

July 14, 2021

To the Congressional Task Force on Alzheimer's Disease and Congressional Neuroscience Caucus:

Cc: Chair/Ranking on Senate HELP, Senate Appropriations, House E&C, House Appropriations

We commend you for your leadership and commitment to educating the public and policymakers about Alzheimer's and other dementias – as well as the need for treatments to address the underlying disease. The National Alzheimer's Project Act (NAPA) was a landmark legislative achievement that has helped focus research and direct resources to treating this debilitating disease over the last ten years.

But there remains one area of the disease that has not yet received adequate awareness: namely, the neuropsychiatric symptoms (NPS) that people with Alzheimer's and related dementias suffer from. We want to take this opportunity to encourage you to elevate awareness of the need to diagnose and better manage neuropsychiatric symptoms of dementia.

Facts about Neuropsychiatric Symptoms (NPS) of Dementia:

- Neuropsychiatric symptoms can include anxiety, aberrant motor activity, irritability, euphoria, agitation/aggression, depression, apathy, hallucinations, and delusions.
- Nearly all people living with dementia experience at least one neuropsychiatric symptom.
- Of the nearly 8 million people experiencing Alzheimer's and other dementias in the U.S., 2.4 million experience hallucinations and delusions associated with dementia-related psychosis.
- People suffering from these symptoms often see or hear things that others do not (hallucinations) or have false beliefs (delusions). For example, someone's mother might have a false belief that that her loved one is stealing her personal items and be verbally and physically aggressive towards their loved one due to this delusion.
- Only about half of those suffering from hallucinations and delusions are diagnosed.
- Dementia-related psychosis (DRP) is often detected late and only brought to the attention of doctors once it has progressed to the point of creating a significant impact on patients and their caregivers.

Problems of Neuropsychiatric Symptoms and Dementia-related Psychosis:

- Symptoms are persistent and progressive as dementia advances.
- People living with dementia suffering from these symptoms have an increased risk of recurrent hospitalization.
- Hallucinations and delusions can lead people living with dementia to take actions that could be harmful to themselves or their families.
- The symptoms are an added burden to the tremendous challenges that family caregivers already face in trying to understand and manage their loved one's disease.
- These challenges are a leading reason that prompt family caregivers to decide to place their loved ones in institutional care settings.

Lack of Treatments:

- There has never been an FDA-approved treatment option for neuropsychiatric symptoms of dementia.
- The current treatment options for dementia-related psychosis include non-pharmacological interventions, such as music therapy.
- Sometimes pharmacologic interventions are prescribed – such as the off-label use of antipsychotics. While the use of these antipsychotics can be successful, they often pose safety risks and are associated with increased mortality and increased hospital admissions. Such antipsychotics are therefore only recommended when psychosis is severe, dangerous, and/or causes significant distress to the person living with dementia.
- The lack of pharmacological options leads to the increased use of off-label antipsychotics without an established positive benefit-risk profile in this vulnerable population.
- In addition, these treatment options can worsen both the cognitive decline and the motor function of certain people living with dementia.
- This puts caregivers and the clinical care community in a no-win situation: having to make hard choices between treating debilitating hallucinations and/or delusions and creating even greater cognitive loss.

What We Need:

People living with dementia, their caregivers and their treating physicians need a safe and effective treatment option for dementia-related psychosis and other neuropsychiatric symptoms. We feel a sense of urgency to address the lack of progress in this area. The promise of helping many more people living with the neuropsychiatric symptoms of dementia and their families with safe and effective innovative treatments is an important part of addressing the overall problem of Alzheimer's disease.

The 10th anniversary of NAPA represents an important milestone in our progress toward treating one of the most debilitating neurodegenerative diseases. We need now to especially educate the public and policymakers about the neuropsychiatric symptoms that the millions of people living with Alzheimer's and other forms of dementia suffer from, as well as ensure that they have proper access to important medical advancements that address these symptoms of the disease.

Please feel free to contact John Schall, Chief Executive Officer of Caregiver Action Network, at JSchall@CaregiverAction.org or 202-454-3971 with any questions.

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's Family Organization

Alzheimer's Foundation of America

AMDA - The Society for Post-Acute and Long-Term Care Medicine

American Society of Consultant Pharmacists

Association of California Caregiver Resource Centers
Caregiver Action Network
CaringKind
Community Council and Dallas Area Agency on Aging
Dementia Alliance of NC
Gerontological Advanced Practice Nurses Association
Gerontological Society of America
Lewy Body Dementia Association
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