# Rural Promising Practice Issue Brief: **C**aring for **O**lder **A**dults and **C**aregivers at **H**ome (COACH)

## Executive Summary

As the United States faces an aging population, the number of individuals and families affected by dementia will continue to grow significantly. Roughly five million Americans aged 65 and older are diagnosed with dementia and this figure is expected to triple to nearly 13 million by 2050.[1]

There is substantial societal cost associated with caring for individuals diagnosed with dementia including increased utilization of health care and financial burdens for caregivers. The total costs associated with caring for individuals with dementia ranged from $159 billion to $215 billion dollars nationwide, accounting for informal care.[2]

Currently, the Department of Veterans Affairs (VA) provides health care and other services to more than 151,000 Veterans with dementia, with an estimated total cost of approximately $4 billion dollars. Additionally, research has identified Traumatic Brain Injury (TBI) and Post-Traumatic Stress Disorder (PTSD) as risk factors for developing dementia.[1] The prevalence of dementia among Service members and Veterans is expected to increase due to the growing rate of TBI and PTSD diagnoses.[1]

Dementia negatively impacts an individual's memory and other cognitive functions resulting in a decreased ability for those affected to function independently.[3] Most Americans living with dementia receive care from family members and friends.[4] In 2015, there were roughly 15 million individuals caring for someone with dementia; these caregivers provided approximately 18.1 billion hours of unpaid care.[5]

The impact of caregiving is complex and varies among individuals. Many studies have found increased levels of psychological distress and lower subjective well-being and physical health associated with caregiving.[4] According to a meta-analysis conducted by *Chien et al.*, caregiver support groups have been proven to reduce depressive and angry feelings, improve caregiver's skills, maintain favorable health behavior and quality of life, and increase social support and satisfaction for caregivers.[6]

Furthermore, many individuals and families impacted by dementia have a strong preference to keep the affected loved one living at home. However, the progressive frailty, caregiver strain, and significant behavioral challenges often result in the individual being moved to a long-term care facility.[7]

To address the needs of Veterans diagnosed with dementia and their caregivers, the Durham VA Medical Center established the Caring for Older Adults and Caregivers at Home (COACH) program. This program focuses on home-based dementia care that assist Veterans with moderate to severe dementia living at home with a caregiver and within 50 miles from the Durham VA Medical Center (VAMC), Greenville Health Care Center, or Morehead City Community Based Outpatient Center.

The program provides support; education on dementia, progression, and behavioral management; referrals and assistance with resources; and recommendations to address safety in the home, delays in nursing home placement, and alleviation of caregiver burden. The COACH program respects the wishes of the caregiver to keep their loved ones living at home for as long as possible. The program focuses on facilitating this goal while improving the quality of life of both the Veteran and the caregiver.

### Who Can Use This Rural Promising Practice?

Social workers and registered nurses with the support of an interdisciplinary team that includes a geriatrician, psychiatrist, and pharmacist with experience in geriatrics and dementia care can adopt this program. The COACH program is designed to support Veterans living with dementia and their caregivers and can be used by VAMCs that have compassionate and experienced staff in the field of dementia care.

Findings suggest that ongoing caregiver support helps the caregiver better cope and deal with loved ones with dementia. Knowing they have someone to talk to about specific caregiving challenge and feeling supported during the overwhelming task of providing care 24 hours a day reduces the caregiver's feelings of isolation and increases their access to critical resources.

## Need Addressed

Caring for Veterans with dementia at home is a difficult task which often results in Veterans being placed in costly long-term care facilities. Many individuals with dementia experience problematic behavioral symptoms, including disturbed emotions, mood, perceptions, thoughts, motor skills, and altered personality traits, which impact their ability to access needed services due to the challenges they face leaving their home environment.

More specifically, outpatient clinic assessments to obtain additional assistance are often inadequate because of the travel involved, emotional stress, and confusion the Veteran may experience. Another challenge individuals living with dementia face is the ability to adhere to drug treatment protocols, increasing the risk for drug ineffectiveness, adverse drug effects, overdosage, underdosage, and negative drug interactions. Behavioral symptoms experienced by individuals living with dementia provide a significant challenge for caregivers and can be a primary predictor of nursing home placement.[7] Due to these challenges, many caregivers often experience loneliness and stress.

# Implementation

The COACH program is an innovative care coordination model that provides home-based support to Veterans with dementia and their caregivers. The COACH program supports patient-centric care by assigning an interdisciplinary team to assess the needs of the Veteran and caregiver, develop a comprehensive treatment plan, and monitor the Veteran's overall well-being. The services offered by the COACH program include the following:

- Home visits by a licensed clinical social worker and registered nurse
- Education on dementia care, progression, and behavioral management
- Medication review and home safety review
- Ongoing monitoring of the Veteran's function or health
- Referrals for other services to support the Veteran and the caregiver
- Caregiver support and education

To enroll in the COACH program, the Veteran must meet the following criteria:

- Be enrolled in the VA health care system
- Be 65 years and older
- Have a cognitive impairment
- Have a home-based caregiver
- Not be institutionalized or prepared to be institutionalized
- Live within a 50-mile radius of the VAMC or from any other COACH program headquarters
- Not receive services from another home-based program (e.g., home-based primary care)

## Overview of COACH Program

The COACH programs provides Veterans and their caregivers with home-based support from a social worker and registered nurse. An interdisciplinary team, including a program coordinator, geriatrician, geriatric psychiatrist, and geriatric pharmacist provides support to the social worker and registered nurse with oversight of the program and the development of the treatment plan.

Once a Veteran and his or her caregiver are screened and found to be eligible for the COACH program, the social worker and registered nurse conduct an initial home assessment. After the initial home assessment, the social worker and/or the registered nurse conduct follow-ups via telephone calls and home visits occurring one, three, and six months after the initial home assessment. The frequency of visits and follow-up may vary based on the needs of the Veteran and caregiver.

After the first year, telephone follow-ups occur at least every three months, and additional home visits occur bi-annually and after hospitalization or a change in condition. Between the scheduled follow-ups, Veterans and caregivers can also initiate contact with the social worker and registered nurse if challenges or questions arise.

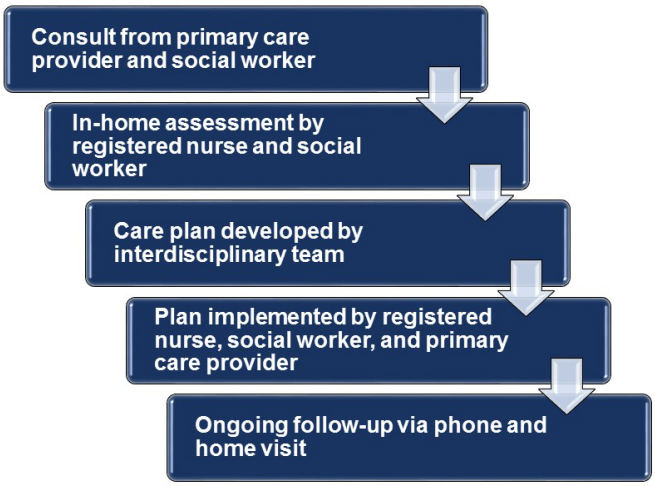
## The COACH Process

The social worker and registered nurse perform a comprehensive medical and psychosocial assessment including a home safety evaluation; assessments of patients' behaviors, cognitive and functional abilities; medication review; caregiver stress and family resources; and caregiver's health literacy; and they

develop a plan to improve caregiver support. The interdisciplinary team meets weekly to develop treatment plans and collaborate with the Veterans' existing care team.

The process for implementing the COACH model requires five steps intended to assess needs, develop a treatment plan, provide needed support and resources, and engage in follow-up activities. The process is depicted in Figure 1.

Figure 1. Five-Step Process for Implementing COACH




### 1. *Consult from Primary Care Provider and Social Worker*

The first step in the process is for a primary care provider and social worker to identify potential Veterans who may benefit from the COACH program. In early implementation phases, the social worker can use data within VISTA to identify and reach out to providers about potential participants. As the program becomes more established and provider awareness increases, participants can be referred to the COACH program through their primary care provider or other clinicians throughout the system.

During the initial screening, the team explains the program, determines whether a) the Veteran and caregiver welcome the support, and b) whether the Veteran meets criteria for the COACH program. Then, services are offered to the caregiver an in-home assessment is scheduled with their permission.

### 2. *In-home Assessment by Registered Nurse and Social Worker*

During the initial home visit, the team evaluates the patient's cognition, functioning level, and behaviors. They also evaluate the caregiver's needs, knowledge of dementia, and stress level and burden; screen for depression; and evaluate coping skills. The team reviews medication safety and compliance. From the initial home visit, the team begins to establish a trusting relationship with the caregiver by offering support and validation. Trust is important to the success of the program as it helps to establish ongoing communication and promotes the adoption and considerations of the team's recommendations.

One of the main components of the COACH program is to address home safety concerns for both the Veteran and the caregiver. All participants receive a home safety evaluation. During the first visit (lasting approximately two to two and a half hours), both the social worker and registered nurse evaluate the needs of the Veteran and caregiver. If the social worker and registered nurse feel there are safety concerns for themselves, the team members might provide follow-up with the Veteran and caregiver over the phone.

While the initial assessment is designed to create a safe environment, the COACH team may continue to make ongoing recommendations to maintain a safe environment for Veterans, and educate caregivers with basic home modifications and placement of assistive devices (e.g., removing rugs, increase light, reducing clutter). Many improvements to the home can be performed at zero to minimum cost. VA has several resources and programs available to assist Veterans and their caregivers with home safety improvements (e.g., ramps, durable medical equipment, ID bracelets, life alerts, grab bars, hand-held showers).

The major focus of subsequent visits is to provide personalized education in multiple areas, addressing each Veteran's particular needs related to disease progression, behavioral management, safety, resources, and long-term care planning.

### 3. *Care Plan Developed by Interdisciplinary Team*

After the initial home visit, the social worker and registered nurse present all COACH Veteran cases at a weekly interdisciplinary team meeting (lasting two and a half hours). The interdisciplinary team formulates or updates a plan comprised of 1) interventions for implementation by the social worker and registered nurse, and 2) recommendations for primary care providers, who continue to provide general medical care to the Veteran.

The team makes recommendations to address poor medication compliance, medication burden, and therapeutic response. Plans and recommendations are

communicated to the Veteran's primary care provider through notes within the electronic medical record, with primary care providers designated as the additional signer of the notes.

Veterans and their caregivers are supported in the implementation of the treatment plan through close communication involving ongoing iterative modifications to the treatment plan to address the evolving needs of Veterans and their caregivers.

### *4. Plan Implemented by Registered Nurse, Social Worker, and Primary Care Provider*

The team implements the plan which includes interventions across four categories 1) medical issues, 2) challenging behaviors, 3) safety concerns, and 4) caregiver burden/stress (See Figure 2). The interventions are based on the needs of the Veteran and caregiver and are intended to improve their quality of life.

Figure 2. Types of Interventions

| Category | Interventions |
|---|---|
| Medical Issues | • Delirium assessment<br>• Anticholinergic burden reduction<br>• Sleep hygiene plans<br>• Strategies to manage activities of daily living<br>• Vision and hearing assistive devices to increase sensory stimulation<br>• Palliative care and advance directives |
| Challenging Behaviors | Evidenced-based Practices:<br>• Communication skills training<br>• Education on reminiscence therapy<br>• Validation therapy<br>• Music<br>• Activities<br>• Environment modification<br>• Geriatric psychiatry consults |
| Safety Concerns | • Driving evaluation referrals<br>• Securing gun access<br>• Strategies to reduce wandering<br>• Fall prevention strategies<br>• Supervised medication intake<br>• Durable medical equipment orders and assistive devices<br>• Home modification plans to install night lights or door chimes, lock toxic products, and remove clutter<br>• Fire prevention strategies |
| Caregiver Burden/ Stress | • Counseling<br>• Stress management<br>• Coping skills<br>• Respite options (e.g., adult day care, home and inpatient respite)<br>• Mental health referrals<br>• Support groups<br>• Realistic expectations<br>• Education on resources<br>• Long-term care planning |

### *5. Ongoing Follow-Up via Phone and Home Visit*

The social worker and registered nurse will continue to execute the plan on an ongoing basis. Follow-up is performed through telephone calls and routine in-home visits. Additionally, the social worker and registered nurse continue to provide education and resources that may be beneficial to the Veteran and caregiver.

One additional resource offered by the COACH program is a monthly dementia caregiver support group open to all dementia caregivers regardless of their eligibility to be enrolled in the COACH program. Education about dementia, disease progression, and behavioral management is also part of an ongoing educational process with caregivers and their families.

The team trains caregivers to use appropriate communication techniques and evidence based approaches such as validation, reassurance, redirection, and reminiscence as alternative or complementary to pharmacological interventions.

# Promising Results

Since its inception, in 2010, the COACH program has made a positive impact on the lives of Veterans with dementia and their caregivers. During the last six years, the program has served almost 600 Veterans with more than 120 new Veterans enrolled each year. For fiscal year 2016, the COACH program received 294 new consults, demonstrating the growing need for specialty care related to dementia. The COACH program has demonstrated the following results:

- Improved quality of life for Veterans with dementia;
- Decreased health care costs resulting from delays in long-term care facility placement;
- Reduced burden on caregiver, from caregiver support groups and education, as reflected in the Zarit burden questionnaire;
- Increased access to dementia-related services;
- Addressed safety hazards at home; and
- Identified and improved Veterans Equitable Resource Allocation (VERA) related to Veterans' needs, supporting the ability for the program to be sustainable.

**The COACH program demonstrates each of the criteria necessary to be a Promising Practice:**

*Improved Access:* The COACH program improves access to unique specialty care for dementia patients by providing services to Veterans in their home setting. The interdisciplinary team works collaboratively to address the needs of Veterans including geriatric psychiatry, physical therapy, and occupational therapy. The social worker and registered nurse are also able to educate the caregiver in accessing VA resources and benefits including Homemaker and Home Health Aide (H/HHA), NI-respite, Contract Adult Day Health Care, inpatient and home respite, and aid and attendance benefits.

*Evidence of Clinical Impact:* The overall impact of the program is the ability to provide care coordination to Veterans with dementia and support services for their caregivers. The program has met and exceeded the ten national dementia care standards: staging of dementia; cognitive, functional, and behavioral assessments; depression; behavioral management; counseling on safety issues; driving; advance care planning; caregiver education; and support. The COACH program has demonstrated the ability to reduce caregiver burden, improve dementia care at home, delay long-term care facility placement, and improve Veteran safety.[8]

### Office of Rural Health Rural Promising Practice Criteria

*Increased Access:* Measurable improvements in access to care and/or services. Examples include reduction in distance traveled to care, reduction in wait times, improved care coordination, and reduction in missed appointments.

*Evidence of Clinical Impact:* Positive results on outcomes of importance to rural Veterans based on evaluations conducted during the implementation of the program and at the end of the pilot period.

*Customer Satisfaction:* Increased patient, provider, partner, and/or caregiver satisfaction.

*Return on Investment:* Improvement in health system performance by 1) reducing the per capita costs of health care, and 2) improving or at least maintaining health outcomes, and/ or 3) positively impact the health care delivery system.

*Operational Feasibility:* Implementation is feasible and known barriers and facilitators of success could easily be shared across implementation sites.

*Strong Partnerships and/or Working Relationships:* Inclusion of VA and/or non-VA partners to maximize the efficacy of the intervention.

*Customer Satisfaction:* The program receives ongoing positive feedback from providers and caregivers. Caregivers have expressed high levels of satisfaction with the program related to quality and staff courtesy. Since 2012, the COACH program has maintained a 100 percent satisfaction rate among 282 caregivers demonstrated in a satisfaction survey.

*Return on Investment:* At the Durham VAMC, the COACH program was able to convert more than 50 percent of the Veterans enrolled in the program to a higher resource allocation category due to their complexity in care. By increasing VERA allocations, the program increased funding to support the COACH program.

*Operational Feasibility:* The Durham VAMC was successful in implementing the COACH program with support of primary care providers and facility leadership. During the first years of the COACH program, the team developed strong policies and procedures and developed critical partnerships that ensured the success of the program.

*Strong Partnerships and/or Working Relationships:* The program serves as a valuable resource to primary care providers and other clinicians in managing Veterans with dementia. The COACH program partnered with recreational therapy programs to offer simultaneous therapy groups for Veterans with dementia while their caregivers attend a caregiver support group. The COACH program also partnered with local community centers to use their facilities for monthly caregiver support groups.

## Adoption Considerations

Keys to adoption for the COACH program include:

- Communication and messaging related to the program's purpose,
- Leadership and resourcing support,
- Strong VA and non-VA coordination, and
- Data collection and analysis.

*Communication and Messaging:* Making the program known to obtain referrals can be accomplished by educating health care providers and leadership in the early stages of the implementation process. It is important to make ongoing presentations using visual support including PowerPoint presentations, brochures, posters, and flyers to disseminate and promote the program.

*Leadership and Resourcing:* Delays in program implementation can be prevented if recruitment and hiring processes starts as soon as possible. This requires the buy-in and support of leadership to staff the program appropriately. Staffing ratios may vary depending on population complexity and geographical dispersion. Appropriate administrative support and staffing is important to avoid staff fatigue associated with caring for an intensive and challenging population.

The pilot site recommended a caseload of 90 patients per one full-time employee (FTE) social worker and one FTE registered nurse. The interdisciplinary teams can remain fairly fixed as long as their workload allows for routine review of all COACH participants at least monthly.

Getting resources in place such as a car, laptops computers, and cell phones are very important and the process to acquire them needs to start as soon as possible. The Durham COACH program secured necessary resources through grants from the VA Central Office and the Office of Rural Health.

Having the support from a part-time program support assistant is valuable for data collection, management, administrative tasks, and scheduling. Currently, the Durham COACH program has one full-time program support assistant who supports two sites and eight staff members.

*Strong VA and Non-VA Coordination:* Developing strong partnership with providers, VA programs, and community programs is critical to the success of the COACH program. The program is effective because it works to integrate its services with a network of VA and community resources, such as VA contracted home care services, the VA prosthetics department, and adult day care centers.

*Data Collection and Analysis:* Collecting data to demonstrate the effectiveness of the program provides critical information to aid in making the program sustainable and informs continuous improvement. Data may include active panel size, nursing home placement, length of stay in nursing homes and hospitals, caregiver satisfaction, ZARIT (caregiver burden) scores and ABIDS (Agitated Behaviors in Dementia Scale) over time, and a change in VERA after enrollment.

Conducting a cost comparison between a similar population and program participants would improve future evaluations of the COACH program. Data collected for a comparison study may include nursing home days and hospitalizations.

# Conclusion and Next Steps

The COACH program provides an innovative care coordination model that supports Veterans with dementia and their caregiver and allows VA providers to meet the needs of rural Veterans by improving access to additional services and resources.

Addressing Veterans' needs within their home environment reduces behavioral symptoms that may have been exacerbated as a result of a clinic visit (e.g., agitation and confusion) and increases home safety while providing needed support to their caregivers.

The Durham VAMC continues to support the COACH program, recognizing the importance of providing care coordination to address the evolving needs of Veterans living with dementia and their caregivers.

The Durham COACH program continues to expand its program both in enrollment and in resources by advertising the program and improving the resources provided to Veterans and their caregivers, including piloting the use of iPads to increase Veterans' cognitive stimulation.

Overall, the COACH program may help VA care for a growing population of Veterans. A more complete cost/benefit analysis is being conducted to understand the financial feasibility of expanding this program nationally. Initial results from this pilot program, however, suggest that the COACH program increases quality of and access to care for Veterans living with dementia and their caregivers.

# Available Resources

The pilot program administrators of this Rural Promising Practice created several resources to aid in its replication at other sites of care, which are available upon request. They include:

- Program instruments including MOCA, ABIDS, ZARIT, Mini-COG
- Home safety evaluation
- COACH program policies and procedures
- Program handbook

Resources are available at:
www.ruralhealth.va.gov/providers/promisingpractices

Support for caregivers:
http://www.caregiver.va.gov/

# Subject Matter Expert

Judith Davagnino, MSW, LCSW, Durham VAMC
Judith.Davagnino@va.gov

# To Learn More

The Rural Promising Practices initiative is overseen by the U.S. Department of Veterans Affairs (VA) Office of Rural Health (ORH) as part of its targeted, solution-driven approach to improving care for the 3 million Veterans living in rural communities who rely on VA for health care. As VA's lead advocate for rural Veterans, ORH works to see that America's Veterans thrive in rural communities. To accomplish this, ORH leverages its resources to increase rural Veterans' access to care and services. To discuss implementing a Rural Promising Practice at your facility or to learn more, visit **www.ruralhealth.va.gov** or email **rural.health.inquiry@va.gov**

# References

1. Sibener, L., Zajanjor, I., Snyder, H.M., Bain, L.J., Egge, R., & Carrillo, M.C. (2014). Alzheimer's disease prevalence, costs, and prevention for military personnel and veterans. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *10*(3), S105-S110.
2. Hurd, M.D., Martorell, P., Delavande, A., Mullen, K., & Langa, K.M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine,* 368, 1326-1334.
3. Plassman, B.L., Langa, K.M, Fisher, G.G., Heeringa, S.G., Weir, D.R., Ofstedal, M.B., Burke, J.R.…Wallace, R.B. (2007). Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology*, *29*(1-2), 125-132.
4. Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228.
5. Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/facts/
6. Chien, L.Y., Chu, S., Guo, J.L., Liao, Y.M., Chang, L.I., Chen, C.H., & Chou, K.R. (2011). Caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry, 26*(10), 1089-1098.
7. Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E.B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology, 3*, 73.
8. D'Souza, M.F., Davagnino, J., Hastings, S.N., Sloane, R., Kamholz, B., & Twersky, J. (2015). Preliminary data from the Care for Older Adults and Caregivers at Home (COACH) program: A care coordination program for home-based dementia care and caregiver support in a Veterans Affairs Medical Center. *The American Geriatrics Society, 63*(6), 1203-1208