

Caregiver Support in a Case of Posttraumatic Stress Disorder and Lewy Body Dementia

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Background: The US Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) provides assistance for at-home caregiving of veterans and defers the costs of care for veterans. In October 2020, PCAFC eligibility expanded to include Vietnam-era veterans.

Case Presentation: We present the case of a Vietnam-era veteran with posttraumatic stress disorder (PTSD) and Lewy body dementia (LBD) who over years of care developed worsening symptoms from his illnesses, including behaviors and psychological symptoms of dementia. Recurrent behavioral episodes and issues with home safety, along with his caregiver's financial need to continue working, led the patient to being placed in a VA-contracted skilled nursing facility. However,

expanded PCAFC eligibility enabled a transfer back to in-home living. We discuss PCAFC expansion and examine trends in veteran health that point to a large burden of dementia and PTSD on both veterans and their caregivers.

Conclusions: This case demonstrates how the PCAFC expansion is likely to benefit other older veterans with service-connected disability, PTSD, and/or dementia. These veterans may now be eligible for a service and funds that may enable at-home living. This expansion has policy implications as the VA manages the budget of this program and institutes measures to limit abuse and waste, as well as research implications as the PCAFC is used to enable at-home aging as an alternative to aging with dementia in a facility.

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Caregiving for a person with dementia in the community can be extremely difficult work. Much of this work falls on unpaid or informal caregivers. Sixty-three percent of older adults with dementia depend completely on unpaid caregivers, and an additional 26% receive some combination of paid and unpaid support, together comprising nearly 90% of the more than 3 million older Americans with dementia.¹ In-home care is preferable for these patients. For veterans, the Caregiver Support Program (CSP) is the only US Department of Veterans Affairs (VA) program that exclusively supports caregivers. Although the CSP is not a nursing home diversion or cost savings program, successfully enabling at-home living in lieu of facility living also has the potential to reduce overall cost of care, and most importantly, to enable veterans who desire it to age at home.^{2,3}

The CSP has 2 unique programs for caregivers of eligible veterans. The Program of General Caregiver Support Services (PGCSS) provides resources, education, and support to caregivers of all veterans enrolled in the Veterans Health Administration (VHA). The Program of Comprehensive Assistance for Family Caregivers (PCAFC) provides education and train-

ing, access to health care insurance if eligible, mental health counseling, access to a monthly caregiver stipend, enhanced respite care, wellness contacts, and travel compensation for VA health care appointments (Table 1).^{4,5}

Patients undergo a rigorous assessment and highly specialized and individualized clinical decision-making process to confirm the service is appropriate for the patient. PCAFC was restructured and expanded on October 1, 2020.⁶ Currently, veterans who incurred or aggravated a serious injury (defined by a single or combined service-connection rating of $\geq 70\%$) in active military service before May 8, 1975, or after September 10, 2001, are eligible for PCAFC.⁶ Most notably, these changes opened eligibility in the PCAFC to caregivers of veterans from the Vietnam, Korean, and World War II eras of conflict and veterans with dependence in activities of daily living (ADL) due to a wider variety of illnesses, including dementia.⁶ The PCAFC is set to further expand to caregivers of otherwise eligible veterans of all eras of service on October 1, 2022, 2 years after the initial expansion, as laid out in the 2018 VA MISSION Act.⁶ Additional information on the history of the PGCSS and PCAFC and eligibility criteria for veterans

TABLE 1 VA Caregiver Support Programs

Legislation/Rule	Key Points	Eligibility	Service Eras Covered	Yearly Cost Estimates ¹⁸
Veteran Benefits, Health Care, and Information Technology Act of 2006 ⁴	Pilot initial CSP	CSP: all veterans with a caregiver	All veterans	\$5 million annual appropriation
Caregivers and Veterans Omnibus Health Services Act of 2010 ⁵	Expanded CSP services across VA; caregiver stipend; created PCAFC, PGCSS	PCAFC: veterans with serious injury from active duty after September 10, 2001; must have inability to perform ADL and need for supervision protection, or instruction due to injury PGCSS: all caregivers of veterans	PCAFC: post-9/11 PGCSS: all veterans	\$100 to \$500 million expenditure from 2010 to 2015 with a 41% growth annually
VA MISSION Act of 2018 ⁶	PCAFC expanded to veterans of all eras, phased over 2 y	PCAFC: veterans who incurred or aggravated a serious injury or illness in the line of duty in the active military, naval, or air service on or after September 11, 2001, or on or before May 7, 1975; and service-connected disability ≥ 70%; and need for in-person personal care services for at least 6 continuous months based on inability to perform ADL or need for supervision, protection, or instruction	Post-9/11, Vietnam, Korean War, World War II	\$1.2 billion for first year of expanded PCAFC, FY 2021
VA PCAFC final regulation ¹⁵	Expands PCAFC eligibility	PCAFC: as above	Expands to cover all eras of service	\$1.5 billion in FY 2022 with expansion to all eras at end of 2022

Abbreviations: ADL, activities of daily living; CSP, Caregiver Support Program; FY, fiscal year; PCAFC, Program for Comprehensive Assistance for Family Caregivers; PGCSS, Program of General Caregiver Support Services; VA, US Department of Veterans Affairs.

and their family caregivers can be found in Tables 2 and 3.

Posttraumatic stress disorder (PTSD) and cognitive impairment are 2 common causes of disability among veterans who receive VHA care. Among older veterans, rates of lifetime development of PTSD reach up to 30%.⁷ Dementia diagnosis is also more common in older veterans compared with age-matched civilians.⁸ Furthermore, a prior diagnosis of PTSD has been associated with nearly a 2-fold increase in risk of development of dementia in older age.⁷ These conditions are also linked to high degrees of service connection. PTSD is the third most prevalent service-connected disability for veterans receiving compensation and cognitive limitation is the third most prevalent category of service-connected disability among veterans.⁹

We present a case of a Vietnam-era veteran with a history of combat exposure and service-connected PTSD, and a later diagnosis of Lewy body dementia (LBD). Through combination of VHA geriatric services, the CSP, and the expanded PCAFC,

the veteran’s primary family caregiver received the materials, support, and financial resources necessary to enable at-home living for the veteran, despite his illness and later complications.

CASE PRESENTATION

A male combat veteran presented to his primary care practitioner (PCP) with concerns of several years of progressive changes in gait, forgetfulness, and a gradual decline in the ability to live independently without assistance. At that time, his medical history was notable for PTSD (50% service connection), which had been diagnosed over a decade prior (but for which the veteran had refused medication or therapy on multiple occasions, stating he preferred to “breathe through” his intrusive symptom flare-ups), localized prostate cancer with a radical prostatectomy (100% service connection), multiple kidney stones with persistent left ureteral inflammation, and arteriosclerotic heart disease (10% service connection). A Saint Louis University Mental Status Exam (SLUMS) performed

TABLE 2 PCAFC Family Caregiver Eligibility¹⁹

Policies and Explanations
Designated family caregiver must be aged > 18 years—there may also be up to 2 secondary (backup) caregivers designated, though this does not increase fund eligibility
The family caregiver must be: Veteran’s spouse, son, daughter, parent, stepfamily member, extended family member (and need not live with the veteran) OR Someone who lives with the eligible veteran full time or will do so if designated as a family caregiver
The family caregiver must be assessed by the VA as being able to complete caregiver education and training. They must demonstrate the ability to carry out relevant tasks and care requirements The education provided to family caregivers is part of the larger Caregiver Support Program, and is available to veterans who are caregivers or caregivers of veterans regardless of PCAFC eligibility
The VA must assess for abuse or neglect at time of enrollment in PCAFC, and eligibility is reassessed every 90 days and with ≥ 1 in-person visit annually

Abbreviations: PCAFC, Program for Comprehensive Assistance for Family Caregivers; VA, US Department of Veterans Affairs.

by the PCP was notable for a score of 9/30, in the dementia range. A computed tomography of the brain demonstrated scattered foci of hypoattenuation attributable to normal aging without any other pathology noted.

The veteran was referred to the Cognitive Care clinic, a local longitudinal multidisciplinary dementia care clinic, along with his spouse/caregiver. Cognitive testing was performed by a licensed clinical psychologist in the clinic and was notable for a Mini-Mental State Exam (MMSE) score of 18/30, also in the dementia range, and a more robust neuropsychiatric battery demonstrated borderline intact memory and language function but impairments in executive function and visuospatial skills. The patient’s clinical history included functional loss over time, with total dependence in instrumental activities of daily living (IADL), or tasks necessary to be fully independent or manage a household, including inability to manage finances, and some need for assistance in ADL, or personal care tasks such as dressing or grooming, including bathing. Physical examination was notable for bradykinesia, a shuffling gait, and rare episodes of speaking to someone who was not in the room, thought to be due to mild nondistressing hallucinations.

A diagnosis of LBD was made. At time of diagnosis, the patient met criteria for probable dementia with Lewy bodies, with 2 of 4 core clinical features (hallucinations and Parkinsonism), and multiple supportive features (gait disturbance, sensory disturbance, and altered mood).^{10,11} The veteran continued to develop more supportive features for diagnosis of LBD over time, including evidence of autonomic instability.

The veteran and his caregiver were educated on his diagnosis, and longitudinal support was offered. The veteran was no longer driving, and due to the severity of his symptoms, the importance of driving cessation was reinforced by the care team. Over the course of the next year, his illness progressed, with more frequent behaviors and psychological symptoms of dementia (BPSD). He began to exhibit nighttime wandering throughout the house and became more anxious and restless during the day. He lost the ability to make his own health care decisions, and his spouse became his activated health care power of attorney (HCPOA). His BPSD became more disruptive to daily life and was accompanied by a change in the character of his hallucinations, with prior nondistressing visions of other people being replaced with visions of war, burning bodies, and violence, much of it related to combat experiences in Vietnam. The BPSD began to include hiding behind furniture, running out of the house, and shouting and crying in response to hallucinations. At times, his BPSD became violent, lashing out in fear against his hallucinations and caregiver.

The veteran’s change in BPSD was concerning for a new baseline, rather than being clearly related to an underlying unmet physical need, such as pain, hunger, sleep, or discomfort. Multiple hospital admissions during that year involved IV hydration and treatment for urinary tract infections (UTI) for several days of inpatient stay at a time, but these behaviors persisted despite infection treatment and hydration. The patient’s changes in BPSD were thought to be secondary to uncovered and intensified PTSD in the setting of progressive dementia. Due to the clear danger the patient posed to himself and others, potential treatment options for these

PTSD-related hallucinations were discussed with his caregiver. The caregiver shared that the patient's BPSD and hallucinations were so distressing that "he would never want to live like this," and that things had progressed to the point that "he has no quality of life."

Oral aripiprazole 2 mg twice daily was prescribed after the risks of infection, cardiac complications, and exacerbation of movement disorder symptoms, such as increased stiffness and falls, were discussed with the caregiver. The caregiver was employed and relied on continued employment for income, but the patient could not be safely left alone. As the patient and his caregiver had reached a crisis point and living at home no longer appeared to be safe, the patient was referred to a VA-contracted skilled nursing facility (SNF) for long-term care. The patient's caregiver was also referred to CSP for support during this transition. Due to the patient's level of service connection and personal needs, as well as the patient and caregiver's preference for the veteran to remain in his home, they were evaluated for the PCAFC for enhanced support to enable home as an alternative to facility living, should the patient respond to the antipsychotic therapy sufficiently, which was evaluated on a regular basis.

After several months, the patient's BPSD had improved significantly, and he was no longer experiencing distressing hallucinations. However, his mobility also declined, and he became fully dependent in most ADL, including transfers, hygiene, and toileting. Due to the COVID-19 pandemic, visitation was limited, which was difficult for both the patient and his caregiver. The veteran and caregiver were approved for PCAFC due to the veteran's combination of service-connected illnesses > 70%, dependence for most ADLs, and need for continuous supervision. A transfer home from the SNF was arranged.

The PCAFC allowed the veteran's caregiver and family members to provide in-home full-time caregiving, as an alternative to facility placement. The caregiver received a variety of support, including access to peer support, instruction on ways to assist in his toileting, hygiene, and transfers, and a caregiving stipend. In addition to offset-

TABLE 3 Additional PCAFC Veteran Eligibility Criteria¹⁹

Additional PCAFC Policy Details and Explanations
Individual must be a veteran or a member of the military undergoing medical discharge and must have a VA primary care team or be willing to obtain one if a caregiver is designated
ADL assistance must be required each time a veteran performs a task; tasks include dressing or undressing, bathing, grooming, adjusting prosthetics or orthopedic appliances, toileting, feeding oneself or swallowing, and mobility (including transfer)
Supervision, protection, or instruction is defined as a functional impairment that directly impacts a veteran's ability to maintain his or her personal safety daily. Higher levels of stipend are available for family caregivers of veterans who require assistance with ≥ 3 ADL a day or who require continuous supervision for personal safety (as opposed to requiring only daily supervision or check-ins)
Personal care services provided by family caregiver must not be simultaneously and regularly provided by or through another individual or entity—if the veteran is having these needs met regularly through another program, they are not eligible
The individual must receive care at home or will do so if the VA designates a family caregiver; however, the PCAFC does not require the funds to be allocated exclusively as an alternative to facility care or only if the veteran is eligible for facility-level care

Abbreviations: ADL, activities of daily living; PCAFC, Program of Comprehensive Assistance for Family Caregivers; VA, US Department of Veterans Affairs.

ting lost wages, the stipend also helped offset the cost of care supplies which were not provided or were not readily available from the VA, which at the time included the patient's preferred nutritional supplement and some supplies for personal care.

The veteran's care needs continued to escalate. A fall at home resulted in a hip fracture, which was treated with surgical pinning. Postfracture physical therapy in a facility was considered, but ultimately was provided at home. The patient also experienced multiple UTIs and resulting delirium, with accompanying agitation and hallucinations. These episodes improved with IV antibiotics and hydration during short hospital stays. Ultimately, a computed tomography demonstrated overflow incontinence likely related to urologic damage from prior kidney stones and stent placement was recommended.

Visiting skilled nurses for the patient's area were difficult to coordinate but were eventually arranged. The patient continued residing in his home with the support of his caregiver, the PCAFC, and the local VA medical center geriatric and transitional care services. The patient was also referred to the palliative care outpatient specialty clinic for discussion of goals of care and assistance with advance care

planning as his illness progressed. Mental health and geriatric psychiatry consult teams were considered for this case but not utilized.

DISCUSSION

Older adult Americans are at high risk of poor financial wellbeing, with nearly one quarter of Americans aged > 62 years experiencing financial insecurity.¹² Even in this case with health care provided by the VA, successful in-home care was challenging and required a dedicated live-in caregiver, care coordination resources, and financial support. As part of its mission of caring for veterans, the VA has instituted CSP, whose mission is to promote the health and wellbeing of family caregivers through education, support, and services.

PCAFC offers enhanced clinical support for caregivers of eligible veterans who are seriously injured. This includes resources, education, support, financial stipends, health insurance (if eligible), and beneficiary travel (if eligible) to primary caregivers of eligible veterans. PCAFC was originally reserved for veterans who had onset of service-related disability after September 11, 2001, with an associated personal care need. In this population, PCAFC demonstrated an increased usage of clinical resources, likely related to increased ease in accessing care.¹³

The cohort of post-9/11 veterans is very different from the cohort of veterans and their caregivers who may now qualify for the PCAFC after its October 2020 expansion. Veterans from the Vietnam, Korean, and World War II eras of conflict have rates of service-connected disability 2 to 3 times higher than those of post-9/11 era veterans and are at greater risk for dementia.⁹ Veterans aged ≥ 75 years who have service connection also report higher rates of difficulty with independent living and self-care compared with their younger peers.⁹ Since dementia and PTSD are common causes of service connection and disability it is likely that a significant proportion of older veterans will be eligible to apply for the newly expanded PCAFC.

To be eligible for PCAFC, a veteran must have a service-connected disability rating of $\geq 70\%$ and must need in-person care services for ≥ 6 continuous months, based on

either an inability to perform an ADL, or a need for supervision, protection, or instruction. PGCSS and PCAFC also may improve access to dementia-specific resources and care. These programs jointly improve access to care, clinical and community resources, and support, and serve to further support in-home care with consistent caregivers who have known the veterans for decades as an alternative to SNF care, as they did in this case. Although in-home care with appropriate support has not been found to be clinically superior, it has been found to be noninferior to SNF living for older adults.¹⁴ More familiar environments and caregivers such as those at home may also reduce the risk of long-term adverse outcomes such as delirium and falls, but there is still more research to be done to examine the ultimate clinical impact of aging in place for people with dementia. Most importantly, for many veterans and their family caregivers, living at home is preferable to SNF care, but may prove especially challenging in the context of advanced-stage dementia without CSP support.

It is not clear how CSP use or increased access to PCAFC will impact costs. However, the PCAFC monthly stipend is scaled to the median wage of a home health aide and to the location of the caregiver, which is considerably less than the cost of recurrent hospitalization or a year of facility-level care.¹⁵ The CSP may eventually be a successful long-term investment in cost savings. In order to ensure the process for PCAFC approval is uniform and prompt as the program expands, CSP has restructured, increasing the number of employees, improving the patient review process, and expanding staff training.¹⁶ The VA plans to continually reassess CSP using the infrastructure of the Caregiver Record Management Application as it continues to expand.¹⁷

CONCLUSIONS

Dementia and PTSD commonly coexist and are a significant source of disability in the service-connected veteran population. This case brings attention to the recent expansion of PCAFC, which now has the potential to support eligible veterans from the World War II, Korean, and

Vietnam-era conflicts, in whom these illnesses are more common. In this case, in-home care was preferred by the veteran and primary caregiver but would not have been possible without a complex intervention. There is still more research to be done on the best way to meet the needs of older adults with dementia, the impact of in-home care, and the system-wide implications of PCAFC, especially as the program grows. However, in-home care is preferable to SNF living for many veterans and caregivers, and CSP will continue to be an essential element of providing care for this population.

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Disclaimer

The opinions expressed herein are those of the authors and do not necessarily reflect those of *Federal Practitioner*, Frontline Medical Communications Inc., the US Government, or any of its agencies.

Ethics and consent

Informed consent for this case study was obtained from the patient's wife and surrogate decision maker as he did not possess capacity to consent at time of submission.

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