

Chapter 6

Linking Veterans with Dementia to VA and Non-VA Services

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Linking Veterans With Dementia to VA and Non-VA Services

INTRODUCTION

The U.S. Department of Veterans Affairs (VA) operates the largest health care system in this country (509,837) and provides many of the kinds of services that may be needed for a person with dementia.¹ Only a small proportion of elderly American women are veterans, but, as of 1990, more than half of all American men over age 65 are veterans, and by the year 2000 that proportion will increase to two-thirds (854). The VA is a *potential source* of services for them. On the other hand, not all veterans with dementia are eligible for VA services, and the VA does not provide all of the kinds of services that may be needed for a person with dementia.

Some people believe that the VA should provide the full range of health care, long-term care, and other services that are needed for all veterans, including veterans with dementia. Others believe that the VA should provide at least all the health care services that are needed for all veterans. Still others believe that for financial and other reasons, the VA should not or cannot provide all needed services for all veterans; they believe that the VA should concentrate its resources on providing certain kinds of services—usually acute medical services—and that eligibility for VA services should be limited to certain types of veterans—usually veterans with service-connected disabilities and veterans with low income.²

The debate about what services the VA should provide and for whom is not the topic of this chapter. The chapter assumes that although the amount and kinds of services provided by the VA and the eligibility criteria for VA services will undoubtedly change from time to time, it is unlikely for a variety of reasons that the VA will ever provide all the services that may be required for all veterans with dementia. Therefore, many veterans **with** dementia will need to use non-VA services as well. The chapter focuses on problems in the process by which veterans with dementia are linked to VA services for which they are eligible and problems in the process

by which they are linked to non-VA providers for services they cannot obtain from the VA.

Over the past few years, the Office of Technology Assessment (OTA) has heard complaints from some families and other informal caregivers of people with dementia about the difficulty of obtaining VA services for a veteran with dementia or even finding out what services are available from the VA for veterans with dementia. At the same time, OTA has heard from other families and informal caregivers about good services provided by the VA for individuals with dementia. Some of the caregivers who have reported that their relative or friend with dementia received good services from the VA say that they “just happened” to learn about the VA services and that they had not expected that the services they needed for the person with dementia would be available through the VA. Conversely, some families and others who have complained to OTA about the difficulty of obtaining VA services for an individual with dementia have reported that they did expect to receive the services they needed from the VA, and that they were disappointed and angry when those services were not available. OTA has also heard about families of people with dementia who have experienced long, frustrating waits during which they did not know whether the person with dementia would receive needed services from the VA.

People’s diverse experiences in applying for and receiving VA services are illustrated in the results of a 1986 mail survey of families and other informal caregivers of people with dementia (926) commissioned by OTA for its previous assessment, *Losing a Million Minds: Confronting the Tragedy of Alzheimer’s and Other Dementias*. Only a few of the 569 caregivers who responded to the 1986 survey reported that they had ever applied to the VA for services for their relative or friend with dementia. Of those that had applied, 45 percent said the person with dementia did not receive the needed services; in two-thirds of those cases, the main reason given was that the individual—although a veteran—did not have a service-connected disability. For the 55

¹For a list of services that may be needed for a person with dementia, see table 1-2 inch. 1.

²The eligibility criteria for VA health care and health-related services are discussed later in this chapter. Veterans **with** service-connected disabilities—i.e., disabilities that were incurred or aggravated during military service—have priority over other veterans in the receipt of VA services.

percent that did receive VA services, 80 percent of the caregivers reported the services were good or excellent; 10 percent reported the services were average; and 10 percent reported the services were poor. One caregiver removed the veteran from the VA facility due to poor care. The survey did not ask the caregivers whether they had expected that the individual they were caring for would receive VA services or how they were linked to the VA services.

This chapter describes the VA health care and health-related services that may be helpful for an individual with dementia. In the course of this study, one OTA staff member visited several VA medical centers that are providing high-quality services of various kinds for veterans with dementia, and some of those services are described. The chapter discusses the reasons why some services that may be needed for an individual with dementia are not available from the VA and why some veterans with dementia are not eligible for VA services. It describes and analyzes existing problems in linking veterans with dementia to VA services for which they are eligible and to non-VA providers for services they need but cannot obtain from the VA.

Many of the problems discussed in this chapter have been addressed previously by the VA, the Senate and House Committees on Veterans' Affairs, and others, with respect to services for elderly veterans (641,820,854,855,859). In the early 1980s, for example, the VA and Harvard University collaborated in a project to develop options for increased coordination and sharing of VA and non-VA resources to improve access to appropriate care for older veterans (721). One product of that collaborative effort, a book entitled *Older Veterans: Linking VA and Community Resources*, raises many of the same problems discussed here with respect to linking veterans to VA and non-VA services (901a). Certain aspects of the service needs of people with dementia and the VA's eligibility requirements make these problems particularly difficult for veterans with dementia, however.

According to VA estimates, there are now about 400,000 veterans with dementia (76). Although the total number of veterans of all ages is decreasing, the number of older veterans is growing rapidly (854). Since the prevalence of dementia increases with age, the growth in the number of older veterans will result in an increase in the number of veterans with dementia. The VA estimates that there will be

50,000 new cases of dementia among veterans in 1990, and that the number of new cases of dementia among veterans will increase to 100,000 per year by the year 2000, before leveling off (76). By the year 2000, there will be 600,000 veterans with dementia (76). This large number of veterans with dementia is likely to create demands on the VA for a variety of services, and to increase the need for effective methods of linking veterans with dementia to VA and non-VA services.

If Congress mandated the establishment of a national system to link people with dementia to services, as discussed in this OTA report, the VA could take one of two possible roles in relation to the system. On the one hand, the VA could assume the sole responsibility for linking veterans with dementia to both VA and non-VA services. On the other hand, the responsibility for linking veterans with dementia to services could be split between the VA and the non-VA linking system; if this were done, the VA would retain the responsibility for linking veterans with dementia to VA services, and the non-VA linking system would assume primary responsibility for linking veterans with dementia to non-VA services. The pros and cons of these two options are discussed in chapter 1. This chapter provides information relevant to evaluating the two options.

VA HEALTH CARE AND HEALTH-RELATED SERVICES THAT MAY BE HELPFUL FOR VETERANS WITH DEMENTIA

The VA provides health care and health-related services through the Veterans Health Services and Research Administration (VHS&RA), previously called the Department of Medicine and Surgery. Administratively, the VHS&RA encompasses 7 Regions, 27 Districts, and 172 VA medical centers (676). Through the VHS&RA, the VA provides acute and extended (long-term) care services for veterans in VA hospitals, nursing homes, domiciliary care facilities, outpatient clinics, and in the veteran's home. Also through the VHS&RA, the VA pays for acute and extended-care services for veterans in non-VA hospitals, nursing homes, and board and care facilities and through non-VA physicians and other health care professionals. In fiscal year 1987, 1.4 million veterans were treated in VA hospitals, nursing homes, and domiciliary care

facilities, and 19.8 million veterans were treated on an outpatient basis by VA staff (857). In that same year, the VA paid for the treatment of 94,000 veterans in non-VA hospitals, nursing homes, and board and care facilities and for 1.8 million outpatient visits to non-VA physicians and other health care professionals.

This section describes the health care and health-related services provided or paid for by the VA that may be helpful for veterans with dementia. In addition to providing and paying for health care and health-related services, the VA also provides education and training for health care professionals and pays for biomedical and health services research. Some of the VA's training and research initiatives that pertain to dementing diseases and the care of people with dementia are also described.

Not all the services described in the following sections can be obtained by all veterans with dementia for a variety of reasons discussed later in this chapter. These reasons include the eligibility criteria for the services and the lack of sufficient VA services in relation to the large number of veterans who need them. In addition, most VA health care and health-related services are furnished at the 172 VA medical centers. As a result, VA services are, in practice, more readily accessible by veterans who live near one of the medical centers than by other veterans. VA services that are only provided by certain VA medical centers are more readily accessible by veterans who live near those centers.

Acute Care Services

Acute medical care in the VA is provided by 172 VA hospitals, 235 VA outpatient clinics, and numerous non-VA hospitals and physicians (815,837). For veterans with dementia, inpatient and outpatient acute medical services are important for the management of acute illnesses and acute episodes of chronic illnesses, both of which can exacerbate the cognitive deficits caused by a dementing illness. Acute care facilities and services are also important for diagnosis and assessment. VA hospitals and outpatient clinics typically employ physicians with the medical specialties that may be needed to diagnose diseases that cause dementia. In addition, VA hospitals and outpatient clinics employ many other health care professionals, including nurses, psychologists, social workers, and other therapists, who frequently function as a multidisciplinary team and do or could

provide comprehensive, multidisciplinary assessments for veterans with dementia.

Extended (Long-Term) Care Services

A variety of long-term care services, called "extended-care" services in the VA, are available at many VA medical centers. Most of these extended-care services are provided in institutional settings, such as nursing homes and domiciliary care facilities, but some are provided in noninstitutional settings. Both types of extended-care services are potentially helpful for some veterans with dementia.

Institutional Extended-Care Services

The VA provides or pays for institutional extended-care services that may be helpful for veterans with dementia through at least five programs. One of these programs provides *extended hospital care in intermediate medical care beds*—i. e., VA hospital beds that are used for veterans who require less than hospital and more than skilled nursing care. A second program, the *VA nursing home program*, provides skilled nursing care in VA nursing homes. In fiscal year 1989, this program served over 27,000 veterans in 118 VA nursing homes (837). The VA nursing homes had a total of 12,530 beds and an average daily census of 11,500.

A third program that provides institutional extended-care services for veterans is the *community nursing home program*, which permits each of the 172 medical centers to place veterans in non-VA nursing homes that provide either skilled or intermediate level care under contract with the VA. In fiscal year 1989, 3,675 community nursing homes cared for 32,000 veterans through this program (837). The average daily census was 9,305.

A fourth program that provides institutional extended-care services is the *domiciliary care program* that is intended for ambulatory veterans who need health-related services but do not require hospitalization or the skilled or intermediate level of care provided in the VA or community nursing home programs. In fiscal year 1989, 18,000 veterans received care in the VA's 29 domiciliary care facilities, which had an average daily census of 6,000 (837).

Finally, institutional extended-care services are provided by *State Veterans' Homes* that receive a per diem grant from the VA for the care of eligible veterans. State Veterans' Homes can also receive

VA grants to build or acquire new facilities; funding is available for up to 65 percent of construction costs. In fiscal year 1989, there were 55 State Veterans Homes in 36 States (837). These State Veterans Homes had a total of 19,000 beds, including nursing home and domiciliary care beds, as well as some hospital beds.

Noninstitutional Extended-Care Services

The VA provides or pays for three programs that offer noninstitutional extended-care services that may be helpful for some veterans with dementia: hospital-based home care, adult day health care, and community residential care. The *hospital-based home care program* provides in-home medical, nursing, rehabilitative, and other services for homebound veterans. A multidisciplinary team furnishes the services and manages the veterans' care. The hospital-based home care program is highly medical in orientation; the provision of nonmedical support services is not permitted as part of the program. In fiscal year 1989, 72 of the 172 VA medical centers had hospital-based home care programs, and 15,700 veterans were served by these programs (837).

The *adult day health care program* was established as a demonstration program by Public Law 98-160 and provides a "medical model" of adult day services (508,837). The program, which first admitted patients in 1985, provides health care, health maintenance, and rehabilitative services for veterans. In fiscal year 1989, 15 VA medical centers were operating adult day health centers with a total average daily census of 318 (837). In addition, 22 VA medical centers were authorized to contract with community agencies for adult day health care services for veterans, and a total of 396 veterans received contracted adult day health services (837).

Lastly, the *community residential care program* provides room, board, personal care, and supervision to veterans who are not in need of hospital or nursing home care but who cannot live independently. Typically these veterans do not have an informal caregiver. After the VA locates a suitable home and the veteran is placed, VA social workers and nurses provide in-home treatment and case management. In fiscal year 1989, 127 of the 172 VA medical centers had a community residential care program, and the programs provided placement for 11,100 veterans in 2,900 homes (837,917).

Special VA Programs of Particular Relevance for Veterans With Dementia

In addition to the acute and extended-care services just described, some VA medical centers have other programs that are particularly relevant for veterans with dementia and their caregivers. The programs are Geriatric Research, Education, and Clinical Centers; Geriatric Evaluation Units; special care units for veterans with dementia; respite care; caregiver support groups; and special informational materials.

Geriatric Research, Educational, and Clinical Centers (GRECCS) were begun in 1975 to provide basic and clinical research and education and training for clinicians and researchers in the field of geriatrics. Each GRECC focuses on specific areas in geriatric medicine and typically provides care for veterans with diseases and conditions in those areas. As of 1989, there were 10 fully operational GRECCs, four of which were caring for at least some veterans with dementia (76). The sites for two additional GRECCs were selected in 1989, and the two sites received partial funding in that year (8,837).³ For more than 10 years, the GRECC at the E.N. Rogers Memorial Veterans Hospital, in Bedford, Massachusetts, has been providing inpatient and outpatient care for veterans with dementia through its Dementia Study Unit. Box 6-A describes the services provided by the Dementia Study Unit.

Geriatric evaluation units (GEUs) are hospital units that use a multidisciplinary team to assess elderly veterans and develop a coordinated plan of care for them. GEUs and their counterparts in non-VA hospitals are discussed in chapter 8, and the GEU at the VA Medical Center in Sepulveda, California, is described in box 8-Kin chapter 8. As of 1989, there were 87 GEUs in VA hospitals nationwide (917).

GEUs usually consist of a group of VA hospital beds, typically from 4 to 20, that are set aside for comprehensive patient assessment. The objective of a GEU is to refine the diagnosis, treatment, and placement plans for older veterans, particularly those with multiple chronic diseases, remediable impairments, or psychosocial problems. The evaluation can take from 1 to 2 weeks or longer, depending on the complexity and severity of the veteran's

³Although the total number of authorized GRECCS is 25, funds have been appropriated for only 12 GRECCs (8,508).

**Box 6-A—The Dementia Study Unit at the E.N. Rogers Memorial Veterans Hospital
in Bedford, Massachusetts**

The Dementia Study Unit of the Geriatric Research, Education, and Clinical Center at E.N. Rogers Memorial Veterans Hospital provides inpatient and outpatient care for veterans with dementia and information and support for their caregivers. The Dementia Study Unit operates three 25-bed wards and is able to serve 75 veterans on an inpatient basis. The unit has an outpatient caseload of about 40 veterans.

Many of the veterans served by the Dementia Study Unit have been diagnosed at one of the large teaching hospitals in Boston or by a private physician but have not received any followup care from those sources. According to the Dementia Study Unit's social worker, the caregivers of these veterans typically manage without assistance for as long as they can and are often physically and emotionally exhausted by the time they reach the VA. Since the VA is the last place these caregivers turn for help, many of them are seeking inpatient long-term care. They are encouraged to keep the veteran with dementia at home for as long as possible, however.

When the veteran and his or her caregiver are first seen at the Dementia Study Unit, a multidisciplinary team—including a neurologist, a nurse, and a social worker—conducts a complete assessment. The neurologist performs a diagnostic evaluation. The nurse assesses the veteran's physical limitations and functioning, and the social worker conducts a psychosocial evaluation. The assessment is almost always conducted on an outpatient basis. It usually involves several interviews with the caregiver and may involve a home visit.

After the assessment, the veteran and his or her caregiver generally return to the VA for regularly scheduled outpatient visits during which the staff reassesses the veteran's condition and provides information, support, and counseling for the caregiver. These visits also help familiarize caregivers with the inpatient setting and prepare them for the likely institutionalization of the patient later on.

In between scheduled outpatient visits, the social worker maintains telephone contact with the caregivers, and the caregivers are encouraged to call the Dementia Study Unit as the need arises. The social worker considers his main role to be expanding the caregivers' knowledge about dementia, informing them about available services, and helping them improve their coping skills. The social worker circulates a newsletter that contains information about VA and non-VA services. He also assists caregivers in arranging services.

The Dementia Study Unit provides respite care for veterans treated on an outpatient basis. The veterans and their caregivers may use up to 2 weeks of respite care once every 3 months.

Eventually, many of the veterans who are seen as outpatients are admitted to one of the inpatient wards as long-stay residents. For these veterans, the Dementia Study Unit provides medical and nursing care; physical, occupational, recreational, and music therapy; dental care; exercise programs; and other services. Support groups are provided for the caregivers of inpatients and outpatients. The "Wives Support Group" run by the Dementia Study Unit is described in box 6-C.

SOURCES: J. Larkin clinical social worker, Geriatric Research, Education and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA, personal communications, Aug. 3, 1988, and July 14, 1989; B. Seltzer, associate director for clinical services, Geriatric Research, Education, and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA, personal communication Aug. 3, 1988; L. Volicer, K. Fabiszewski, Y. Rheume, et al., *Clinical Management of Alzheimer's Disease* (Rockville, MD: Aspen Publications, 1988).

condition. GEUs often provide comprehensive assessments for veterans with dementia, but some GEUs do not admit veterans with severe, irreversible dementia, especially if the veterans' dementia has been diagnosed and evaluated previously (394,869).

VA special care units are inpatient care settings for veterans with Alzheimer's disease and other dementing diseases. It is estimated that about 40 VA medical centers have special care units. Typically these units are comprised of intermediate medical care beds in a VA hospital. In 1985, VA special care units ranged in size from 18 to 46 beds (855). Evidence from several special care units indicates

that most veterans who are admitted to special care units remain there for the rest of their lives due to the general debilitated state of the veteran and the typically overburdened status of the caregiver at the time of admission (82,751). On the other hand, as discussed below, some and perhaps many VA special care units use certain beds on the unit for short-term respite care for veterans with dementia. Box 6-B describes the special care unit at the VA Medical Center in Coatesville, Pennsylvania.

Respite care was offered by approximately 100 VA medical centers as of 1989 (837). In the VA, respite care is strictly limited to an institutional

Box 6-B—The Alzheimer's Center at the VA Medical Center in Coatesville, Pennsylvania

The Alzheimer's Center at the VA Medical Center in Coatesville, Pennsylvania, is the largest VA special care unit for veterans with dementia. The special care unit has 91 beds on 2 wards. The nursing staff consists of 13 RNs, 6 LPNs, 34 nursing assistants, and a nursing supervisor. Two physicians and one physician assistant provide medical care for residents on the two wards.

The special care unit--like other VA special care units--is usually filled to capacity and has a waiting list. Admission to the unit almost always comes through the VA Medical Center's geriatric evaluation unit. The great majority of residents on the unit are male veterans, but as of May 1989, two of the residents were female veterans. One end of each ward is reserved for veterans with advanced conditions who are confined to a bed or a chair.

The special care unit provides many services in addition to nursing and medical care, e.g., occupational therapy, speech therapy, music therapy, pet therapy, and exercise programs. It has an outdoor fenced-in area that residents are encouraged to use, and many of the residents participate in a horticulture program where they take care of plants and make floral arrangements.

Residents of the special care unit who are ambulatory can take advantage of special outings--such as a May 1989 fishing trip. The unit also has activities that include family members, such as a Father's Day picnic held in June 1989.

The resident's wives and other family members are encouraged to join the family support group that meets once a month for educational presentations and gives family members an opportunity to share their experiences and feelings with one another. Many of the residents' wives also perform volunteer activities on the special care unit.

Sometimes veterans are transferred from the Alzheimer's Center to the VA hospital for acute medical care. Since the special care unit is located in the VA medical center, transfers back and forth to the hospital can be accomplished with greater ease than they can in the non-VA health care sector.

SOURCES: L. Swingler, medical social worker, Alzheimer's Center, VA Medical Center, Coatesville, PA, personal communication, May 23, 1989; C. Curato, ward secretary, Alzheimer's Center, VA Medical Center, Coatesville, PA, personal communication, May 24, 1989; L. Bristol, Alzheimer's Center supervisor, VA Medical Center, Coatesville, PA, personal communication, May 26, 1989.

setting, i.e., a VA hospital or nursing home. The respite care is intended to provide short-term care for the veteran in order to relieve his or her primary caregiver. Each veteran can receive a maximum of 30 days annually, with each admission limited to a maximum of 14 days.

OTA does not know how many VA respite programs serve veterans with dementia, but VA officials report that the implementing guidelines do not preclude serving veterans with dementia (480). At least one respite program designed specifically for veterans with dementia was instituted at the Palo Alto VA Medical Center in 1979 (64). The Dementia Study Unit at the GRECC in Bedford, Massachusetts, described in box 6-A, and the special care unit at the Coatesville, Pennsylvania VA Medical Center, described in box 6-B, both provide institutional respite care for veterans with dementia.

Support groups for spouses and other caregivers of veterans with dementia are provided by some VA medical centers. Box 6-C describes a meeting of the Wives Support Group run by the Dementia Study Unit at the GRECC in Bedford, Massachusetts.

Other VA medical centers have support groups for caregivers of veterans with all kinds of disabilities. Still other VA medical centers encourage caregivers to participate in an Alzheimer's Association or other non-VA support group. These support groups afford the caregivers an opportunity to share their experiences in coping with the illness and to give and receive emotional support from the other caregivers.

Some VA medical centers have developed **special informational materials** for caregivers of veterans with dementia. One example is the VA Medical Center in Minneapolis, Minnesota, which has developed a series of booklets on topics of importance to caregivers of veterans with dementia, including "What is Alzheimer's Disease?" "The Role of the Caregiver," "Managing From Day-to-Day," and "Working With Bureaucracies."

VA Education, Training, and Research Programs

In addition to providing and paying for health care and health-related services for veterans, the VA's VHS&RA also has two other functions: providing education and training for health care professionals

Box 6-C---The Wives' Support Group at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts

One OTA staff member attended the August 3, 1988 meeting of the Wives' Support Group run by the Dementia Study Unit at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts (see box 6-A). At the time of the meeting, with one exception, each of the husbands of the women who attended the meeting were long-stay residents of the Dementia Study Unit's inpatient wards. The remaining husband was enrolled in the Dementia Study unit's outpatient program and was being cared for at home by his wife, awaiting an opening on one of the inpatient wards.

Of all the many stories that unfolded during the meeting of the Wives' Support Group, the most striking was the similar scenario portrayed by each woman of her experience seeking help in the non-VA health care sector, which eventually ended with her finding out about the VA's special Alzheimer's program completely "by accident. Before finding out about the VA program, all but one of the wives had taken their husbands to the family doctor and were referred to a neurologist. All the wives said that after the neurologist confirmed the Alzheimer's diagnosis, they did not receive any information about what to do from there. One woman stated that she was actually relieved by the diagnosis, but they all admitted that Alzheimer's was a difficult disease to come to terms with, and many said they felt 'abandoned' by the non-VA health care system.

The wives' stories about how they found out about the VA's special Alzheimer's program all included the common theme of having found the program "by accident. One woman said that, by chance, she saw a TV program that mentioned the VA program. Another heard about the VA through a friend. A third woman had a daughter who had worked previously at the Bedford VA hospital, and another had seen **a TV Guide listing on a memory program that talked about the Geriatric Research, Education, and Clinical Center** at the VA hospital. Only one woman had learned about the program by contacting the VA directly.

As noted above, only one member of the support group was still caring for her husband at home. She said that she was dependent on the support group for reassurance and could not imagine having to go through any more of the 'ordeal' without the help of the support group. At one point, she tearfully explained how frightened she is when her husband, who is apparently much larger than she, becomes confused and agitated-all the while not hewing who she is. All the other wives understood.

Another wife of a World War I veteran attempted to explain the tremendous guilt she felt when her husband was still at home and she needed help. She said she did not feel that she should "bother" her children to give her a hand. Now, years later, she still feels guilty, despite the fact that her daughter, who attended the meeting with her, assured her that all her children wanted to help.

The wives agreed that since they found the VA program, they were "saved" from an "awful" existence. The program offered them the solace, advice, coping mechanisms, and the services they needed to survive the time that their husbands were outpatients. The VA program gradually acquainted them with the inpatient unit and gave them a comfortable familiarity when the time came to admit their husbands to the inpatient wards.

SOURCE: Wives Support Group, Geriatric Research, Education, and Clinical Center, E.N. Rogers Memorial Veteran Hospital, Bedford, MA, Aug. 3, 1988.

and sponsoring medical research. These two functions are important for veterans with dementia because some of the education and training and research programs focus on Alzheimer's and related dementias.

The VA conducts the largest education and training effort for health professionals in the United States and is the principal training resource in geriatric medicine (854,857). Annually, through affiliations with over 1,000 educational institutions, including schools of medicine, nursing, and other health professions, about 100,000 students, includ-

ing about half of the physicians in this country, receive some or all of their clinical training through the VA (507).

In fiscal year 1988, the VA supported about 8,350 full-time medical residency positions, with geriatrics among the areas receiving special emphasis (76). A significant number of nursing students receive VA scholarships for training in geriatric/gerontological nursing (831). Many of these individuals have contact with dementia-specific programs and/or veterans with dementia.

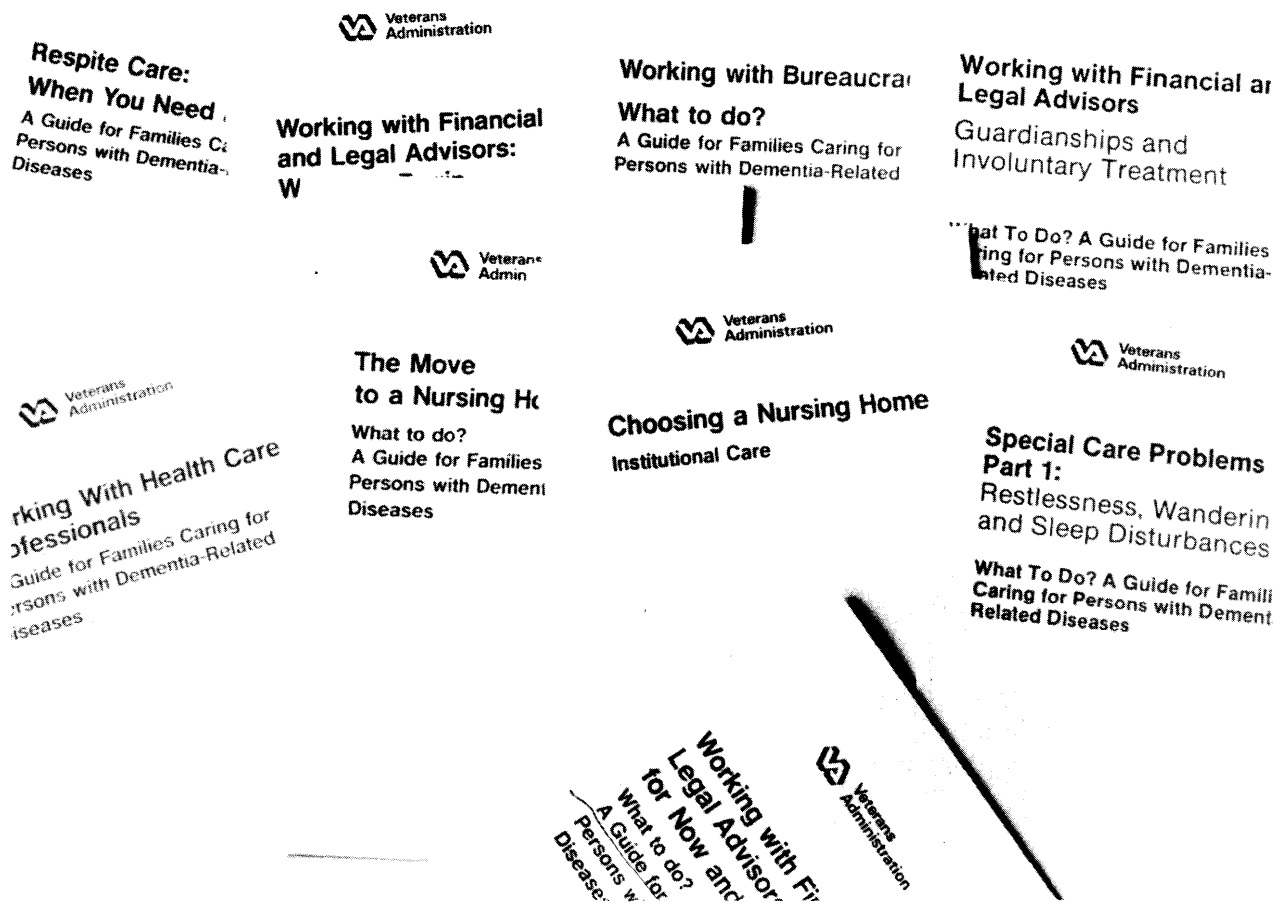


Photo credit: Gretchen Kolsrud

The VA Medical Center in Minneapolis, Minnesota, has developed a series of informational booklets for caregivers of people with dementia.

As noted earlier, GRECCs provide training for clinicians in the field of geriatrics. The VA Interdisciplinary Team Training Program in Geriatrics also provides clinical training in geriatrics for students in various health disciplines, such as nursing, psychology, and social work, to develop knowledge and skills in providing interdisciplinary team care. In 1988, the Interdisciplinary Team Training Program in Geriatrics funded support for almost 200 health professionals from various disciplines (76).

The VA's Office of Research and Development in the VHS&RA each year funds over 4,000 researchers with a budget of approximately \$200 million (76). For fiscal year 1988, over \$2.6 million of the VA's total research budget was devoted to research pertaining to dementia. In addition, VA researchers reported receiving another \$2.9 million for dementia-related projects from non-VA sources.

Summary and Implications

The preceding section has described many VA services that may be helpful for veterans with dementia and their caregivers, including some services specifically designed for veterans with dementia. That these services exist highlights the importance for veterans with dementia and their caregivers of effective methods by which they can be linked to VA services for which they are eligible.

On the other hand, the information just presented makes it clear that the VA does not provide all the services that may be needed for veterans with dementia. Certain services, e.g., in-home respite care, are not provided by the VA at all. Other potentially helpful services are provided by some VA medical centers and not others. As of 1989, for example, approximately 100 of the 172 VA medical centers provided institutional respite care, and 15 of

the 172 centers had adult day health care programs. One reason for the differences among VA medical centers in the services they provide is that VA medical centers have some discretion about which services they provide.⁴ Institutional respite care is a service that each VA medical center has the option to provide. Another reason for the differences among VA medical centers in the services they provide is that Congress, faced with budget constraints, sometimes authorizes and/or funds the provision of certain services at only a few VA medical centers. Adult day health care is a program that only a few VA medical centers are authorized to provide.

The great majority of VA health care and health-related services are provided at VA medical centers, which means that the services are more readily accessible by veterans who live near one of the medical centers. The 172 VA medical centers are not uniformly distributed across the country, and some have very large catchment areas (662,724). As a result, some veterans and their caregivers have to travel long distances to access VA services, and some may not be able to access VA services (481,662,823). This problem is exacerbated when the needed services are not provided by the nearest VA medical center.

As noted earlier, some people believe that the VA should provide more services of various kinds, and other people believe that the VA cannot or should not provide more services. This OTA assessment does not address the question of what services the VA should provide. In the context of this assessment, the fact that the VA does not provide all the services that may be needed for veterans with dementia points to the importance of effective methods by which veterans with dementia can be linked to non-VA services. The fact that some veterans live too far from a VA medical center to access VA services underscores the importance of those methods.

Many of the extended-care services provided by the VA are institutional or residential in nature. With respect to the care of elderly veterans in general, the

VA has been criticized for overemphasizing institutional services and underemphasizing in-home and other noninstitutional services (8,48 1,509,662). These same criticisms are generally relevant to the care of many veterans with dementia. On the other hand, institutional and residential care services are appropriate for some veterans with dementia who have no relative or other informal caregiver to help them and for some veterans with dementia whose relatives and friends are unable to take care of them.⁵ That the VA provides primarily institutional and residential extended-care services emphasizes the importance of effective methods of linking veterans with dementia who need such services to the VA and, conversely, the importance of linking veterans with dementia who need services not available from the VA to non-VA service providers.

The VA is sometimes also criticized for overemphasizing medically oriented services and underemphasizing nonmedical, supportive services (8). Veterans with dementia need both medical and nonmedical services. Some people believe that the VA should provide more nonmedical, supportive services. In the context of this OTA assessment, however, the fact that the VA provides more medically oriented services reinforces the need for effective methods of linking veterans with dementia who need such services to the VA and effective methods of linking veterans with dementia who need nonmedical, supportive services to non-VA providers if ~~these~~ services are not available from the VA.

PROBLEMS IN LINKING VETERANS WITH DEMENTIA TO VA SERVICES

Some people, including some veterans and their families, believe that the VA will provide all the health care and long-term care services the veteran needs and that the veteran will be able to obtain these services simply by virtue of the fact that he or she is a veteran. The preceding section pointed out that some of the services that maybe needed for veterans with dementia are not available from the VA at all or

⁴The VA's planning process (called Medical District Initiated Program Planning-MEDIPP) allows each VA medical center some degree of discretion about the type and amount of services it will offer. The MEDIPP process then coordinates the individual medical centers' plans at the district level.

⁵In response to congressional requests and a mandate of Public Law 99-576, the VA prepared a report on "Alternatives to Institutional Care," which was presented to Congress in January 1988 (860). The report describes the VA's noninstitutional services for elderly veterans and veterans with chronic mental illness, including various pilot and demonstration projects intended to evaluate the effectiveness of noninstitutional services for these patient groups. The report points out the importance of institutional care for some types of veterans.

are only available from certain VA medical centers. This section discusses problems in linking veterans with dementia to services that *are* available from the VA. The discussion focuses on the complexity of the eligibility criteria for VA services, the difficulty of determining whether a veteran with dementia will receive VA services, and the lack of accurate information about what services are available. All three of these problems are frustrating for families and others who are trying to plan and arrange services for a veteran with dementia.

The Complexity of the Eligibility Criteria for VA Services

In 1986, Congress passed Public Law 99-272, which substantially revised the eligibility criteria for VA health care and health-related services. The law specified three categories of veterans—"A," "B," and "C"—for the purposes of eligibility determination. The law mandated a means test for certain veterans and certain services and, for the first time, required the VA to provide hospital care for certain veterans. In 1988, Congress passed Public Law 100-322, which further revised the eligibility criteria for outpatient care. The resulting criteria are extremely complex. Although the eligibility criteria for VA services can be and frequently are summarized in one or two paragraphs, such a summary fails to convey a true sense of their complexity. Since that complexity is one of the major problems in linking veterans with dementia to VA services, the eligibility criteria are described in greater detail here.

The three categories of veterans specified by Public Law 99-272 are as follows:

Category A includes any veteran who:

- has a service-connected disability;
- is a former prisoner of war;
- served during the Spanish-American War, Mexican border period, or World War I;
- may have been exposed to certain toxic substances while on active duty in Vietnam;
- may have been exposed while on active duty to ionizing radiation from nuclear testing or participation in the American occupation of Hiroshima or Nagasaki, Japan;
- has an income below \$15,833 for a single veteran and \$18,999 for a married veteran, plus \$1,055 for each additional dependent⁶;

- is eligible for Medicaid; or
- receives a VA pension.

Category B includes any veteran who does not have a service-connected disability, does not meet the other criteria for category A, and has an annual income between \$15,833 and \$21,110 for a veteran with no dependents and between \$18,999 and \$26,388 for a veteran with dependents.

Category C includes any veteran who does not have a service-connected disability, does not meet the other criteria for category A, and has an annual income over the category B amounts.

Determining whether a veteran is eligible for and will receive a service is complicated not because of the three categories just listed, but because of other factors that affect the determination. One of the factors is whether the condition for which the veteran needs treatment or services resulted from military duty (i.e., whether the condition is service-connected). Another factor is what services the veteran needs. The VA is required to provide certain services for certain veterans, as discussed below, but most services for most veterans must be provided only on a "space available" basis. Thus, the services are not an entitlement; a veteran's eligibility for them is not absolute but, instead, depends on whether there is "space available" in the service program (641,741). As a result, a given veteran might be determined to be eligible for and receive a given service from one VA medical center that had "space available" but not from another VA medical center that did not have "space available." Lastly, the eligibility criteria for regular VA services are sometimes waived for services provided as part of a research or demonstration program. The following sections describe the eligibility criteria for many of the kinds of services described earlier in this chapter as potentially helpful for veterans with dementia.

Hospital Care

Public Law 99-272 required that the VA provide free hospital care for any category A veteran who:

- is being treated for a service-connected disability;
- has a service-connected disability and is being treated for any disability;

⁶The dollar figures in this section are for 1988. The figures for subsequent years are adjusted in the same manner as VA pensions.

- was discharged or released from active duty due to a disability incurred or aggravated in the line of duty and is being treated for any disability;
- has a disability resulting from VA treatment or the pursuit of vocational rehabilitation and is being treated for any disability;
- has a service-connected disability rated at 50 percent or more and is being treated for any disability;
- is a former prisoner of war and is being treated for any disability;
- served in the Spanish-American War, Mexican border period, or World War I and is being treated for any disability;
- may have been exposed to certain toxic substances while on active duty in Vietnam or to ionizing radiation from nuclear testing or participation in the American occupation of Hiroshima or Nagasaki Japan, and is being treated for a condition possibly related to that exposure; or
- has a nonservice-connected disability and is unable to defray the cost of medical care, including:
 - a. veterans who receive VA pensions,
 - b. veterans who are Medicaid eligible, and
 - c. veterans with yearly incomes below \$15,833 for a single veteran and \$18,999 for a married veteran, plus \$1,055 for each additional dependent.

All other veterans may be eligible for VA hospital care at the discretion of the VA medical center and if there is space is available. Category B veterans may be eligible for flee hospital care if there is space available. Category C veterans may be eligible for hospital care if there is space available and if they pay a deductible. In 1988, the deductible was \$540 for the first 90 days, and \$270 for each subsequent 90-day period up to a maximum of \$1,350 a year (76).

Outpatient Care

Public Law 100-322 required that the VA provide outpatient care for any category A veteran who:

- is being treated for a service-connected disability,
- has a service-connected disability rating of 50 percent or more, or
- is disabled as a result of VA treatment or in pursuit of vocational rehabilitation (817).

Public Law 100-322 further required the VA to provide, as medically indicated, outpatient services in preparation for, as followup to, or to obviate the need for, hospital admission for any veteran who:

- has a 30 percent or 40 percent disability rating, or
- has an annual income below \$9,940 (a figure that is increased by \$1,055 for each dependent and is adjusted annually) (817).

The VA may provide outpatient care for some other veterans in preparation for, in **followup** to, or to obviate the need for hospital admission in the following order of priority.

Priority Group I: any category A veteran who:

1. has a service-connected disability rated at less than 30 percent or needs a compensation or pension examination;
2. is a former prisoner of war or was exposed to toxic substances in Vietnam or ionizing radiation from a nuclear explosion;
3. served in World War I or the Mexican border period or is receiving an “aid and attendance” pension or a similar VA pension; or
4. has income greater than \$9,940 and less than the category A threshold (e.g., \$15,833 for single veterans) (817).

Priority Group II: any category B veteran.

Priority Group III: any category C veteran who agrees to pay a copayment of \$25 per visit.

Nursing Home Care

Nursing home care is a discretionary benefit that may be given to all veterans to the extent that space and funding are available as long as it is given in the following priority order:

Priority Group I: any category A veteran who:

1. has a service-connected disability and is being treated for any condition;
2. was discharged or released from active duty due to a disability incurred or aggravated in the line of duty and is being treated for any condition;
3. has a disability resulting from VA treatment or in pursuit of vocational rehabilitation and is being treated for any condition;
4. is a former prisoner of war and is being treated for any condition;

5. may have been exposed to certain toxic substances while on active duty in Vietnam or to ionizing radiation from a nuclear test or participation in the American occupation of Hiroshima or Nagasaki, Japan, and is being treated for a condition possibly related to that exposure;
6. served in the Spanish American War, the Mexican border period, or World War I and is being treated for any condition;
7. has a nonservice-connected disability and is unable to defray the cost of medical care otherwise, including:
 - a. veterans who receive VA pensions,
 - b. veterans who are Medicaid eligible, and
 - c. veterans with yearly incomes below \$15,833 for a single veteran and \$18,999 for a married veteran, plus \$1,055 for each additional dependent.

Priority Group II: any category B veteran.

Priority Group III: any category C veteran who agrees to pay the deductible.

Care in a VA nursing home is free for veterans in priority groups I and II. Veterans in priority group III must pay a copayment. Length of stay in a VA nursing home is not restricted for veterans in any of the three priority groups. Veterans in any of the three groups can be admitted to a VA nursing home from their home, a hospital, or a residential care setting.

Care in a non-VA nursing home through the VA's community nursing home program (described in the previous section) is also free for veterans in priority groups I and II. Veterans in priority group III must pay a copayment. Length of stay in a non-VA nursing home is not restricted for veterans being treated for a service-connected disability and veterans who were previously hospitalized primarily for the treatment of a service-connected disability. For all other veterans, care in a non-VA nursing home is restricted to 6 months, and many VA medical centers limit the allowed length of stay to 2 to 3 months.⁷

Except for veterans being treated for service-connected disabilities, veterans admitted to a non-VA nursing home through the community nursing home program must be admitted from a VA hospital. This requirement sometimes poses a problem for

veterans with dementia who need nursing home care: the problem arises because VA hospitals may not consider a cognitive impairment alone as a sufficient reason for hospital admission, and veterans with dementia may not have an acute illness or another condition that would justify hospital admission.

Domiciliary Care

Veterans who need domiciliary care can qualify if their annual incomes are below the "aid and attendance" pension level—\$9,940 for the veteran without dependents (a figure that is increased by \$1,055 for each dependent and is adjusted annually), or if, as determined by the Secretary, they have no adequate means of support. In clarifying these eligibility criteria, the conferees for the Veterans' Benefits and Services Act of 1988 stated that veterans with service-connected disabilities should be given first priority and that income alone should not be used to deny them eligibility for domiciliary care (817).

Eligibility Criteria for Other VA Programs

VA research and demonstration programs and some other VA programs often provide services for veterans who would not necessarily be eligible for VA services under the general eligibility criteria. With respect to GRECC programs, for example, a veteran whose situation "fits" into the research being conducted by the GRECC can be admitted to the program, regardless of whether the veteran meets other eligibility criteria. In order to qualify for the inpatient and outpatient care provided by the Dementia Study Unit at the GRECC in Bedford, Massachusetts (see box 6-A), a veteran must have a diagnosis of Alzheimer's disease (440). If this criterion is met, the veteran can be admitted into the program and receive free services whether or not he or she has a service-connected disability or a qualifying income level. Likewise, VA special care units can admit veterans on the basis of their diagnosis or condition, independent of the general eligibility criteria for VA hospital or nursing home care.

Situations like these in which the general eligibility criteria for VA services are not strictly applied add to the complexity of VA eligibility criteria.

⁷A veteran with dementia who has a service-connected disability unrelated to the dementia would not qualify for unrestricted nursing home care in a non-VA nursing home unless the care were needed for the veteran's service-connected disability.

Although one would not want to require VA research and demonstration programs and other special programs to admit only veterans who meet the general eligibility criteria for VA services, it is easy to understand why the existence of completely different sets of eligibility requirements for apparently similar services might be confusing for families and others who are trying to locate and arrange services for a veteran with dementia.

The Difficulty of Determining Whether a Veteran With Dementia Will Receive VA Services

The complexity of the eligibility criteria for VA services--especially as the criteria interact with the factor of "space availability"--make it difficult to determine whether a veteran with dementia will receive VA services. With the exception of the hospital and outpatient services that the VA is now mandated to provide for some veterans, most VA services, including the extended-care and special services discussed earlier in this chapter, are provided on a "space available" basis. Since the availability of specific kinds of VA services usually cannot be known with certainty much before the time when the services are to be used, it may be difficult, if not impossible, for families and other informal caregivers to know in advance whether a veteran with dementia will receive the services.

The factor of space availability is important in determining whether veterans with all kinds of disabilities will receive VA services, but it may be especially important for veterans with dementia. As is obvious from the preceding review of the eligibility criteria for VA services, veterans with service-connected disabilities have the highest priority for VA services. Since most diseases that cause dementia occur late in an individual's life, long after he or she is discharged from military service, dementia is seldom considered a service-connected disability (724). Some veterans with dementia have another service-connected disability or meet one of the other previously listed criteria that give an individual high priority for receiving VA services. For veterans with dementia who do not meet any of these criteria (e.g.,

all category B and C veterans), space availability is a major factor determining whether they will receive VA services.⁸

The availability of VA services is affected by both the supply of and the demand for services. The supply of all VA services depends on the funds available to the VA as a whole and to individual VA medical centers. The supply of specific kinds of services depends on decisions at the national, district, and individual VA medical center level in regards to which services will be funded. The demand for VA services depends on the number of veterans who need the services, the availability and cost to the veteran of non-VA services, veterans' and their families' awareness of VA and non-VA services, their perception of the relative quality of VA v. non-VA services, and other factors (641, 662,741).

Since the availability of VA services is determined by the supply of and the demand for services, availability changes in response to changes in both the factors that affect supply (e.g., the funds available to the VA) and the factors that affect demand (e.g., the number of veterans who need services). A full analysis of these factors is beyond the scope of this OTA assessment. It is clear, however, that current pressures to contain Federal spending are placing limits on the funds available to the VA. At the same time the VA is faced with increased demand for services because of the growing number of older veterans (8,490,815,820,854). The number of veterans over age 65 increased from 3 million in 1980 to 7 million in 1990 and is expected to increase to 9 million by the year 2000 (854). Historically, veterans have relied primarily on non-VA services. From 1979 to 1981, for example, only 13 percent of all veterans' hospitalizations were in VA hospitals (823). That could change, however, if the cost of non-VA services increased or their availability or quality decreased (741).

Spurred by an awareness of the increasing number of older veterans, the VA and other government agencies have tried to project the future demand for VA services (805,824). In 1984, the VA published a report projecting future demand and setting goals for

⁸In 1984, about 30 percent of the veterans treated in VA hospitals had a service-connected disability, and 70 percent did not. On one particular day, Sept. 30, 1984, 16 percent of the veterans treated in VA hospitals were being treated for a condition related to their service-connected disability, and 84 percent were being treated for a nonservice-connected condition (823). OTA is not aware of more recent data on these issues. Presumably, however, if there has been an increase since 1984 in the proportion of veterans being treated in VA facilities who are being treated for a service-connected disability or who at least have a service-connected disability, veterans with dementia who do not have a service-connected disability are less likely to receive services.

specific VA programs considered important in caring for older veterans (e.g., GRECCs, GEUs, hospital-based home care, adult day health care, and community residential care).⁹ With the exception of hospital-based home care, the VA is far from reaching its 1990 objectives for these programs.¹⁰

The preceding discussion suggests that the supply of certain VA services is unlikely to meet the demand for the services on a national level and that veterans with dementia who do not have a service-connected disability and do not meet one of the other criteria that give an individual high priority for receiving discretionary VA services may be unlikely to receive the services. During testimony at a hearing in April 1989, representatives of two veterans organizations testified that some VA medical centers were turning away category B and C veterans (490,882). One representative of a service organization said that several VA medical centers have publicly announced the discontinuance of all types of care for category B and C veterans (490). On the other hand, the supply of and demand for VA services varies at different VA medical centers, and as discussed earlier, the eligibility criteria for different VA services also vary. Despite the problems of space availability, therefore, it is likely that some, and perhaps many, veterans with dementia will continue to receive VA services.

The Lack of Information About VA Services

As noted in the beginning of this chapter, OTA has heard complaints from some caregivers of veterans with dementia about the difficulty of finding out what services are available from the VA. Anecdotal evidence suggests that many veterans and their families are not knowledgeable about what services are provided by the VA. In the course of this study, it has become clear to OTA staff that many non-VA health care and social service professionals, service providers, information and referral agencies, case managers, and others who refer people with dementia to services also are not knowledgeable about VA services. This lack of knowledge includes both a lack of general awareness of services, referred to as service *consciousness in this* report, and a lack

of knowledge about specific services, referred to as *service knowledge in this* report.

OTA is not aware of any research on how families and other informal caregivers of veterans with dementia, who are eventually linked to VA services, find out about the services. VA medical centers frequently have printed brochures that describe the services they provide, but these brochures seem to be of only limited utility for caregivers of veterans with dementia. Anecdotal evidence indicates that some caregivers find out about potentially helpful VA services by contacting a VA medical center directly. Other caregivers find out about such services from veterans organizations that may not only give them information about services but also help them obtain the services. Still other caregivers find out about VA services from anon-VA health care or social service professional, service provider, or case manager who has previously learned about the services from another client, a professional meeting, or another source. OTA does not know how many caregivers learn about VA services in any of these ways. Often, however, it seems that caregivers find out about potentially helpful VA services in completely haphazard ways. As described in box 6-C, all but one of the members of the Wives Support Group at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts, said they found out about the special Alzheimer's program at the VA hospital "by accident," from a friend, an acquaintance, or a TV program they happened to watch. Probably some caregivers only learn about some of the VA's extended-care services and the special VA programs described in this chapter after their relative or friend with dementia has been admitted to a VA hospital for an acute medical condition.

Given the variation among VA medical centers in the amount and kinds of services they provide and the complex issue of space availability that affects what services are really available though a VA medical center, it is easy to understand why there would be a lack of accurate information about VA services. Until recently, the VA itself has not been fully aware of the kinds of services it is providing for veterans with dementia. In 1988, the VA conducted

⁹The projections in the VA's 1984 report were made before the 1986 and 1988 revisions to the eligibility criteria for VA services. OTA is not aware of any projections of future demand for VA services that take those revisions into consideration.

¹⁰Currently, with hospital-based home care programs at 73 medical centers, the VA is close to its 1990 goal of 76 medical centers with hospital-based home care programs. Only 87 VA medical centers have GEUs, still 33 short of the 1990 goal of 120 centers. There are 12 GRECCs, 18 GRECCs shy of the 1990 goal of 30. Adult day health care is available through 15 VA medical centers, 25 below the 1990 goal of 40 programs. Community residential care is available through 127 VA medical centers, although the 1990 goal was to have that program in effect in all 172 VA medical centers (854,917).

a survey of all 172 VA medical centers to find out what programs and services were available for veterans with dementia (76). The results of the survey have been compiled into a directory for internal VA use in referring veterans and their caregivers to services and responding to public inquiries about the location of services for veterans with dementia across the country. It is hoped that the directory will allow the VA to provide more accurate information about services (76). The directory cannot solve the problem of determining whether an individual veteran with dementia will actually receive VA services, however, because that determination depends to a great extent on space availability at the time the veteran needs the services.

Summary and Implications

The complexity of the eligibility requirements for VA services, the difficulty of determining whether a veteran with dementia will receive VA services, and the lack of information about VA services complicate the process of linking veterans with dementia to VA services. Anecdotal evidence indicates that many caregivers of veterans with dementia do not know what VA services are available and do not know how to find out. As a result, some caregivers may not apply for services the veteran needs and could receive from the VA. Other caregivers may assume mistakenly that the VA will provide the needed services. When these caregivers finally do apply to the VA for services--often very late in the course of the veterans' illness when the caregiving situation has become unmanageable--they may find that the services they need are not available, that the veteran is not eligible for the services, or that the programs that provide the needed services are full.

The recently completed directory of VA services for veterans with dementia should allow the VA to provide more accurate information about services. With the exception of certain services now mandated for certain veterans, however, most VA services are provided on a "space available" basis. Since space availability cannot be determined much before the time when the veteran will use the services, families and other informal caregivers generally cannot know in advance whether the veteran will receive VA services. This is true of the extended care services and many of the special VA programs described earlier in this chapter. Without that information, families and others cannot plan ahead for the care of a veteran with dementia.

Some caregivers of veterans with dementia contact the VA directly for information about services, but other caregivers would be unlikely to contact the VA unless they were referred by another source. The same factors that make it difficult for caregivers to know about potentially helpful VA services also make it difficult for non-VA health care and social service professionals, service providers, information and referral agencies, case managers, and others who refer people with dementia to services to know about VA services. Anecdotal evidence suggests that some individuals who refer people with dementia to services have an informal connection to someone at the VA and contact that person from time to time when they need information about VA services (404), but many agencies and individuals that refer people with dementia to services probably do not have such a contact at the VA and may not know how to find out about VA services.

Over the years, the VA has participated in several cooperative initiatives with other community agencies, one purpose of which has been to inform the other agencies about VA services so that they can provide accurate information about VA services for veterans they may see as clients. Some VA medical centers and area agencies on aging (AAAs) have worked together to develop information and referral procedures to help the AAAs make appropriate referrals for VA services (662). Facilitating appropriate referrals of veterans to the VA for services is also one of the positive outcomes of many of the "sharing agreements" discussed later in this chapter.

Finally, with respect to the policy question of the role of the VA in relationship to a national system to link people with dementia to services, it is clear that ***only the VA can finally link veterans with dementia to VA services***. Non-VA health care and social service professionals, service providers, information and referral agencies, and case managers can refer veterans with dementia to the VA, and these referrals can be more or less appropriate. Likewise, a non-VA linking system could refer veterans with dementia to the VA. Given the complexity of the eligibility requirements for VA services, however, especially as they interact with the factor of space availability, it is clear that the VA must determine whether a veteran will receive VA services and which services he or she will receive. These functions cannot be performed by the non-VA linking system, and this OTA report does not consider that an option.

PROBLEMS IN LINKING VETERANS WITH DEMENTIA TO NON-VA SERVICES

Although the VA provides many of the services that may be needed for veterans with dementia, some veterans with dementia are not eligible for VA services, and some services that are needed for people with dementia are not available from the VA or are only available from certain VA medical centers. As a result, many veterans with dementia are likely to need non-VA services as well.

The VA has at least four mechanisms by which it links veterans to non-VA services. Two of these mechanisms—hospital discharge planning and case management—directly link individual veterans to non-VA services. The other two mechanisms—“sharing agreements” and the functions of the “community services coordinator” at each VA medical center—generally coordinate VA and non-VA services, thereby indirectly facilitating veterans’ access to non-VA services. This section briefly describes each of the four mechanisms and discusses problems that may interfere with their effectiveness. The section also identifies certain types of veterans who are unlikely to be linked to non-VA services through the four mechanisms.

It is interesting to note that although some people believe that the VA should provide the full range of health care, long-term care, and other services needed for all veterans, the VA often describes its role as providing certain services and attempting to ensure that veterans have access to the other services they need through the four mechanisms discussed in this section (837,860). In that sense, hospital discharge planning, case management, Community services coordination, and joint initiatives with non-VA agencies are the means by which the VA tries to promote continuity of care and ensure the availability of comprehensive services for veterans even though it cannot provide all the services directly.

VA Mechanisms for Linking Individual Veterans to Non-VA Services

The Social Work Service at each VA medical center has primary responsibility for linking individual veterans to non-VA services and implements that responsibility largely through hospital discharge planning and case management. Veterans who need

non-VA services can come to the attention of the Social Work Service in several different ways:

- veterans who are receiving inpatient care in a VA hospital maybe referred to or identified by the Social Work Service as needing hospital discharge planning;
- veterans who are receiving extended-care services through certain VA programs routinely receive case management, which is usually provided by the Social Work Service;
- veterans who apply to a VA medical center for services but are denied VA services for any reason (e.g., they are not eligible, there is no space in the service program, or the VA medical center does not provide the services they need) may be referred by the admissions office to the Social Work Service; and
- veterans and their families who are not receiving any VA services may contact the Social Work Service directly for assistance in finding non-VA services.

Each VA medical center has a policy for hospital discharge planning. Within that policy, the Social Work Service is required to have discharge planning procedures that include:

- the provision of a multidisciplinary assessment;
- the development of a plan of care that incorporates quality of life concerns;
- the involvement of the veteran, the veteran’s family, and significant others in discharge planning;
- the Provision of referrals to non-VA service providers and assistance in arranging non-VA services; and
- the provision of referrals to VA extended-care services (858).

In fiscal year 1987, VA social workers provided hospital discharge planning for 420,000 veterans (857).

VA case management includes the five functions identified by OTA as core case management functions (i.e., client assessment, care planning, service arrangement and coordination, monitoring, and reassessment), plus screening (236). The VA routinely provides case management for veterans who are receiving extended-care services through certain VA programs, such as the hospital-based home care program, the community nursing home program, and the community residential care program. The

Social Work Service generally has primary responsibility for the provision of case management in these programs, but in some instances, the case manager may be a VA nurse or another member of the treatment team, depending on the veteran's needs (236). In these programs, case management includes arranging and coordinating both VA and non-VA services (858).

The Social Work Service at each VA medical center is required to identify veterans in certain "at risk" categories and to provide hospital discharge planning and case management for them, as needed (858). Veterans *with* dementia might be included in several of the "at risk" categories, e.g., "chronically ill," "incompetent," or "age 70, disabled, and living alone." OTA is not aware of any data on the number of veterans with dementia who receive hospital discharge planning or case management through the VA.

VA hospital discharge planning and case management are provided primarily for veterans who are already receiving or are eligible for VA services: by definition, VA hospital discharge planning is provided for veterans who are receiving inpatient care, and VA case management is provided most often for veterans who are receiving VA extended-care services. On the other hand, the Social Work Service at each VA medical center is not strictly limited to helping veterans who are already receiving or are eligible for VA services (620). Two situations in which VA social workers might assist veterans who are not already receiving or eligible for VA services were noted earlier: 1) situations in which veterans who apply for but do not receive VA services for any reason are referred by the admissions office to the Social Work Service, and 2) situations in which veterans or their families contact the Social Work Service directly for assistance in finding non-VA services (620). OTA does not know how frequently either of these situations occur. VA social workers are probably more likely to provide information and referrals than comprehensive case management in these situations.

Four software programs have been developed by the Social Work Service Special Interest Users Group to assist VA social workers with discharge planning and case management. The four programs are:

- *The High-Risk Screening Program*, which is intended to identify veterans who are most likely to need social work services, including discharge planning and case management;
- *The Case Registry System*, which is intended to help social workers keep track of veterans throughout the course of their care;
- *The Community Resources Managers Program*, which is intended to help the Social Work Service at each VA medical center maintain an accurate and easily accessible list of non-VA services and service providers by type and geographic location of the provider; and
- *The Contract Nursing Home Budget and Census System*, which is intended to help social workers maintain information about VA patients in non-VA nursing homes under contract with the VA (236,856).

Problems in Linking Individual Veterans to Non-VA Services

According to several sources, one of the most difficult problems encountered by the VA in linking individual veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level—the same problem encountered by anyone who tries to locate and arrange services in many communities (481,854,860). Although some VA medical centers are using the Community Resources Managers Program software or other systematic procedures to develop and maintain an accurate list of non-VA services, obtaining the necessary information to keep the list up-to-date can be time-consuming and difficult, just as it is time-consuming and difficult for non-VA information and referral agencies, case managers, and others.

The complexity and fragmentation of non-VA services at the community level exists irrespective of the mechanisms by which the VA links individual veterans to non-VA services, but two other problems in linking individual veterans to non-VA services are related to those mechanisms. One problem is that the VA mechanisms for linking individual veterans to non-VA services are available primarily, although not exclusively, to veterans who are already receiving or are eligible to receive VA services. Many veterans with dementia are unlikely to receive or to be eligible for VA services and therefore may not

receive help from VA social workers in finding non-VA services.

A second problem is that the mechanisms by which the VA links individual veterans to non-VA services are more easily implemented for veterans who live near a VA medical center, but some VA medical centers have a very large catchment area, and many veterans in their catchment areas live far from the center. In general, it is probably more difficult for the Social Work Service at a VA Medical Center to maintain an accurate list of non-VA services for geographic areas that are far from the VA medical center than for areas near the center. Likewise, it is more difficult for VA social workers to provide case management for veterans who live far from the medical center. As a result, these veterans may not receive adequate assistance from the VA in linking to non-VA services.

The Minneapolis VA Medical Center has developed a case management program that successfully addresses the latter problem (316). The case management program serves veterans in three areas that comprise 23 primarily rural counties in south central and southeastern Minnesota and 16 primarily rural counties in western Wisconsin. The program is intended to help frail elderly veterans obtain the VA and non-VA services they need to live independently and avoid premature institutionalization. The VA has assigned a VA social worker to each of the three designated areas to provide outreach, case management, caregiver support, and patient advocacy.

VA Mechanisms for Coordinating VA and Non-VA Services

In addition to hospital discharge planning and case management, the VA has at least two mechanisms by which it attempts to coordinate VA and non-VA services and thus indirectly facilitate veterans' access to non-VA services. One of these mechanisms is "sharing agreements" between VA medical centers and non-VA agencies in which the non-VA agencies provide services for veterans in exchange for information, technical assistance, consultation, and other services from the VA medical center. Although there were informal arrangements for sharing resources and expertise between VA

medical centers and non-VA agencies before 1975, official support for formal "sharing agreements" began in 1975 with a working agreement between the VA and the Administration on Aging (820). One sharing agreement between a VA medical center and an AAA in West Virginia is described in box 6-D.¹¹

The second mechanism by which the VA attempts to coordinate VA and non-VA services is through the designation of "community services coordinators" who are intended to be the focal point for contact between the VA and non-VA agencies (859). Since 1985, the VA has required the Social Work Service at each VA medical center to identify a community services coordinator. The functions of the community services coordinator are as follows:

- to identify and assess existing non-VA health care, social, and volunteer services;
- to coordinate and integrate the VA's services and activities with the non-VA health and social services network, including AAAs;
- to make available the full range of non-VA services to aging veterans and their caregivers;
- to facilitate VA staff involvement in joint activities with AAAs and other community agencies, including program development, sharing services, and cooperative planning;
- to integrate and link non-VA resources into the VA's Medical District Initiated Program Planning (MEDIPP) process; and
- to facilitate joint development of health education and disease prevention programs (859).

In addition to the community services coordinator at each VA medical center, there is a community services coordinator at the VA Medical District level who is responsible for developing new programs, drawing up cooperative agreements between the VA and community providers, and integrating the concerns of the community services coordinator at each medical center into the District's planning process.

Some VA medical centers are part of a consortium of agencies that is unique to a specific locality. One example is the VA medical center in Tulsa, Oklahoma, that is part of the Long-Term Care Management Authority of Tulsa described in chapters 1 and 7. Another example is the VA medical centers in the Chicago area that are part of the VA/AAA Council, described in box 6-E. Like sharing agreements and

¹¹The sharing agreement described in box 6-D does not require the VA to provide direct services for nonveterans, but the VA is permitted to provide direct services for nonveterans in the context of a formal sharing agreement.

Box 6-D-The "Sharing Agreement" Between a VA Medical Center and an Area Agency on Aging in West Virginia

The Louis A. Johnson VA Medical Center in Clarksburg, West Virginia, has a formal (signed by both parties) sharing agreement with the area agency on aging (AAA) in nearby Fairmont, West Virginia. The agreement delineates the service coordination and case management functions the AAA is obligated to provide for veterans discharged to the community from the VA hospital and the training the VA is obligated to provide for AAA staff members and other non-VA service providers.

When a veteran is discharged to the community from the VA hospital, the Social Work Service at the VA medical center notifies the AAA. The AAA provides an assessment and, based on the results of the assessment, links the veteran to non-VA services he or she needs, such as home-delivered meals and homemaker and chore services. Since the VA medical center does not have a hospital-based home care program, the AAA also arranges for home health services, if they are needed. In return for the case management provided by the AAA, the VA furnishes training on specific topics to AAA staff and the staff of other non-VA agencies.

Through the sharing agreement, veterans who are discharged from the VA hospital are assured of receiving help in obtaining the non-VA services they need to remain at home. The AAA director believes that the formality of the sharing agreement has been important to the program's success over the years and advocates this type of agreement for all VA medical centers.

SOURCE: J. Hunter, director, Area Agency on Aging, Fairmont, West Virginia, testimony to the Joint Hearing of the Subcommittee on Hospitals and Health Care of the Committee on Veterans' Affairs and the Select Committee on Aging, House of Representatives, U.S. Congress, Washington, DC, Apr. 23, 1985; T. Moody, chief, Social Work Service, Louis A. Johnson VA Medical Center, Clarksburg West Virginia, personal communications, Oct. 5, 1988 and July 13, 1989.

the functions of the community services coordinators, the involvement of VA medical centers in local consortiums with non-VA agencies results in greater interaction between the staff of the VA medical centers and of the non-VA agencies and thereby facilitates veterans' access to non-VA services.

**Problems in Coordinating
VA and Non-VA Services**

According to VA officials, the major problem with the community services coordinator program is understaffing. Typically, one social worker is designated to this position in a half-time capacity and must function as the community services coordinator in addition to his or her other responsibilities (620). The primary problem with formal sharing agreements is that although the formal agreements are usually effective in coordinating VA and non-VA services, very few VA medical centers have established them. According to one VA official, the typical VA medical center has, at best, a verbal agreement with the local AAA (620).

At a 1985 joint hearing of the House Select Committee on Aging and the Veterans' Affairs Subcommittee on Hospitals and Health Care, VA officials testified that virtually all VA medical centers have established contact with AAAs, and that such contact has greatly increased the number of appropriate referrals from the VA to community

agencies, and vice versa (820). A witness representing the leadership council of aging organizations testified, however, that, despite some unique local arrangements between VA medical centers and AAAs, the connections between VA medical centers and non-VA agencies in their catchment areas are generally fragmented (343).

Summary and Implications

VA hospital discharge planning and case management help link veterans to non-VA services. VA community services coordinators and formal sharing agreements and other arrangements between VA medical centers and non-VA agencies help to coordinate VA and non-VA agencies and thereby indirectly facilitate veterans' access to non-VA services. A major problem in linking veterans to non-VA services is the complexity and fragmentation of non-VA services at the community level. As discussed throughout this OTA report, a national system to link people with dementia to services would help families and others find the services they need to care for a person with dementia. One option discussed in chapter 1 is that if such a national linking system were established, VA hospital discharge planners and case managers could refer veterans with dementia to that system for assistance in locating and arranging non-VA services.

Box 6-E—The VA/AAA Council of the Chicago Area VA Medical Centers and Three AAAs

Since 1985, the VA medical centers in the Chicago metropolitan area and three area agencies on aging (AAAs) have been working together to “provide comprehensive and coordinated social and health services to a rapidly expanding population of older veterans. Together they formed the Metropolitan Chicago Veterans Administration/ Area Agency on Aging Collaboration Council-known as the VA/AAA Council.

The purposes of the VA/AAA Council are: 1) to identify areas for potential collaboration; 2) to act as an information clearinghouse and a “best practice” forum for coordinated programs and services for older veterans; 3) to facilitate joint program development, coordination, evaluation, and service delivery to older veterans; 4) to review proposed projects and make recommendations for their implementation; and 5) to help obtain funding for joint activities.

Each year the VA/AAA Council establishes priorities. This is done by sharing the agencies’ specific needs and priorities for their own target populations and then identifying common areas of concern. One of the projects of the VA/AAA Council is an adult day health care program called the Alzheimer’s Family Care Center. The Alzheimer’s Family Care Center, which opened in 1987, is the result of collaboration between two VA/AAA Council members-the VA West Side Medical Center and the Chicago Department on Aging and Disability-and two nonmembers-Rush-Presbyterian-St. Luke’s Medical Center and the Chicago Chapter of the Alzheimer’s Association. The center serves both veterans and nonveterans, but veterans have priority for 40 percent of the enrollment slots.

SOURCE: “Working Together---Metro Chicago’s VA and AAA--To Assist Chicago’s Elderly Veterans,” *Aging Network News*, May 1989, vol. 6, No. 1, pp. 3-4.

Currently, VA hospital discharge planning and case management are provided primarily for veterans who are already receiving or are eligible for VA services. As a result, some veterans who are not already receiving or eligible for VA services may not receive from the VA the help they need to find non-VA services. If a national linking system were established, that system might be given primary responsibility for helping veterans who are not already receiving or eligible for VA services to find the non-VA services they need, while the VA retained primary responsibility for helping veterans who are receiving or are eligible for VA services to find non-VA services. The other type of veterans who may not receive the help they need from the VA to find non-VA services is veterans who live far from a VA medical center. It is possible that the national linking system should also be given primary responsibility for linking those veterans to non-VA services. If, in contrast, the VA were to have primary responsibility for linking all veterans to non-VA services, it would need more staff and more resources than it now has for that purpose.

CONCLUSION

By the year 2000, there will be 9 million veterans over age 65, including two-thirds of all males over age 65 in this country. As the number of elderly veterans increases, so will the number of veterans

with dementia. The VA estimates that there will be 600,000 veterans with dementia by the year 2000.

The VA operates the largest health care system in the United States and currently furnishes many of the kinds of services that maybe helpful for veterans with dementia. Those services include acute medical care, diagnosis, multidimensional client assessment, nursing home and domiciliary care, hospital-based home care, adult day health care, institutional respite care, and several other programs of particular relevance for veterans with dementia and their caregivers. These services are not available at all 172 VA medical centers, however, and not all veterans with dementia are eligible for them. Moreover, some services that may be needed for veterans with dementia are not provided at all by the VA, and many VA services are furnished only on a “space available” basis, so that even if a veteran is eligible for a service and the service he needs is provided by a VA medical center that is accessible to him, he may not receive the service because the program is full.

Unless the VA were to provide all the services that may be needed for all veterans with dementia (a possibility OTA considers very unlikely), veterans with dementia are likely to need both VA and non-VA services, and effective mechanisms must be in place to link them to both. Problems of several kinds interfere with the process by which veterans

are linked to VA services. The eligibility criteria for VA services are extremely complex. Veterans and their families do not understand the criteria and may assume the veteran is eligible for services when he or she is not, or vice versa. They also may not be aware of potentially beneficial services provided by the VA. Non-VA agencies and individual professionals and service providers who work with veterans with dementia often do not understand the VA's eligibility requirements and may not be knowledgeable about VA services. As a result, they may not be able to give veterans and their families accurate information about available services or eligibility for the services.

Other problems interfere with the process by which veterans are linked to non-VA services. Each VA medical center's Social Work Service has a community services coordinator whose job is to identify non-VA services in the community, and the VA has developed a software system to help the Social Work Service at each VA medical center maintain an up-to-date list of non-VA services. The community services coordinator position is staffed only half-time at many VA medical centers, however, and the complexity and fragmentation of non-VA services in many communities makes it difficult for anyone to maintain an accurate, comprehensive resource list.

Without effective methods for linking veterans with dementia to both VA and non-VA services, the veterans will not receive services they need, and

their families are likely to be frustrated and upset. The policy question discussed in chapter 1 is the appropriate division of responsibility between the VA and a non-VA linking system for connecting veterans with dementia to services. If a national linking system were established, it could have primary responsibility for linking veterans with dementia to non-VA services. Alternatively, the VA could have primary responsibility for linking veterans to non-VA services. The pros and cons of these two alternatives are discussed in chapter 1.

As discussed earlier, the complexity of the eligibility requirements for VA services, especially as they interact with the factor of space availability mean that only the VA can finally link veterans to VA services. This report does not consider the possibility that the national linking system could perform that function. On the other hand, the linking system would have to be somewhat knowledgeable about VA services and eligibility requirements in order to know when to refer veterans with dementia and their caregivers to the VA. Finally, it is clear that the VA services are important for veterans with dementia, and the VA must be involved in the planning and operation of a national system to link people with dementia to services regardless of the specific responsibility it assumes for linking veterans with dementia to non-VA services.