



Department of Health

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Dear Colleagues:

This holiday season, I am focusing on people caring for an older or disabled adult and the people who are recipients of that care. Firstly, I am going to tell you about new quality improvements in identifying and treating people living with Alzheimer's disease that you can implement in your practice. As for my second topic, I will tell you about a new resource the Department has developed for caregivers.

Alzheimer's Disease: Many of us see the impact of dementia firsthand—both in our practices and in our personal lives. The numbers reinforce what we know to be true: Alzheimer's disease, the most common cause of dementia, impacts the lives of an estimated 400,000 people living with the disease in New York State. Over one million caregivers in New York support them, providing unpaid care valued at \$15 billion.ⁱ

Though we have yet to find a cure for this fatal disease, there is hope. Federal dollars for funding research on Alzheimer's disease and other dementias approached \$1 billion in 2017. We have also seen more focus on care and support for those currently facing the disease. New York State became a nationwide leader in this effort in 2015 through a \$27 million effort to fund community support providers and by creating ten clinical Centers of Excellence in Alzheimer's Disease (CEAD). I highly recommend that you utilize the [center in your region](#) as a resource for training, technical assistance, and referrals.

As part of our continued efforts to educate providers on this important topic, this month's session of my Commissioner's Grand Rounds series covered "The Science of Aging and Alzheimer's." I invite those of you who were not able to attend or watch the live webcast to view the recording posted on our [website](#), for which you can earn CME credit.

The progress we have made is promising, but more remains to be done—and all of us need to play a role in this effort. Based on clinical research, we are not yet where we need to be in terms of quality care for people with dementia. For example, the diagnosis of Alzheimer's disease is disclosed to the patient and caregivers less than 50% of the time,ⁱⁱ which limits their ability to access support services. Pain is often unrecognized and poorly managed in people with dementia. Behavioral and psychiatric symptoms, such as depression, frequently go undetected and untreated. People with dementia may not be assessed for functional changes, safety concerns, and driving impairment, all of which put them at risk. Last, but not least, we know we need to do a better job at engaging and educating caregivers.

In response to the need for better care, the National Plan for Alzheimer's Disease called for the creation of quality measures, an important step in improving and measuring changes in care practices. A [recent update](#) to existing quality measures, published jointly by the American Academy of Neurology (AAN) and American Psychiatric Association (APA), establishes nine areas in which quality of care could be improved:

1. **Disclose the diagnosis** to patients and their caregivers. Include that the patient has dementia and what disease is the underlying cause. This disclosure enables families to access available services and support to help them plan for the future.
2. **Educate and support caregivers**, whose role is stressful and often impacts their own health and well-being. The Department funds evidence-based caregiver education and support [in every region of the state](#).
3. **Screen for behavioral and psychiatric symptoms**, such as depression, which is common in people with dementia. Managing these symptoms will help both the patient and caregiver.
4. **Screen for safety concerns** to help patients prevent falls and other accidents, for which they are at increased risk. This enables families to make adjustments that can help prevent dangerous situations.
5. **Screen for driving safety** regularly, as the skills necessary for safe driving are impacted by dementia, and assessment can both prevent accidents and enable families to plan for alternative options for travel.
6. **Ensure patients have an advance care plan** documented in their medical record, as well as a surrogate decision maker.
7. **Screen for pain**, which so often goes undetected, at every visit. People with dementia cannot always express when they are in pain, so evaluation of verbal and non-verbal expressions of pain is key.
8. **Treat dementia** pharmacologically—and non-pharmacologically--according to established guidelines. Evidence suggests this happens in as few as one-third of primary care practices.

I encourage you to review this recent publication on [quality measures for managing dementia](#)ⁱⁱⁱ and to further educate yourself on these important facets of care. The attention we all put on improving care goes a long way toward supporting people with dementia, their caregivers, and our larger community.

New York State Caregiver Guide: I am pleased to announce that the Department has produced a very [special guide](#) to assist all those caring for an older adult or disabled loved one. The 140-page Caregiver Guide comes in a custom-made box that includes a pen, a notepad, and sticky notes in multiple colors. It is designed to help people who are not medical professionals navigate the healthcare system, alongside or on behalf of a loved one who either needs assistance or is not able to participate. Its ten color-coded sections cover topics including “Communicating with Healthcare Professionals”, “Legal and Financial Planning”, and “Creating Your Care Team”.

Printed in a large font size, on colorful, glossy pages, the guide describes the various types of care available in New York State and their differences, provides web addresses for resources (i.e., Medicaid and Medicare) and explains legal issues such as HIPAA (Health Insurance Portability and Accountability Act). It also contains places for note-taking and comes in a sturdy box with a pocket for storing important papers. A shoulder strap makes it easier to carry to medical appointments.

Perhaps most importantly, the book reminds caregivers to take some time to care for themselves, too. It emphasizes the need for a team approach to the many caregiver tasks, which include helping loved ones with grocery shopping, recreation, grooming, and laundry, in addition to managing healthcare appointments and medication.

Free copies of the book will initially be distributed by seven organizations in New York State to non-professional caregivers helping a friend or family member.

In this first pilot run, 1,000 copies have been printed for distribution. The following sites will be distributing guides to caregivers through their programs and services:

- NYC: CaringKind, Presbyterian Senior Services
- Capital Region: St. Peter's Nursing and Rehabilitation Center, Eddy Alzheimer's Services
- Finger Lakes: Lifespan
- Western New York: Alzheimer's Association, WNY
- Statewide: New York Independent Living Open Doors Program

A survey asking for feedback, as well as a self-addressed stamped envelope, has been packaged with the guide. The Department intends to incorporate community feedback received during the pilot into a larger printing and future statewide distribution of the guide.

These initiatives are several of the efforts New York State is engaged in as part of our commitment as the first Age-Friendly State. To all who are caregivers, thank you for what you do.

Monthly physician letters can now be viewed on the Department's [website](#).

And to everyone, I wish you and your loved ones a warm, safe, healthy, and happy holiday season!

Sincerely,

Howard A. Zucker, M.D., J.D.

ⁱ Alzheimer's Association. (2018). 2018 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 14(3), 367-429

ⁱⁱ Alzheimer's Association. (2015). Special Report: Disclosing a Diagnosis of Alzheimer's Disease, 2015 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 11(3), 332-84.

ⁱⁱⁱ Sanders, A.E., Nininger, J., Absher, J., Bennett, A., Shugarman, S., & Roca, R. (2017). Quality improvement in neurology: dementia management quality measurement set update. *The American Journal of Psychiatry*, 174(5), 493-498.