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Submitted via electronic mail

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Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
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Re: Draft National Plan to Address Alzheimer's Disease

Dear Dr. Lamont:

The American Occupational Therapy Association (AOTA) is the national professional association representing the interests of more than 140,000 occupational therapists, students of occupational therapy, and therapy assistants. The practice of occupational therapy is science-driven, evidence-based, and enables people of all ages to live life to its fullest by promoting health and minimizing the functional effects of illness, injury, and disability. Occupational therapy practitioners do important work with individuals who have Alzheimer's disease (AD) and their families, and AOTA appreciates the opportunity to provide comments to the Department of Health and Human Services (HHS) as it works to implement the National Alzheimer's Project Act (NAPA).

Occupational Therapy and Alzheimer's Disease

Five goals form the foundation of the Draft National Plan: (1) Prevent and effectively treat AD by 2025, (2) Optimize care quality and efficiency, (3) Expand supports for people with AD and their families, (4) enhance public awareness and engagement, and (5) track progress and drive improvement. AOTA sees the profession of occupational therapy as a key partner in each of these five areas. Occupational therapists and occupational therapy assistants work with individuals who have AD and with their families to maximize occupational engagement, promote safety, and enhance quality of life. A variety of skilled techniques are used when working with an individual who has AD, depending on the focus of the intervention, the stage of the disease process, and the treatment setting.

An occupational therapist's evaluation of a person with AD begins with an occupational profile of the individual's valued occupations, roles and routines, as well as his or her current level of occupational performance. Often the caregiver is crucial in supplying this information as the person with AD may be unable to provide accurate information, or may be unaware of his or her own deficits. It is essential to identify the remaining abilities of the person with AD rather than to focus solely on what he or she can no longer do. Some examples include:

- Identifying performance patterns (i.e., habits and routines) that can be maintained which will prolong independence and assist with adjustment to new living settings such as a health care facility or a daughter's home. Practitioners also consider information stored in the patient's procedural memory, which often remains stable for the longest period of time in someone with AD. Performing well-learned basic activities of daily living (ADLs), such as combing one's hair, is an example of utilizing procedural memory. Practitioners learn what the client's hobbies and occupations are which will help with planning the intervention to stimulate patient interest and active participation.

- Determining what type of cueing strategies the individual best responds to, and instructing staff on how and when to utilize these strategies during various activity demands. (E.g., does the patient require a one-step verbal command or does he or she need tactile cueing in addition to verbal cues? Can the client follow multi-step commands?)

- Determining the time of the day that the person is most alert to maximize performance with activities. (E.g., if the client's typical routine pre-illness was working at night and sleeping during the daytime, then changing that routine may be challenging. The optimal time for engagement in activity may be late afternoons.)

Other areas of consideration include accompanying conditions such as visual loss, or hearing loss. Education of the caregiver (e.g., family or facility staff or both) is a priority and expertise of occupational therapy practitioners, and the therapist should include identification of caregiver concerns about occupational performance and handling difficult behaviors as part of the evaluation. *See* attachments 1 and 2.

For a person in the early stage of AD, occupational therapy intervention may focus more on compensation for the loss of cognitive abilities and recognition of remaining abilities rather than on the remediation of deficit areas. This is helpful since new learning may be impaired or absent as the dementia progresses.

For persons in the later stages of the disease, the intervention focus may become adaptation of the environment and instruction of caregivers to promote continued occupational performance, as well as learning ways to minimize any unwanted behaviors (such as agitation, combativeness during caretaking) or complicating conditions (such as weight loss, or falls). Addressing the safety of the person with AD is paramount.

The ultimate goal of occupational therapy intervention for someone with AD is to set up a program to promote independence, participation in the community, utilize retained abilities for as long as possible, ensure safety, and enhance quality of life.

Goal 1: Prevent and Effectively Treat AD by 2025

In the absence of a cure, this goal seeks to develop effective prevention and treatment modalities by 2025. Toward this end, HHS proposes to convene an AD research summit with national and international scientists (Action 1.A.1) and convene a scientific workshop on other

dementias in 2013 (Action 1.A.4). AOTA asks that you include occupational therapy in these events. HHS also plans to solicit public and private input on AD research priorities (Action 1.A.2) and continue clinical trials on the most promising lifestyle interventions (Action 1.B.6). In these areas, AOTA asks HHS not to neglect research on effective treatment, education, and support for caregivers and to study lifestyle interventions for caregivers

Outreach efforts to more effectively inform the public about research findings and results are also planned, and AOTA reminds the department to take advantage of using professional associations to educate members and providers (Action 1.E.3).

Goal 2: Optimize Care Quality and Efficiency

HHS recognizes that high-quality care for people with AD requires an adequate supply of qualified, culturally-competent professionals with appropriate skills and expertise. AOTA notes that the Draft Plan places the bulk of its emphasis on physician providers, when patients will be seeing many other allied health care professionals in the new health care system. It is the non-physician practitioners, such as occupational therapists, who provide most of the support for patients with AD and certainly their caregivers. The $6 million dollar investment of the Obama Administration for provider education and outreach should include specialized training for occupational therapy, and other efforts by both the Veteran's Administration (VA) and Health Resources and Services Administration (HRSA) should include support not only for physicians and nurses, but other qualified and licensed professionals (Strategy 2.A.2).

As far as dementia-specific work (Action 2.A.3; 2.D.1), occupational therapy has a proven track record in caring for patients with dementia and is working with the American Medical Association (AMA) –convened Physician's Consortium for Performance Improvement (PCPI) to develop and manage quality measures for dementia. *See* Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers. *Journal of the American Medical Association* 30(9), 983–991; Strzalecki, M. (2010). The dementia care difference. *OT Practice* 15(12), available: http://www.aota.org/Pubs/OTP/2010/OTP071210.aspx.

In examining improved care transitions through Medicare's Community-Based Care Transitions Program and the Aging and Disabilities Resource Center (ADRC) Evidence-Based Care Transitions Program (Action 2.F.2), AOTA reminds decision-makers that occupational therapy has an established role in discharge planning, home evaluation, safety, and caregiving training that is an asset in these areas.

Goal 3: Expand Supports for People with AD and their Families

This third goal acknowledges the important role that caregivers plan in the life of a person with AD: they provide care and support, help lessen feelings of depression and stress, and help delay nursing home placements. To further support caregivers, HHS plans to partners with private organizations to review the state of the art of evidence-based interventions that can be delivered by community-based organizations (Action 3.B.3). Occupational therapy should be part of these private-public partnerships.

HHS has also noted that medications, including anti-psychotic drugs, can be used inappropriately to manage the difficult behaviors of nursing home residents who have AD. Occupational therapy practitioners would like to be part of collaborative efforts to reduce inappropriate and off-label use of behavior modifying drugs and agents. AOTA encourages the use of occupational therapy interventions to address inappropriate behaviors without the use of pharmaceuticals.

Goal 4: Enhance Public Awareness and Engagement

In order to further its goal of enhancing public understanding of AD and engagement stakeholders who can help address the challenges faced by persons with the disease and their families, HHS plans, in part, to work with state and local governments to improve coordination and identify model initiatives to advance AD awareness and readiness (Strategy 4.B). AOTA applauds plans to involve state and local governmental entities to further the National Plan, but we wish to note the importance of involving professional associations at the state level in these efforts.

Goal 5: Track Progress and Drive Improvement

Finally, HHS plans to identify the gaps in existing data and pursue roads to expand and enhance the data infrastructure in this field and to make data more easily accessible to federal agencies and researchers (Strategy 5.A). Occupational therapy practitioners are also cognizant of information gaps related to the study of AD, and will be interested to access and utilize any improvements HHS is able to make, particular in the area of new quality measures, participating in new data collection efforts, or more easily viewing improved data sets or links between data sets.

Conclusion

AOTA looks forward to working with HHS to implement NAPA. AOTA's Occupational Therapy Practice Guidelines for Alzheimer's Disease are en route via U.S. mail, and additional materials about occupational therapy contributions to the field are available upon request; please do not hesitate to contact us with questions at (301) 652-6611 ext. 2023 or jhitchon@aota.org.

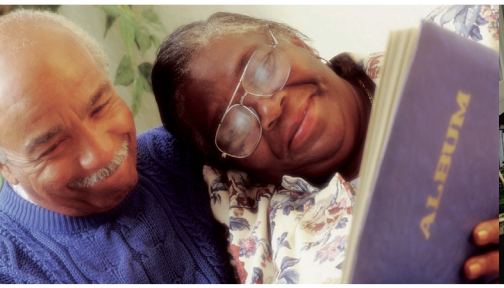
Respectfully submitted,

Jennifer Hitchon
Regulatory Counsel

Attachments:
1. AOTA Tips for Living Life to Its Fullest: Living with Alzheimer's Disease
2. AOTA: Caring for the Adult Caregiver

TIPS For Living Life To Its Fullest

LIVING WITH ALZHEIMER'S DISEASE



ALZHEIMER'S DISEASE is caused by destruction of nerve cells in the brain and typically appears in middle to late life. It affects both men and women of all ethnicities, cultures, and backgrounds. The disease is a slowly progressing form of dementia, and the rate of progression differs for each person. Persons with Alzheimer's disease experience memory loss; language problems; and changes in decision-making ability, judgment, and personality.

Early symptoms of Alzheimer's disease include frequently repeating statements, misplacing items, difficulty finding names for familiar objects, getting lost on familiar routes, and changes in personality and emotional responses. In the middle stages, those with Alzheimer's disease forget basic information about the world, such as how to use common objects or how to get from point A to point B. In the later stages, skills like dressing, bathing, and reading become more difficult, and in the final stages the person returns to the functioning of an infant.

Occupational therapy practitioners help people with Alzheimer's disease and their caregivers to live life to its fullest by adapting the environment and focusing on what they *can* do to maximize engagement in activity (occupation), promote safety, and enhance quality of life. The following tips are from occupational therapy practitioners working with people with Alzheimer's disease.

If you would like to:	Try these activity tips:	An occupational therapy practitioner offers expertise to:
Help the person do things independently.	In the middle stages, large, clearly written signs with step-by-step directions can help the person continue to do basic tasks like microwave a frozen meal or get dressed. The person is likely to need instructions repeated many times. Patience is key.	Observe the person at home and recommend changes to make it easier to do things more independently, such as create new routines, modify existing routines, or add adaptive equipment. The occupational therapist can also determine if the person responds better to certain types of cueing and other communication strategies, and work with you to use those strategies.
Keep the person safe.	Remove access to dangerous items, such as flammable liquids, stairwells, and medications; remove control knobs on potentially dangerous appliances such as the stove; and provide supervision when preparing meals.	Work with you to create a safety plan based on the needs of you, the person, and other caregivers. For example, the occupational therapist may determine how the person will safely obtain meals when no one is available to help in the kitchen.

If you would like to:	Try these activity tips:	An occupational therapy practitioner offers expertise to:
Prevent a fall or other injury.	Remove or secure throw rugs and clutter, and keep furniture and other items in their familiar locations. Provide good lighting for walking pathways.	Complete a home safety evaluation. Recommendations might include adding safety equipment, such as bathroom grab bars or railings, or creating workspace so the person can do activities while seated.
Prevent wandering.	Sometimes people with Alzheimer's disease pay attention to simple signs such as "stop" on the door. You can also purchase a GPS locator for the person, and install deadbolts on doors and windows.	Modify activities the person once enjoyed to provide mental stimulation during times when wandering may be a concern.
Maintain an emotional connection.	Revive shared interests through photos and memories. Long-term memory is usually better than short-term memory. Encourage the person to share his or her life story with you.	Help create activities that you and the person can do together and teach you strategies to effectively manage difficult or unusual behavior (e.g., the person thinks you are someone else, is dressing inappropriately, cries easily, etc.).
Have some time to yourself.	Caregiving is a rewarding but stressful job. Schedule time for yourself even if it's only for short periods. Remember, you need to take care of yourself first, in order to care for someone else. Ask for assistance from those you know or call your local Area Agency on Aging.	Improve quality of life. Research has shown that occupational therapy can be more powerful than medication in helping people with Alzheimer's disease to function while reducing caregiver burden.

Need More Information?

Occupational therapy for Alzheimer's disease is a covered service under Medicare and many other payers and may be provided at home or in a skilled nursing facility. Ask your physician for a referral or contact an occupational therapist in private practice who specializes or has expertise in working with those who have Alzheimer's disease. You can find additional information through the American Occupational Therapy Association at www.aota.org.

Occupational therapy is a skilled health, rehabilitation, and educational service that helps people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations).

AOTA® The American Occupational Therapy Association, Inc.

Living Life To Its Fullest®
OCCUPATIONAL THERAPY

Caring for the Adult's Caregiver

Caring for an older adult can be rewarding and fulfilling, but can also place great physical, emotional, and financial demands on those who take care of them. More than 80 percent of late-life care is provided by unpaid family members. Sometimes the needs of a caregiver are secondary to those of the aged person in need of care. But failing to meet one's own needs can lead to stress, depression, and physical problems on the part of the caregiver.

Occupational therapists can help caregivers achieve a balance in which the older adult's needs are met as well as the rest of the family's.

What can an occupational therapy practitioner do?

- **Promote** well-being through activities that encourage creativity and coping strategies.
- **Provide** strategies to balance work, caregiving, and family demands.
- **Recognize** that the needs of caregivers must be met in addition to the needs of an older adult with a disability or disorder.
- **Encourage** caregivers to accept that feeling stress, anger, frustration, and sadness at the situation is not uncommon, and that it is acceptable to express these feelings.
- **Explore** coping strategies and encourage healthy activities such as exercise, group or individual therapy, and hobbies.
- **Stay informed** of current research on conditions and intervention techniques to share with clients.

What can families do?

- **Join** a therapy or discussion group for caregivers of older adults.
- **Share** the responsibility of caring for an older adult.
- **Ask** others for help.
- **Develop** a schedule that distributes caregiving responsibility.
- **Consider** adult day care or home health aides to provide occasional breaks to full-time caregivers.
- **Create** moments of joy throughout the day by participating in pleasurable activities, if only for a few minutes.

Need more information?

Frequent depression and stress is a serious problem and could cause physical and emotional complications to all family members. If you would like to consult an occupational therapist, practitioners are available through most hospitals, medical centers, and clinics. Talk to your family physician or contact your local health officials for more information about occupational therapy.

Occupational therapists and occupational therapy assistants are trained in helping people with a broad range of physical, developmental, and behavioral conditions. In addition to treating illness and disability, occupational therapy encourages wellness through a balance of healthy and meaningful life activities.

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