

AAN issues ethical guidance for dementia diagnosis and care

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The American Academy of Neurology (AAN), the world's largest association of neurologists with more than 36,000 members, is issuing ethical guidance for neurologists and neuroscience professionals who

care for people with Alzheimer's disease and other dementias. The new position statement is published in the July 12, 2021 online issue of *Neurology*, the medical journal of the American Academy of Neurology. This update to the 1996 AAN position statement was developed by the Ethics, Law, and Humanities Committee, a joint committee of the American Academy of Neurology, American Neurological Association and Child Neurology Society.

"Dementia care and scientific understanding have advanced considerably, including greater recognition of non-Alzheimer's dementias and advances in genetics, brain imaging and biomarker testing," said position statement author Winston Chiong, MD, Ph.D., of the University of California San Francisco and a member of the AAN's Ethics, Law, and Humanities Committee. "This American Academy of Neurology position statement focuses on day-to-day ethical problems faced by clinicians, patients and families in the course of [dementia care](#)."

The position statement was developed before FDA approval of the new medication aducanumab and does not address that drug.

The AAN position statement notes that communicating a [dementia diagnosis](#) can be ethically challenging. Some families may request withholding a diagnosis from their loved one, but that may deprive the person of important opportunities to plan for future needs. In most cases, the statement says family members' fears about potential emotional harm can be lessened by compassionate disclosure and so it recommends ways to communicate serious information.

"Caring for people with dementia requires respecting their autonomy and involving them in their care preferences as early as possible so their wishes can be known, while acknowledging their diminishing ability to make decisions," said Orly Avitzur, MD, MBA, FAAN, President of the

American Academy of Neurology. "This position statement offers guidance in accordance with core ethical principles, supporting the American Academy of Neurology's mission to promote the highest quality patient-centered neurologic care."

The position statement notes that Alzheimer's disease is only one form of dementia and symptoms can vary depending on which form of dementia a person has. Some forms begin with behavior disturbances that may be misinterpreted as a psychiatric rather than neurologic disorder.

The statement distinguishes between genetic or biomarker testing in people with symptoms of dementia and testing in people who do not have symptoms but are believed to be at risk of future dementia. Genetic and biomarker testing in people without symptoms of dementia is not recommended except in a research context. The statement recommends that anyone undergoing [genetic testing](#) should receive genetic counseling before and after receiving results.

Ethnic and racial disparities are persistent in dementia and dementia care. The statement notes that Black and Latino people are at higher risk for developing dementia compared with white and Asian people, likely due to social and economic differences earlier in life, and often experience delays in receiving a diagnosis of dementia due to poorer access, unequal care by the medical establishment, and the subsequent mistrust that this unequal care generates. It says doctors should be aware that those with ethnic or cultural backgrounds different from their own may have different perceptions of illness and priorities for care than they do.

For decision-making, planning in the early stages of dementia is crucial. The statement says people with dementia should be encouraged to discuss their overall goals with their families and doctors, create advance

health care directives, and engage in other financial and legal planning as a guide for when they are no longer able to make decisions. In moderate stages, people may still be able to participate in decision-making by relaying their values to guide care decisions. When a person can no longer make decisions, their representatives should give priority to preferences the person previously expressed.

For [daily activities](#) such as driving, cooking and managing finances, the position statement recommends that doctors and family members remain alert to ways of monitoring a person's activities to lessen risks while preserving their independence and dignity when possible.

The AAN also recognizes the potential for abuse and says doctors should look for and document physical signs of abuse, isolation of the person from trusted family or friends, failure to pay for care needs and malnutrition.

The position statement recognizes that for some patients in advanced stages, there are ways to maintain care for a person in the home. But it also suggests that doctors recommend reassessing whether in-home care remains feasible when caregivers experience burnout.

While some may request physician-hastened death, which is legal in some states, the statement points out that such laws generally do not apply to people with dementia. These laws require that someone have an estimated survival of six months or less yet still be able to make decisions on their own. People with such advanced dementia typically are not able to make these decisions.

Finally, the position statement notes that families often bear significant financial strain associated with [dementia](#) care and says new ways of providing and financing long-term care are needed.

Provided by American Academy of Neurology

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