEO, Scientific advisory chairman, and director of strategic planning and others about the importance of reducing fear of the disease. This can be done by increasing public education by improved brochures, apps, and seminars about memory loss and dementia, emphasize the many causes, and treatments of these disorders, including AD. The message I have repeatedly received from these leaders is that they believe they are doing a very good job and it is not their responsibility to reduce public fear of the disease beyond their current message.

Last year at the international AD disease meeting in Boston and at one of the strategic meetings attended by many of the Alzheimer’s state chapters, an historical event occurred while I was in attendance. Three board members from different state chapters stood up and announced that they all have AD, are active on their board, and they are tired of hearing all the negative features of the disease especially furnished by the NAA. They said they are alive and well, are making the best of their life and time and do not want to be written off by everyone. This started putting nails in the coffin about the national message of the disease.

I believe the NAA is farsighted on this important matter due to at least two obvious reasons:

- They do not have a specialty physician on the direct board who is practicing in “the trenches” and sees cognitive impaired patients with their loved ones everyday who are there for the first time and are only worried about Alzheimer’s. Patients and their loved ones are surprised to hear about the many medical and neurological disorders that can mimic AD and that all causes including AD are treatable, with current pharmacological and non-pharmacological treatments. The majority of the national board members are administrative and scientific advisors who are not taking care of individuals who have cognitive complaints. Many specialists in cognitive disorders around the country receive research grants from the NAA and will not jump on this bandwagon to help reduce fear of AD as I have discussed.

Many individuals with memory complaints are afraid to seek medical help because of the fear of having or getting AD. I give over 50 free public seminars on memory loss and dementia yearly and discuss the many possible causes of these disorders including anxiety and stress, sleep disorders, medications, silent strokes, metabolic and nutritional disorders, head trauma, normal pressure hydrocephalus, and the list goes on and on. Most of these conditions are treatable including AD. After each of my seminars numerous attendees come up and tell me they were unaware of all this information and they were planning to get a medical evaluation for themselves or a loved one. The more people who visit a physician for cognitive complaints and who are in general “less fearful” of AD, the more can be helped earlier, regardless of the cause. This approach will also increase the number of people who will be diagnosed with AD and contribute to the NAA for more research funds, etc. Emphasizing research and hope for a cure of AD is a very positive message but does not reduce any fear and worry about the disease in the millions of current baby boomers.

Alzheimer’s Association and the National Institute on Aging organized a large workshop to bring the National guidelines up to date. Our state committee reviewed these guidelines and incorporated the new information into the Texas guidelines. The Texas version was peer reviewed by many members of the Texas Alzheimer’s Research Consortium and other state experts and was completed and approved in early 2013.

The Texas and the National AD guidelines have included the new category of MCI, which involves cognitive impairment in one or more categories of cognitive function but does not or only minimally impairs activities of daily living. Patients with this disorder can remain stable for many years (30-40 percent), the remainder will slowly progress over five to seven years to dementia often due to AD, vascular, Lewy body or frontal temporal dementia. It’s not uncommon in clinical practice for a health care provider to diagnose dementia in an individual who actually has MCI. This can be a serious mistake, since the activities of daily living and treatment is different from dementia. We found that the new national guidelines were not user friendly for the public and the majority of health care providers, because of the use of heavy medical terms along with research information that was beyond simple understanding.

Members of our state committee are currently marketing these guidelines all over Texas. This includes public and professional seminars with simple PowerPoint presentations and getting this information to newspapers, which can mention the guidelines and where they can be accessed. It is by no means a final document. It will be updated as new information develops.
In 2014, the best standard of care gleaned from the guidelines in evaluating a patient with cognitive symptoms including memory changes should be:

A family member or good friend should accompany the visit.

Patients with cognitive complaints are usually not aware of all their day to day capabilities and deficiencies which is essential information

Thorough history of the cognitive complaint and general medical health should be taken.

An office cognitive test such as the Montreal Cognitive Assessment Test (MOCA, best for memory loss and dementia), Mini-mental State Exam (MMSE, Poor for memory disorders but good for dementia), Mini-cog (not detailed enough) etc. should be performed.

The person(s) accompanying the patient should complete an activity of daily living assessment evaluation (see guidelines) privately so there are no arguments or disagreement with the patient about the information that can occur in an open discussion.

The health care provider should do a thorough medical and neurological physical exam.

At the end of the evaluation, looking at the full acquired information, the health care provider should have an idea if the patient has: normal cognitive function for age, MCI, or dementia. Based on the history and medical knowledge, a list of possible causes should be listed and appropriate tests ordered. If the health care provider is not sure of the level of cognitive impairment then neuropsychological assessment should be ordered. This will not only determine the level of cognitive function but will also give important information about underlying depression and/or anxiety.

After all tests are completed, the patient and accompanied person(s) should return for follow up visit and a diagnosis of the level of cognitive impairment should be given along with a possible cause. If the cause is unknown further tests may need to be considered (see guidelines). In 2014 we have enough information about cognitive disorders that one should be able to give a probable or definitive diagnosis of a person’s cognitive decline and institute a non-pharmacologic and/or pharmacologic treatment program followed by close follow-up every 3-4 months. Current neurological information including appropriate radiological and spinal fluid testing is available to specifically diagnose the more common cause of dementia which include: AD, vascular, both AD and vascular, Parkinson’s, Lewy body and frontal temporal dementia. It is important to know that all these dementias except frontal temporal will respond (slow decline) to the standard acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) in the mild-to-moderate disease stage and adding memantine (Namenda) in the moderate to severe disease stage. Donepezil is also available in a higher dose (23mg) in moderate to severe disease.

To say the patient has dementia in 2014 and the cause is unclear does not give us enough information in regard to specific prognosis and treatment. A second opinion to further help determine the probable or definite cause should be obtained.

CONCLUSION

Medicine has a long way to go to cure or eradicate AD but slow progress is being made, and the majority of world countries are involved in research. We believe the Texas Guidelines on AD are user friendly and educational for the general public and all health care providers. We must aggressively diagnose and treat cognitive impairment in our medical practices and at the same time try to reduce its worry and fear, especially for AD.

The website to access the State of Texas AD guidelines is: www.dshs.state.tx.us/alzheimers

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