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Anciens Combattants Canada

DEMENTIA CARE EVALUATION

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Audit and Evaluation Division

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1.0 Executive Summary

The Evaluation was undertaken to determine if the needs of clients who are residing at home are being met. The evaluation also assessed community-based services for dementia care.

Dementia is a chronic clinical syndrome characterized by a progressive deterioration of mental and physical capabilities that affect a person's ability to function normally and independently. Dementia consists of symptoms such as loss of memory, judgement and reasoning, and changes in mood and behaviour. Simple tasks or activities of daily living, such as bathing, dressing, eating or toileting, and more complex activities such as preparing meals, managing medication, walking and attending to finances become progressively difficult for a person with dementia.

- 1 in 11 Canadians over age 65 have Alzheimer's disease or a related dementia.
- Women represent 62% of people affected by all forms of dementia.
- 4,818 Veterans are in receipt of dementia drugs through Program of Choice (POC) 10.
- The majority (85%) of Veterans in receipt of dementia drugs are still living at home.
- 9% of these Veterans have active case plans.
- $18.8 million was provided in Veterans Independence Program (VIP) contributions to these Veterans.
- The yearly VIP contributions were nearly twice as much as that of the average VIP recipient ($5,662 compared to $2,965) for 2007-2008.
- Treatment expenditures totalled 14.1 million dollars for the year 2007-2008.
- The yearly average amount paid for treatment to this clientele was 35% greater than that of the average treatment expenditures for all Veterans ($3,440 compared to $2,540).

Canada is experiencing a demographic shift which contributes to shortages, inconsistencies and waitlists in the health care and home care systems. Some examples include: a shortage of service providers, particularly those with a specialty in geriatrics and dementia; a variance in services available among provinces and within individual health authorities; and limited access to dementia specific services. There is no duty on VAC's part to identify all prospective clients for all prospective needs.

VAC does not maintain statistics on estimated or actual clients with dementia. There are no service standards for dementia care, nor have program objectives been developed. These issues constrained the evaluation.

In order for VAC to effectively assess that the needs of clients with dementia are being met, the Department would have to institute a method to identify all such clients and then put program objectives and performance measures in place. At this point in time, there is not enough evidence to support whether or not a dementia specific program should be established.

VAC's Veterans Independence Program (VIP) is well respected in the health care community as an example of a successful home care program. However, individuals interviewed by the evaluation team made several observations regarding potential improvements to certain areas of VAC programming and policies as they pertain to persons with dementia.

- There are regulatory and policy constraints on certain VIP elements that would be beneficial to persons with dementia. In particular, VAC's ambulatory care (i.e., day programs) should be reviewed to determine if the current rates are in line with community program pricing.

- VAC could consider expanding the role of its Occupational Therapists to include educating persons with dementia and their caregivers, completing cognitive assessments, and ensuring the person with dementia has meaningful, purposeful activities.

- In an effort to expedite clients obtaining additional services, VAC should review the benefits grids to determine if low dollar value, low risk elements could be added. Items, such as bed alarms, motion sensors and prompting devices are often necessary aids for persons with dementia but are currently not included in the benefit grids.

- It is important that persons with dementia be followed up on a regular basis as part of care planning. Currently, clients in receipt of VIP are followed up annually, usually via telephone, unless they are case managed. The evaluation found that only 9% of dementia clients are being case managed, which suggests that the majority of clients with dementia are not being followed up with on a frequent basis. Researchers and advocates provided a definition of case management which could be used as a benchmark for successful case management of persons with dementia living at home.

- Finally, district office staff expressed a desire for additional tools and guidance regarding persons with dementia. Client Service Agents (CSAs) are the first point of contact for all clients, so enhancing the tools CSAs use to follow up with clients would improve the chances of early detection of dementia and help ensure supports to be put in place.

VAC is in a good position to improve the quality of life for clients with dementia. VIP is a national home care program, and policy changes that occur are rolled out nationally. Overall, VAC's current VIP and Health Care programs cover most of the main elements for dementia care. The recommendations made in this report are predominantly related to policy and guidance. Further research is required to determine the need for and cost-effectiveness of dementia specific programming.

RECOMMENDATIONS:

In order for the Department to assess whether the needs of Veteran clients with dementia residing at home are being met by services available through VAC and the provinces, including community-based services:

R1 It is recommended that the Director General, Policy and Programs, develop a tool or method to identify and track clients with dementia. (Essential)[1]

R2 It is recommended that the Director General, Policy and Programs, review the rates for ambulatory care to determine if they are in line with community pricing for day programs. (Important)

R3 It is recommended that the Director General, Policy and Programs, assess the cost-effectiveness and impact of expanding the role of occupational therapists in terms of the level of services they provide to persons with dementia. (Important)

R4 It is recommended that the Director General, Policy and Programs, review the benefit grid to determine if low risk, low dollar value benefits for persons with dementia should be added. (Important)

R5 It is recommended that the Director General, Service Delivery Management in consultation with the Director General, Policy and Programs, consider developing a tool or strategy to ensure standardized and successful case management for persons with dementia living at home. (Essential)

R6 It is recommended that the Director General, Service Delivery Management in consultation with the Director General, Policy and Programs, consider developing a tool to assist Client Service Agents in identifying dementia. (Important)

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[1] See Appendix A for definitions of the Significance of Recommendations.

2.0 Evaluation Context

On May 22, 2008, the Audit and Evaluation Committee of VAC approved an evaluation of dementia care for clients living at home. The evaluation was undertaken to determine whether the needs of Veteran clients with dementia residing at home are being met by services available through VAC and the provinces, including community-based services. The Terms of Reference for this evaluation can be found in Appendix B.

3.0 Evaluation Methodology

The Evaluation Design is based on the collection and analysis of both qualitative and quantitative information gathered to help answer the issues identified in the evaluation framework. The evaluation study draws on findings from data analysis of program costs, program activity and demographic characteristics; in-person and telephone interviews with representatives from VAC, provincial representatives, researchers, service providers and Alzheimer's Societies; a review of case files, and a supporting review of documentation and research literature. A detailed list of primary and secondary data collection methods is presented in Appendix C.

3.1 Limitations of the Approach

During the review of the findings, some limitations of the methodology should be acknowledged. VAC does not maintain statistics on how many clients have dementia. Therefore, the evaluation team identified clients with dementia by identifying those clients who, in fiscal year 2008, were in receipt of one or more drugs commonly prescribed for dementia (i.e., Ebixa, Aricept, Reminyl and Exelon). There was a total of 4,818 clients in the sample.

This methodology has two important limitations:

1) The statistics presented on clients with dementia should not be understood to be a complete representation of all VAC clients with dementia. Not all Veterans are eligible for reimbursement for prescription drugs under VAC's Health Care Program.
2) Although these drugs are primarily prescribed for Alzheimer's disease, they are sometimes prescribed for other forms of dementia. It is important to note, however, that they can also be prescribed for memory loss that is not dementia related.

Due to resourcing and timing constraints, client interviews were not conducted. The evaluation addressed this limitation by relying on alternate data sources. Specifically, the evaluation relied on prior studies that interviewed caregivers in the general population and interviews with a variety of informants who had primary interactions with clients and their caregivers.

4.0 Introduction

Dementia is a chronic clinical syndrome characterized by a progressive deterioration of cognitive and intellectual capabilities that impact a person's ability to function normally and independently. Dementia is one of the most debilitating conditions affecting elderly people today and is the most common cause of institutionalization, morbidity and mortality[2]. Currently, the estimated number of people living with dementia in Canada is 500,000. Alzheimer's disease is the most common form of dementia, accounting for approximately two-thirds of all dementia. Vascular dementia is the second most common, accounting for 20%. Interestingly, women represent 62% of all dementia cases, 72% of all cases of Alzheimer's disease, and 47% of vascular dementia[3]. The Alzheimer Society of Canada's web site (www.alzheimer.ca) provides more information on the various types of dementia.

Dementia is classified into the following three stages[4]:

- Mild (early) dementia: Symptoms of mild dementia include impaired ability to comprehend or use language, impaired ability to perform previously learned motor activities, and impaired ability to identify objects. The ability to plan, organize and sequence is impaired. The person may also be irritable, hostile, and agitated. Persons with mild dementia do well in a routine, home environment.

- Moderate dementia: Moderate dementia impairs a person's ability to perform simple daily activities, such as bathing, dressing, and toileting. Persons with moderate dementia are unable to learn new information, are often confused, and may become lost in familiar surroundings. The person may become irritable, anxious, self-centred, inflexible, or anger more easily, or they may become more passive. They may become paranoid and believe people are stealing from them, or that their spouse is being unfaithful. Behavioural issues that may occur include wandering, physical aggression or sexual inappropriateness.

- Severe (late) dementia: In severe dementia, patients can no longer perform the most basic activities, such as eating or walking. They become totally dependent on others; all memories are completely lost; and reflex motor function, such as the ability to swallow, is lost. The eventual result is coma and death.

The prevalence of dementia in Canada is dependent on a person's age. Specifically, 26% of people over 84 years of age have dementia, while the percentage diminishes to

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[2] Beers, Mark H., and Robert Berkow, ed. The Merck Manual of Geriatrics. 3rd ed. USA : Merck & Co. Inc, 2000.

[3] Alzheimer's Society of Canada, 2009.

[4] Beers, Mark H., and Robert Berkow, ed.

about 7% for those aged 75 to 84 and 1% for people aged 60 to 74[5]. In the next ten years, as the baby boomers reach 65 years of age, the proportion of elderly people in Canada is predicted to exceed 16% of the population. With 60,150 new cases of dementia in Canada currently occurring each year, the number of people with dementia is predicted to more than double over the next generation, reaching between 1.0 and 1.3 million Canadians[6]. Due to this increase the need for care and treatment for dementia will reach levels never observed before. Annual costs are estimated to be more than US $83 billion in North America and US $314 billion world-wide[7].

There is no cure for dementia; however, the decline in function can be delayed in persons with mild to moderate dementia by remaining active and being in a familiar, supportive environment[8]. Persons with dementia are strongly affected by their environment and, for the most part, fair better in a familiar home setting rather than institutional care. There are some situations where a person with dementia would fair better in a monitored institutional setting, such as when the individual is living at home alone, is not able to care for himself and has no caregiving assistance. If the person with dementia is content and safe in the home, it is important to ensure they stay at home for as long as safely possible to ensure a good quality of life. Studies conducted in this area agree that it is equally important that individuals with dementia complete activities that provide meaning and purpose and help to remain socially, mentally, and physically active.

Among all available treatments, drug interventions are recognized as the most effective in delaying, or slowing down, the impact on cognition and function. Early assessment and diagnosis are essential because drugs are more effective when taken earlier in the progression of dementia[9]. Early recognition of the disease also means the person with dementia is able to discuss advance care planning with their family/caregiver and put forth their wishes and opinions for their care plan. Other treatment options (though not researched and promoted as well as others[10]) include cognitive and physical training. These training activities can help prolong cognitive function and assist in avoiding falls.

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[5] Chertkow, Howard MD. “Diagnosis and treatment of dementia: Introduction”. CMAJ (2008). 178(3).

[6] Alzheimer Society of Canada, 2009.

[7] Wimo, Anders, et al. “An estimate of the total worldwide societal costs of dementia in 2005". Alzheimer’s & Dementia 3 (2007): Elsevier.

[8] Beers, Mark H., and Robert Berkow, ed.

[9] Alzheimer Society of Ontario. Home Care and Dementia Response Paper of the Alzheimer Society of Ontario to the Caplan Report: Realizing the Potential of Home Care. August 2005.

[10] Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia. 146 Approved Recommendations. July 2007.

Typically, intellectual and other cognitive functions decline over a period of 2 to 10 years, depending on the cause or nature of the dementia.[11]

In addition to appropriate drug interventions, medication management is an important service for persons with dementia, as there will most likely come a time when they will no longer be able to manage their medications on their own[12]. Improper monitoring of drugs can lead to forgotten medications, duplicate dosages, and severe interactions with other medications.

When caring for persons with dementia, there is no "one size fits all" approach; rather, the care should be based on the individual's needs and the needs of the caregiver. This idea is closely linked with the idea of personhood. Personhood in dementia is an approach that was first introduced in the late 1980's and is described as "a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements"[13].

Often, a person's identity is linked to their cognitive abilities and the concept of the person as a whole is dismissed. Quality of life, which is frequently discussed as a major component of dementia care and home care, can be measured not only by one's health and security, but also by their interactions with society and by how one is perceived within one's social context. Though dementia is a debilitating disorder, there remain opportunities to treat individuals with dementia as persons, with respect and dignity and as contributors to society[14].

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[11] Beers, Mark H., and Robert Berkow, ed.

[12] Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia.

[13] Bartlett, Ruth, and Deborah O'Connor. "From personhood to citizenship: Broadening the lens for dementia practice and research". Journal of Aging Studies (2007), Vol. 21 (107-118). www.scienedirect.com.

[14] Bartlett, Ruth and Deborah O'Connor.

5.0 Key Findings by Objective

5.1 Assessing Community-based Services for Persons with Dementia Living at Home

This section of the report will provide an overview of the services offered in various Canadian communities and discuss the related challenges and constraints.

In order to assess the community-based services, it was necessary to identify what services are available for persons with dementia. As a first step, the evaluation team conducted an internet search, reviewed documents and interviewed representatives from various provinces in order to inventory the services. Because services vary throughout the country, the evaluation team chose four locations to gain an understanding of the challenges faced. The locations chosen were Sydney, Nova Scotia; Toronto, Ontario; Saskatoon, Saskatchewan; and Vancouver, British Columbia. A detailed table of services offered in the sites visited can be found in Appendix D. The results of the interviews and document review were used to identify some of the gaps and challenges in providing services for persons with dementia living at home.

The main community-based services available in the community are delivered by provincial health authorities, not-for-profit organizations, voluntary organizations and for-profit companies. The services fall mainly into provincial home and community care, which may include nursing, personal care (such as help with bathing, dressing, and feeding), physiotherapy, occupational therapy, speech therapy, social work, dietitian services, homemaking, and respite services.[15] In addition, there are day programs, meals on wheels, and friendly visitors[16]. Additional community-based services not provided under provincial home and community care may include the following: companionship, transportation services, information hotlines, educational seminars, Safely Home®, Wandering Registry[17], counselling and support groups.

In larger metropolitan areas, such as Toronto and Vancouver, there are a multitude of services offered; however, in smaller communities, certain services may not be available (e.g. day programs, transportation). Persons with dementia living in rural areas are often at a disadvantage because there are fewer services offered, fewer

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[15] Respite care is most commonly defined as temporary care of a person which provides relief for their caregiver. Respite care can take many forms, including brief stays in institutions, a formal caregiver (e.g. a nurse) providing in home respite for daytime, overnight or 24 hours. Respite may be covered under provincial home care programs.

[16] Health Canada. http://www.hc-sc.gc.ca/hcs-sss/home-domicile/commun/index-eng.php

[17] The Safely Home® and the Wandering Registry assist police in finding a registered member who is lost. It is a nationwide program developed by the Alzheimer Society of Canada in partnership with the Royal Canadian Mounted Police. A member's vital information is stored confidentially on a police database and can be accessed by police anywhere in Canada. (www.alzheimer.ca)

medical specialists, longer distances to travel, and fewer care providers[18]. The variances among provincial ministries of health, regional health authorities and communities, can lead to differences in eligibility, funding and service offerings. Therefore, the availability of services and associated cost, are largely dependent on the community where the person resides.

In addition to geographical differences, there are other challenges in terms of dementia care for persons living at home, which are well recognized and documented. The following gaps were identified as a result of documents reviewed and interviews conducted:

- A shortage of health care professionals;
- The need for greater awareness of dementia, both in the health care system and the general public;
- The need for greater ability to respond to the specific needs of people with dementia;
- A shortage of support available to caregivers; and,
- The need for greater integration, collaboration, and communication between care providers and health authorities.

The following sections elaborate further on the gaps identified above.

Availability of Health Care Professionals

Canada is facing a shortage of health care professionals, including a shortage of geriatric specialists. The Canadian Medical Association estimates that about 5 million Canadians do not have access to a family physician and by 2018 an additional 4.5 million Canadians may be without a doctor[19]. In fact, a National Physician Survey[20] conducted in 2007 indicated that over 6% of physicians plan to retire from clinical practice within the next two years. The potential loss is over 4,000 physicians by 2010.[21] Over the past decade, the Canadian Medical Association has expressed

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[18] Interviewees and document reviews often agreed that although rural areas usually have less formal resources and services available, there is often a strong sense of community and individuals have close bonds with family, friends and neighbours.

[19] CMA letter to Mr. Rajotte, MP. Canadian Medical Association. February 23, 2008. http://www.cma.ca/multimedia/cma/content_images/Inside_cma/Submissions/2008/rajotte-en-08.pdf.

[20] The National Physician Survey is a major ongoing research project conducted by the College of Family Physicians of Canada, the Canadian Medical Association, and the Royal College of Physicians and Surgeons of Canada. The survey collects the opinions of all physicians, 2nd year medical residents and medical students from across the country and is the largest census survey of its kind.

[21] CMA letter to Mr. Rajotte, MP.

increasing concern that Canada is not producing enough health providers[22] to meet the demand, now and in the coming years[23].

According to a 2006 Canadian study[24], there are fewer students entering the field of geriatric medicine, further compounding the shortage of geriatricians. The study estimates that there were under 200 geriatricians working in Canada in 2006[25] compared with an anticipated need of between 512 to 607 geriatricians. The lack of interest in pursuing the study and practice of geriatrics was perhaps due to the following[26] [27]:

- Geriatric medicine is complex and challenging. The elderly often present with a multitude of chronic health issues, and therefore a knowledge of many disciplines is required.

- Long-term care and working with the elderly are not always areas that are attractive to individuals;

- Geriatrics is sometimes referred to as "the poor cousin" to more lucrative branches of medicine, like cardiology. Students graduating with high student loans may be drawn to more lucrative areas that will enable them to pay their debt off faster.

In respect of a shortage of health care professionals, nursing is one of the most affected areas, partly due to stress and burnout from heavy workloads. Many nurses are retiring or leaving their profession early due to these issues. There is also a low number of students enrolling in nursing programs[28]. The Canadian Nurses Association projects that by 2011, Canada will be in need of approximately 78,000 nurses[29].

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[22] The Canadian Medical Association notes that the need for health care professionals is not only felt by physicians, the shortage is commonly affecting other providers such as nurses, pharmacists, technicians, the institutional and health facilities community, etc.

[23] CMA letter to Mr. Rajotte, MP.

[24] Barclay, Laurie MD. "Shortage of Geriatricians May Hinder Healthcare for Elderly". Medscape Medical News. September 12, 2006. http://www.medscape.com/viewarticle/544464.

[25] Canadian Medical Association statistics for 2009 indicate that there are currently 219 geriatric medical specialists in Canada. http://www.cma.ca/index.cfm/ci_id/16959/la_id/1.htm.

[26] "Geriatric Doctors in Short Supply". CanWest News Service. November 6, 2007. http://www.canada.com/topics/news/national/story.html?id=406bd325-6421-40da-bf0e-8002964195d2&k=56738

[27] Barclay, Laurie MD.

[28] Carlson, Daryl-Lynn. "Critical Health Care Crisis". Financial Post. May 9, 2007. http://working.canada.com/resources/story.html?id=f47d8f1f-a0cd-4d2a-8ef0-e8d664cc07fd.

[29] "The Nursing Shortage - The Nursing Workforce". Canadian Nurses Association. 2002. http://www.cna-aiic.ca/CNA/issues/hhr/default_e.aspx.

The shortage of new health care recruits, combined with a large number of baby boomers retiring and an aging population are all predictors of a potential health care crisis. In the midst of all this, it is also important to keep in mind that rural areas are usually more affected than urban areas, as there are fewer specialists, resources and training available.

Dementia Awareness Among the General Public and In the Health Care System

There is a need for increased public awareness in order to improve knowledge of dementia, its warning signs as well as treatment and support options. Since dementia is complex, many individuals do not understand the condition, its progression, and how it affects a person and their families.

An Ipsos-Reid Poll conducted by the Alzheimer Society of Canada in 2002 indicated that though 87% of Canadians felt they were familiar with Alzheimer's, 81% felt that they would be looked upon or treated differently if people knew they were diagnosed with Alzheimer's disease[30]. Further, a public opinion poll conducted by the Alzheimer Society in 2006 also showed that Alzheimer's disease is the second most feared disease for Canadians as they age[31]. These figures, along with opinions expressed by interviewees and caregivers from the Murray Alzheimer Research and Education Program (MAREP) Ontario Caregiver Needs Project, suggest that there continues to be a stigma[32] towards dementia and that persons with dementia and their caregivers may not feel comfortable talking about the illness and its effect on their families. This could lead to a loss of friendships and support and isolation, adding further burden and challenges for the person with dementia and their caregiver[33]. It is important for everyone to be aware of dementia and its effects so that dementia can be diagnosed early and the stigma towards dementia can be reduced or eliminated.

Beyond a need for increased awareness among the public, it is the opinion of key informants, and supported by the results of the literature review, that training and education is needed for all individuals who provide care to persons with dementia. A specific skill set is required to care for someone with dementia and all levels of care providers should be aware of the core knowledge and skills to care for someone with dementia to help understand the stages of the disease, as well as the complexities of

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[30] Ipsos-Reid. Public Opinion Poll Summary. On behalf of Alzheimer Society of Canada. July 2002. http://www.alzheimer.ca/english/media/stigma03-release.htm.

[31] Leger Marketing. Brain Health Public Opinion Poll. On behalf of Alzheimer Society of Canada. October 2006. http://www.alzheimer.ca/english/media/headsup07-pollsummary.htm.

[32] Stigma and Alzheimer's Disease Media Kit. Alzheimer Society of Canada. 2003. http://www.alzheimer.ca/english/media/stigma03-release.htm.

[33] Torjman, Sherri and Makhoul, Anne. Caregivers and Dementia. The Caledonia Institute of Social Policy : Ottawa, June 2008.

dementia[34]. Persons with dementia require cueing to perform daily activities, supervision to ensure they are safe and an understanding of the person with dementia and their experiences.

Greater Capacity to Meet the Specific Needs of People with Dementia

Based on interviews and a document review, service providers, including home care workers, acute care workers, day program facilitators, and long-term care facilities, are not always equipped to manage or treat persons with moderate to severe dementia. These issues, combined with shortages of health care personnel and facilities facing high staff turnover, means some service providers (such as day program facilitators) may need to place additional restrictions on persons with dementia, especially if the person is prone to wandering, incontinence, and/or behavioural issues such as aggression.

Interviews with from health care professionals and a review of caregivers' opinions identified the following three areas where the Canadian home care system could better meet the needs of persons with dementia:

1. Home care services are task oriented or custodial in nature and are not geared to the individual. Home care workers have a tight schedule and a large clientele, and the time they have to spend with a client is often limited to the specific tasks they have to accomplish. This situation is very difficult for persons living at home with dementia who often require more time, attention and encouragement to perform routine activities than their counterparts. Though time consuming, it was felt by key informants, and supported in publications regarding dementia care, that building a relationship with a person with dementia and their caregiver is important and will ensure better and more specialized care. The Merck Manual of Geriatrics indicates that as part of a supportive environment it is also important to encourage and provide opportunities for physical and mental activity, and social interaction[35]. Unfortunately, the shortage of home care workers and limited funding in this area makes it difficult to overcome these challenges and provide the needed level of support.

2. Many interviewees identified the rotation in home care workers visiting clients' homes as being potentially problematic for persons with dementia. The change of home care workers can cause confusion and responsive behaviours such as frustration and aggression from the person with dementia. As indicated through interviewees and in previous reports, including the MAREP caregiver needs studies,

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[34] A Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia recommendation indicates that "All clinicians caring for patients with mild to moderate AD [Alzheimer's disease] have to acquire the core knowledge and skills required to manage this condition."

[35] Beers, Mark H., and Robert Berkow, ed.

inconsistency and continual turnover in home care workers can be overwhelming and unnerving for clients with dementia and their caregivers as consistency, routine, and familiarity in their environment are significant factors in successful dementia care. Therefore, caregivers can be reluctant to access home care services.

3. Finally, some interviewees indicated that in certain provinces home care workers are not able to accommodate the client's daily routine and schedule. Current home care schedules often do not provide for consistent visitation times. A stable daily routine is very important for persons with dementia; an unstable routine can trigger anxiety and confusion in the individual as they try to understand what is happening, sometimes leading to unfavourable behavioural responses (e.g. aggression). The potential effect of the change in environment on the person with dementia can also make the caregiver hesitant to use services.

In conclusion, the manner in which the home care system is working is not targeted for people with dementia. Not only is there a need for additional resources and dementia specific knowledge and expertise, but there is a need for consistency in the personnel providing home care services.

Supporting Informal Caregivers

The level of community-based care has increased over the last two decades due to a shift from institutional to community-based care. The opinions expressed by researchers and health care professionals indicate that the quality of life for a person at home (versus in an institution) is generally better as it provides a supportive and familiar environment. The effect of this trend has put additional pressure on informal caregivers because they are providing support for longer periods than in the past.

Informal caregivers offer their time and support with little or no remuneration, and often without recognition. The informal caregivers of people with dementia, who are for the most part family members[36], are considered the hidden backbone of the health and long-term care systems in Canada, contributing over $5 billion of unpaid care per year[37]. In some cases, informal caregivers give up their career and lose pensionable years in order to care for their loved one. Informal caregivers who took part in the MAREP study felt that a tax break, additional assistance in the home, or subsidizations would be beneficial and appreciated.

Many informal caregivers face health problems of their own, including depression and chronic illnesses. In MAREP's extensive literature review on caregiver needs,

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[36] The 1994 Canadian Study on Health and Aging indicated that 70% of all informal caregivers in Canada are women and 30% are employed.

[37] Alzheimer's Disease Fact Sheet. Alzheimer Society of Canada. 2009. http://www.alzheimer.ca/english/media/adfacts2009.htm.

numerous findings support the existence of significant implications on caregivers' psychological and physical health. They tend to have 50% more visits to physicians and take up to 86% more prescribed medications than their non-caregiving peers. In fact, depression is nearly twice as common in caregivers of a person with dementia than other caregivers. As well, the added stress of caregiving can interfere with proper nutrition and exercise, and lead to increased rates of smoking and alcohol consumption. Therefore, caregiving can have serious consequences on a person's physical health (e.g. cardiac and back problems, migraines, colitis, and elevated blood pressure)[38], as well as their mental health. The health status of an informal caregiver may lead to them becoming unable to provide care to their loved one, which could result in both the caregiver and the care receiver being admitted to acute care, or long- term care.

Though dementia is a condition that affects the entire family, there are often not enough supports in place for family members to help them cope with the devastation of the illness. For example, society tends not to recognize or support family members in their grief over the loss of the person with dementia when they are still alive. Although the person with dementia may have been lost long before they die, it is only when they actually pass away that it is socially acceptable to grieve openly and there are supports in the community to help in the process. This is known as "disenfranchised grief"[39].

Caring for someone with dementia can be very demanding. With more people wishing to remain at home, the need for informal caregivers will continue to grow; therefore, it is important that caregivers receive support to help alleviate stress and burn out. Support can come in many forms, such as support groups, counselling, in-home respite, day programs, home care support, etc. The support should be individualized depending on the caregiver's needs.

Respite might need to be defined better as the term is often misunderstood. Most often, people think respite means the person with dementia must leave the home, but this is not the case. Specialists in the area of dementia and respite indicate that respite should be an experience for the caregiver. In other words, respite should be defined as a chance for the caregiver to take care of themselves in the way they wish and should be based on their individual needs. Besides in-home relief and day programs, other respite options could include counselling for the caregiver, access to a 24-hour hotline, or advice from qualified professionals.

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[38] Dupuis, Sherry, Tim Epp and Bryan Smale. Caregivers of Persons With Dementia: Roles, Experiences, Supports and Coping: Stage 4 : A Literature Review. Ontario Dementia Caregiver Needs Project. Murray Alzheimer Research and Education Program : University of Waterloo, 2004.

[39] "Disenfranchised grief refers to losses that are not appreciated by others. In effect the individual has no perceived "right" to mourn. The loss is not openly acknowledged or socially sanctioned and publicly shared. " (Doka, Kenneth J. Chapter 10: Grief and Dementia. Disenfranchised grief: Recognizing hidden sorrow. Lexington, MA: Lexington Books. 1989. www.scribd.com/doc/3785950/Grief-and-Dementia. p.5)

Some studies show that there are clear benefits to the caregiver if respite services are used regularly over a period of time. Respite can allow caregivers to remain active and social in their own lives and help reduce stress and chronic illnesses that can result from an exhausting caregiving schedule. Relief time also represents an opportunity for the care receiver to connect with their community and to interact with other people experiencing the symptoms of dementia. However, there are varying opinions on the level of benefit of respite for caregivers. Some studies show that respite services are often used too late in the caregiving cycle (i.e., used as a stepping stone to long-term care) to be a long-term benefit. The common finding in most studies is that both formal and informal respite are under-utilized by caregivers[40].

Interviews and document reviews support the findings that some caregivers can be hesitant to use respite services for a variety of reasons, such as not wanting to upset the care receiver with the change in environment by sending them to a day program or by having a stranger come into the home. In some instances, the preparation work may actually make things harder for the caregiver instead of giving them some relief. Sometimes, it can also be emotionally draining for the caregiver to handle the repercussions of respite if it is not conducive to the needs of the person with dementia. In addition, the hours of provision may be inflexible to the caregiver/care receiver schedule.

Dementia research and views from caregivers on in-home and out-of-home respite vary; the likelihood of using respite appears to be linked to individual/cultural views, caregiver overload, benefits perceived for the caregiver/care receiver, and the availability/cost of services[41]. In terms of respite programs in long-term care institutions, there are generally long waitlists and few beds available for short-term stays. Interviewees and caregivers feedback in the MAREP studies agree that services often must be booked significantly ahead of time (months in some instances), leaving caregivers with the task of predicting when they may wish to attend a support group, do their banking, or attend an appointment.

Notwithstanding the apparent under-utilization of respite, caregivers indicated that there are areas where improvements could be made. The Ontario caregivers in the MAREP studies, identified the following improvements to respite: more hours of respite provided, more flexible respite options, access to 24-hour in-home respite, overnight respite, or weekend respite. Key informants echoed this sentiment. In addition, the survey of community services and interviews with health care personnel indicates that in areas where in-home respite is offered, it is often costly.

Integration, collaboration, and communication among stakeholders

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[40] Dupuis, Sherry, Tim Epp and Bryan Smale.

[41] Dupuis, Sherry, Tim Epp and Bryan Smale.

Caregivers often have difficulty manoeuvring the health care and community support systems. Sometimes, caregivers may not access services because of the difficulty and labour intensiveness of navigating the system and finding suitable resources in their area. A large portion of interviewees felt that although there are various organizations to assist in navigating and providing services, it can be difficult for individuals to know where to go for help.

Both caregivers and service providers interviewed in the MAREP study indicated a need for greater collaboration and communication among service providers. Knowledge of community services can be difficult because of program/staff turnover. Programs can change because of lack of funding, change in political agendas, change in board of directors, change in staff, etc. Caregivers and service providers in the MAREP studies identified a need for a common referral process and “one-stop shopping”.

First Link ® is a partnership program with health care professionals and Alzheimer Societies that has been launched in various regions across Canada. The program helps ensure that individuals diagnosed with dementia receive support and information early in their diagnosis. First Link partners include family physicians, geriatric specialists, pharmacists, social service workers in health facilities and community agencies, and staff working in family practices. Essentially, a First Link partner asks the person’s permission to forward his/her name to the Alzheimer Society, after which, the Alzheimer Society will follow up with the individual and their family to provide information and support[42]. The Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia recommended that primary care physicians refer patients to the Alzheimer Society and in particular, the First Link, where available.

In response to some of the issues identified in this section, individual provinces have acknowledged the need for an organized approach to address issues surrounding dementia care through the development of dementia strategies and frameworks. The provinces are working towards greater integration through the development of dementia networks and web sites listing services in the community. The following section will explore VAC’s role in dementia care.

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[42] Alzheimer Society of Canada. http://www.alzheimer.ca/english/society/FirstLink.htm

5.2 Assessing VAC's Services and Benefits for Persons with Dementia

5.2.1 Demographics on VAC Clients with Dementia

For the purpose of this analysis, and because of methodology limitations, the profile of Veterans with dementia is based only on those clients who were taking at least one of the drugs usually prescribed for treating dementia, i.e., Aricept, Reminyl, Exelon and/or Ebixa, from April 1, 2007 to March 31, 2008. The methodology limits the ability to evaluate the actual size of the client population with dementia and the reader will have to be cognizant of this when reviewing the statistics. The numbers presented are likely an under-representation of the actual number of clients living at home with dementia.

The sample population consisted of 4,818 clients who were in receipt of dementia drugs under VAC Health Care Program's Pharmacy Program of Choice (POC 10). The sample represents, 4% of all 134,838 War Services (WS) and Canadian Forces (CF) Veterans clients, and 6% of all people receiving prescription drugs though POC 10 (80,348 POC 10 recipients). The *1994 Canadian Study on Health and Aging* indicated that approximately 50% of persons with dementia are living at home. Of the 4,818 clients in the sample, 85% lived at home and 15% were living in Long-term Care (LTC) institutions. Since the drugs are commonly prescribed for early to moderate dementia, it is not surprising that most clients in receipt of these drugs are living at home.

The majority of clients in the sample were male (88%) and between 80 and 89 years old (81%), with an average age of 86 years. In the sample, the majority of Veterans reside in Ontario (44%), British Columbia (20%), Quebec (9%) and Nova Scotia (7%). These proportions are similar to the provincial distribution of all Veteran clients where the majority reside in Ontario (35%), British Columbia (19%), and Quebec (11%).

Of the Veterans in the sample, 81% were in receipt of VIP. The VIP contribution to Veterans in the sample for 2007-2008 totalled $18.8 million or 6% of the total VIP contributions ($303 million) for the year. Contributions were proportionally higher in Ontario (7%), Nova Scotia (8%) and Prince Edward Island (9%) than the national average (6%).

The yearly VIP contributions to Veterans in the sample were almost two times greater than that of the average VIP recipient, indicating that this group of clients requires more VIP services than their counterparts. Clients in the sample used on average 10% more VIP services than the average VIP client (1.91 elements compared to 1.73). Across Canada, the amounts paid per client in VIP contributions for housekeeping, personal care, nursing home care and ambulatory care services to clients in the sample were on average 29% to 40% higher than the amount paid for the same services for all VIP clients.

At the provincial level, Veterans in the sample obtained on average between 1.4 and 3.3 times more in VIP contributions than their average provincial counterparts. In fact, Veterans in the sample in the Atlantic provinces, Quebec, Ontario, British Columbia and the Prairies received respectively 2.5, 1.9, 1.8, 1.6 and 1.5 times more money in VAC VIP contributions on average than in other provinces.

VAC's treatment expenditures to Veterans in the sample totalled $14.1 million, or 5% of VAC's total treatment expenditures for the year 2007-2008. The treatment expenditures incurred by Veterans in the sample for medical supplies (9%), prescription drugs (7%), and aids for daily living (6%) were greater than the national average (5%) for all Veterans.

The average yearly amount paid for treatment to Veterans in the sample was 35% greater than the average treatment expenditures for all Veterans. This difference can partially be explained by the fact that VAC's treatment expenditures for prescription drugs (POC 10) to Veterans living at home with dementia were on average 56% greater than that of all Veterans receiving POC 10 benefits.

Among the different category of treatments received by Veterans in the sample, the majority of VAC's expenses were for prescription drugs - POC 10 - (65%), special equipment - POC 13 - (10%) and audio services - POC 3 - (8%). These three programs of choice accounted for 81% of the total treatment expenditures reimbursed by VAC to Veterans in the sample for 2007-2008.

In summary, clients in receipt of dementia drugs represented about 6% of all people receiving prescription drugs through POC 10. Of the clients receiving dementia drugs, 85% were living at home. The yearly VIP contributions to Veterans with dementia living at home was almost two times greater than that of the average VIP recipient, indicating that this group of clients require more VIP services than their counterparts. The average yearly amount paid for treatment to Veterans in the sample was 35% greater than the average treatment expenditures for all Veterans. The major cost drivers were in the area of nursing, home care and housekeeping.

Detailed tables concerning VIP and treatment expenditures can be found in Appendix E.

5.2.2 Overview of VAC Services and Benefits

VAC offers a range of services and benefits which are designed to meet the changing needs of qualified Veterans. The following programs and services outlined are available to qualified clients who are living at home[43]:

Disability Pension Program

VAC clients with a medical disability that is related to their service may be eligible for a disability pension pursuant to the *Pension Act*. A disability pension is a monthly amount given to a qualified individual, and is calculated based on the following:

- relation of the disability to service; and
- the assessment of the extent of the disability.

In addition to the disability pension, a client may be entitled to other awards under the *Pension Act*, including attendance allowance, clothing allowance, exceptional incapacity allowance and prisoner of war compensation. The attendance allowance is payable to a disability pensioner who is totally disabled and in need of assistance with daily living tasks.

The disability pension is a gateway to other programs VAC offers, such as the Health Care Program, VIP, and Long-Term Care Program.

Veterans Health Care Regulations

Pursuant to the *Veterans Health Care Regulations*, VAC delivers services benefits and care under three distinct programs:

1. Part I - Health Care Benefits

VAC offers 14 kinds of health benefits, also known as Programs of Choice (POCs). The POC include, among others, medical, surgical and dental care, prescription drugs, aids for daily living, and hearing and vision aids. The description of the POCs can be found on VAC's Web site (www.vac-acc.gc.ca).

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[43] In 2005, the Government of Canada passed The *Canadian Forces Members and Veterans Re-establishment* and *Compensation Act*, often referred to as the New Veterans Charter. The New Veterans Charter consists of a suite of programs available to Canadian Forces Veterans, which include lump sum payments (disability award) and allowances, job placement services, group health insurance, rehabilitation services, and financial assistance. The focus of this evaluation was on the clients who did not fall under these programs and services.

There are two types of eligibility under each POC:

1) *A Line benefits*, refers to the benefits available to clients because the need for the benefit is directly related to the client's pensioned condition; and

2) *B Line Benefits*, refers generally to the benefits available to clients, other than disability pensioners, to the extent that the benefits are not available to them as insured services under a provincial health care system. The eligibility is often linked to the client meeting a means test or their having qualified for the Part II - VIP.

The Department also offers supplementary health benefits, treatment allowances and other miscellaneous benefits. The ability to access VAC health benefits may depend on the client's eligibility, health needs and whether these services are available through their home province.

2. Part II - Veterans Independence Program (VIP)

VIP is a national home care program which provides services to eligible clients following an assessment that the provision of those services would assist them to remain self-sufficient at their principal residence.

Under VIP, VAC clients may receive financial assistance to help pay for grounds maintenance, housekeeping, personal care, certain home adaptations, care and support by health professionals, and social transportation. VIP is not meant to replace existing provincial and community-based services, but instead to offer a "top up" to those services.

The ability to access VIP services depends on an individual's health needs and the availability of services through another federal, provincial or municipal program. There are eligibility requirements as well as frequency and dollar limits associated with each of the elements under VIP. Detailed information on the VIP elements can be found on VAC's Web site (www.vac-acc.gc.ca).

Where it is not reasonably practicable for the VIP services to be provided at the client's principal residence, the client is eligible for intermediate care in a community facility, to the extent that the care is not available to them as an insured service under a provincial health care system.

(3) Part III - Long-Term Care Program

Eligible clients may qualify for intermediate care or chronic care at the Department's contract facilities, or at more than 1,900 community facilities across the country.

VAC's Policy on Respite

VAC defines respite care as "benefits, services or care provided to an eligible client for the purpose of giving relief to an informal caregiver who is the primary caregiver". At VAC, respite care is not distinguished in terms of the tasks that are performed but instead by the purpose for which the tasks are performed.

VIP offers various opportunities to provide respite to an informal caregiver by offering services to eligible clients at home. For example:

a) housekeeping or grounds maintenance services can help reduce the total burden on the caregiver;
b) personal care provided by a substitute caregiver on a regular basis can allow the informal caregiver to leave the home for a period of time (a few hours, a day at a time, or possibly overnight);
c) day care for clients can be provided under Ambulatory Health Care Service to assist in reducing caregiver burden (particularly in instances where the client has dementia); or
d) temporary institutional care can be provided under Intermediate Care Service to allow the informal caregiver to have a period of time off. Perhaps for a vacation, visiting family, or to receive any required health care for themselves.

In addition, health care benefits may be provided to a client to offer respite to caregivers on a limited basis. This includes the provision of certain special equipment or limited nursing services[44]. Respite care, in the form of long-term care in a departmental facility or contract bed, and chronic care in a community facility can also be provided. The length of respite care would vary according to client's needs, the caregiver's needs and the availability of a respite bed.

5.2.3 Observations and Recommendations

This section of the report will present findings obtained during the team's fieldwork regarding VAC services and benefits for Veterans with dementia living at home, and will make recommendations pertaining to any associated issues and potential areas for improvement.

Relevance - Identifying Clients with Dementia

An extensive study on caregivers perceptions and attitudes conducted by MAREP identified the following six core services that should be included in each province in Canada under home care:

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[44] VPPM, Volume Two - Health Care Programs, Chapter 1.1.7, Subsection 3.15

1. education and information about dementia;
2. respite care (adjusted to the family's need i.e., in-home, day program, etc.);
3. meal programs (nutrition);
4. transportation services (eliminate isolation and provide ease to reach; programs and services);
5. in-home support services (e.g. housekeeping); and
6. in-home personal care services (e.g. bathing, nursing, etc.).

VAC's VIP program includes most of these areas. VAC's Health Care Program complements the VIP home care services through its treatment benefits. In addition, respite in a long term care institution can be provided through the Long-Term Care program or under VIP. It would appear that VAC services are such that they could meet the needs of Veterans with dementia living at home.

If VAC wishes to ensure that clients with dementia living at home are benefiting from all the services available, then program objectives and performance measures should be established. The first step in this process would be to have a method to identify clients with dementia. For illustrative purposes, performance indicators could include the following:

- turnaround times for follow up with persons with dementia;
- services in place for persons with dementia (in particular, medication management, safely home registry, access to nutrition, social transportation, day programs, respite, etc.);
- enrollment in/satisfaction with day programs;
- use of/satisfaction with respite;
- number of acute care visits by client and/or caregiver;
- coping abilities of caregiver;
- number of referrals to/from the Alzheimer Society; and
- quality of life indicators.

VAC does not presently have the ability to track and identify all clients that may be living with dementia. To be able to do so, would assist the Department in assessing whether the needs of clients with dementia who are residing at home are being met through services available through VAC, and the provinces including community-based services. Presently, there is not enough evidence to support whether or not a dementia specific program be established.

R1 It is recommended that the Director General, Policy and Programs, develop a tool or method to identify and track clients with dementia. (Essential)

<u>Management Response:</u>

Management recognizes that dementia is prevalent in the predominantly aged male Veteran population (indications are that as many as 60-80 percent of Canadians aged

85 and over have some form of cognitive impairment) and can be an indicator of the need for interventions and supports, as are any number of medical conditions.

The existing client screening tool screens for increased risk, as identified by any change in circumstances or the health of the individual client that could be a predictor of needed interventions on his or her behalf.

The implementation of the Case Management Review includes a review of screening tools to help identify clients in need of case management. Within this context, the needs of elderly clients with dementia as well as their caregivers will be given careful attention.

Management Action Plan:

Corrective Actions to be taken	**OPI (Office of Primary Interest)**	**Target Date**
The Director General, Policy and Programs Division will strike a working group with Service Delivery and Commemoration to review general screening and assessment and other tools with Departmental physicians, as well as experts in the psychogeriatric community through the Gerontological Advisory Council, to ensure that the Department has in place a holistic approach to responding to those clients with dementia, as well as their caregivers.	DG, Policy and Programs Division	October 30, 2009

Improvements to Ambulatory Health Care Services

The right day program can be beneficial for a person with dementia and can help the person remain active, feel productive, and have social interactions. Day programs can also be beneficial for the caregiver because it offers them respite from their caregiving responsibilities. It has been shown that day programs can delay institutionalization, reduce family stress and improve caregiver's psychological well-being[45]. VAC will reimburse eligible clients the costs of day programs under the Ambulatory Health Care Service of the Veterans Independence Program. Also included in Ambulatory Health Care Service are health assessments, diagnostic services and transportation of the client to receive the service.

District office (DO) staff felt that consideration should be given as to whether the current prescribed rates for day care programs allow sufficient access for clients living at home

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[45] Dupuis, Sherry, Tim Epp and Bryan Smale.

with dementia. The current maximum rate for ambulatory care is $1,033.16 per client per calendar year. Current costs for adult day programs vary across the country and within municipalities, but average from $25 to $40 per day (transportation to and from the day program may also be required in excess of the fee). If the client were to access day programs alone, and not any of the other services under Ambulatory Care, the maximum rate would allow for the client to attend day programs between 25 to 40 days per year. Attending day programs on a frequent basis ensures that the person with dementia acclimatizes to the new environment which will help lessen anxiety, while promoting social interaction and mental stimulation. District offices are able to increase the amount for ambulatory care on an exceptional basis, which requires various approval levels, including Head Office approval.

R2 It is recommended that the Director General, Policy and Programs, review the rates for ambulatory care to determine if they are in line with community pricing for day programs. (Important)

Management Response:

The rates for ambulatory care are set out in the *Veterans Health Care Regulations* and can accommodate the needs of the majority of clients, most of the time.

In cases where individual needs exceed that which can be provided within the set rates, the Department has the authority to exceed the rates: where it is necessary to provide an appropriate standard of service or care; or for humanitarian reasons - for example , in cases where there would be an unacceptable impact on the client’s health.

To ensure that the rates are comparable to other jurisdictions, the Director General, Policy and Programs agrees to conduct a comparative review of the rates for ambulatory care, as compared to community pricing.

Management Action Plan:

Corrective Actions to be taken	**OPI (Office of Primary Interest)**	**Target Date**
Review VIP rates for ambulatory care, as compared to rates in the various provincial jurisdictions, to ensure that these rates are congruent with provincial rates, and reasonable given the intention and scope of the program.	DG, Policy and Programs Division	October 30, 2009
Propose any required rate adjustments.	Director, Continuing Care Programs	November 30, 2009

Role of Occupational Therapists

VAC's interdisciplinary team consists of medical doctors, nurses, social workers and occupational therapists. Currently, VAC's occupational therapists are contract employees working part-time. They are contracted to complete assessments and make recommendations for equipment, home adaptations, aids for daily living, etc. It was felt by DO staff interviewed that the role of occupational therapists could be expanded as they have additional areas of expertise. This could include completing cognitive assessments, working with clients and caregivers to develop coping strategies, focussing on safety, encouraging the completion of meaningful activities, and educating clients and their caregivers. Although more studies may be required, several studies conducted on the subject have found that occupational therapy can assist in providing a better quality of life for persons with dementia by helping to improve activities of daily living, including social interaction, and helping to reduce the strain on caregivers [46].

According to the Canadian Association of Occupational Therapists, the primary goal of occupational therapists is to enable people to participate in the occupations which give value to their lives[47]. Meaningful, purposeful work is important because it provides persons with dementia opportunities to live with dignity and to feel they are contributing to society. Occupational therapy is included in provincial and regional home and continuing care and is sometimes used in helping individuals with mental/emotional challenges. Occupational therapists can help individuals lead an independent, purposeful and satisfying life by developing an individualized plan that may consist of assistance in retraining of everyday skills or learning new skills, improving safety in the home through home adaptations, encouraging social interaction and providing guidance/education to family and caregivers. Health Canada[48] and the World Health Organization[49] also outline the importance of occupational therapy in care for elderly with psychiatric/psychological needs.

The interdisciplinary team is widely used in health care, especially when caring for the elderly who have complex needs (medical, psychological, and social). Enlarging the role of occupational therapist on VAC's Health Care Team would enable the team to maximize expertise and have a broader spectrum of knowledge and skills. However, since VAC occupational therapists are on contract, it may not be cost-effective to

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[46] Graff, Maud J L, et al. "Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial". BMJ 33 (2006) : 1196. www.bmj.com

[47] CAOT Position Statement: Occupational Therapy and Primary Health Care. Canadian Association of Occupational Therapists (2006).

[48] Health Canada. http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/recru/therapists-ergotherapeutes-eng.php

[49] World Health Organization Division of Mental Health and Substance Abuse. "Psychiatry of the Elderly: A Consensus Statement". Geneva, 1996. http://www.who.int/mental_health/media/en/17.pdf

expand their role; for example, if the cost of extending the contract exceeds the benefits provided.

R3 It is recommended that the Director General, Policy and Programs, assess the cost- effectiveness and impact of expanding the role of occupational therapists in terms of the level of services they provide to persons with dementia. (Important)

Management Response:

Currently, the Department does not employ occupational therapists (OTs) as salaried employees. Rather, all OTs providing services to VAC are engaged on a contract, or fee-for-service basis. As of April 2009, VAC has approximately 50 occupational therapists on contract.

As part of its work with health professionals, the Department is in the early stages of developing a work description for OTs with a view to determining whether or not VAC's work would be competitive in the marketplace, and allow for recruitment.

Exploration of the role of the OT within the Client Service Team would need to take into consideration the scope of practice of their professional association.

Management Action Plan:

Corrective Actions to be taken	OPI (Office of Primary Interest)	Target Date
Work is currently underway to develop a work description for OTs and to determine whether the Department may wish to recruit OTs as salaried health professional employees within the ambit of the interdisciplinary Client Service Team.	Director, Case Management and Program Performance	January 2010

Improvements to Benefit Grid

VAC maintains a list of benefits available in a benefit grid for each POC. Each grid includes information about specific treatment benefits, benefit prerequisites and benefit limits, including frequency and financial limits. DOs have the authority to authorize and approve benefits for certain POCs provided the benefit is listed in the grid. If the benefit is not listed in the grid, then the DO must decide if they want to provide the benefit on an exceptional basis. In order to have the benefit approved on an exceptional basis, the DO must write a statement as to why the benefit is required and submit it to Head Office for approval. Although there is no data to determine the frequency with which these requests are made, there could be less administrative work and faster service for persons with dementia if certain low-risk, low-dollar value items that can assist in everyday living, were added to the grid. These items could include motion sensors, bed alarms, door alarms, and automated prompting devices.

R4 It is recommended that the Director General, Policy and Programs, review the benefit grids to determine if low-risk, low-dollar value benefits for persons with dementia should be added. (Important)

Management Response:

A Benefit Grid Review Project is currently under way with the objective of updating the existing codes within the grids to address, amongst other things, benefits that were not currently listed, but should be. Working groups across relevant areas of VAC were established to conduct the review; these groups identified issues with more than 800 codes. Priority is being given to the issues identified by the VAC's Appeals unit, Exceptional Benefits Unit, and the Regions.

In June 2009, Audit and Evaluation released its report on the Audit of the Programs of Choice (POC), recommending, among other things, that VAC review the 14 POCs and associated benefit grids with the goal of streamlining and reducing the number of individual codes.

Consideration will be given to the addition of low-risk, low-dollar value benefits related to dementia, within the context of the broader Benefit Grid Review Project and in light of the Audit recommendations. It will be achieved within the context of existing processes.

Management Action Plan:

Corrective Actions to be taken	OPI (Office of Primary Interest)	Target Date
In concert with the Benefit Grid Review, Program and Operational Managers will consider addition of certain low-risk, low-value benefits to the revised grids depending upon priority and projected demand for such products, a determination will be made regarding the need for the addition of individual benefits within codes.	Director, Disability and Treatment Benefits	April 2010

Case Management

District office staff opinion varied on whether all persons with dementia should be case managed. Interestingly, most external researchers and advocates interviewed felt that all clients with dementia should be case managed. This could be due to varying definitions of "case management". District office staff generally felt that clients should be case managed when the severity of the illness has progressed and when the supports in place are no longer meeting their needs. This is consistent with the VAC Case Planning Practice Manual, which stipulates that persons with dementia do not need to be case managed if the services and benefits are meeting their needs.

It was widely agreed that frequent follow-up is required for persons with dementia. Currently, VAC follows up with clients in receipt of VIP on an annual basis and clients are counselled to contact the Department if they are in need of more assistance in the meantime. This presents problems for persons with dementia because they may not realize they are in need of help. In addition, caregivers may be hesitant to ask for help or do not think they need help. Clients who are case managed are followed up with every 90 days, but only 9% of the sampled dementia clients had an active case plan. Therefore, there are few dementia clients who are being contacted frequently and on an ongoing basis by the Department. For clients who are not case managed, individual area counsellors determine when to follow up with the client. One Health Care Team raised concerns that they felt there were many Veterans with dementia living at home who are not being contacted by the Department. Without an indicator to identify clients with dementia, the program managers and program deliverers will have difficulty determining which clients require follow-up, or the frequency with which they are following up with them.

Researchers and medical professionals were asked what successful case management of a person with dementia would look like. Their responses provide insight into what VAC could strive toward in terms of dementia care:

- Case management should begin with the diagnosis of dementia and would involve the physician making a referral to VAC. VAC may wish to partner with the Alzheimer Society through their First Link program.
- After diagnosis, an occupational therapist should go into the home and conduct an assessment for safety and evaluate the home.
- Case managers should be proactive, rather than reactive, and should have an appropriate case load[50].
- Case managers should follow up frequently with the caregiver and care receiver via telephone and should conduct a home visit every four months, depending on the severity of the illness.
- Families must also play a role and should be encouraged to advocate on behalf of the person with dementia and take an active role in case management.
- Case management should include the caregiver in all assessments and contacts with the client, while respecting the clients right to make their own decisions.
- Case managers should build a rapport with the caregiver, and this also means it should be the same case manager making contact.
- Case management should involve end of life care, based on the person with dementia's wishes (i.e., either at home or in an institution).

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[50] In one of the provinces visited, case managers specialized in dementia and had a case load of approximately 150 active clients. Depending on the complexity of the dementia, the case load could be reduced.

A number of area counsellors in the field indicated that they would appreciate some type of guideline or checklist which would help them determine what is expected in terms of care for persons with dementia. The points listed above could be used to create such a tool. There are several other materials which would also be useful, including the FAST-ACT©[51], which provides recommended action to assist persons with dementia and their families as the dementia progresses. Also of use is the Cognitive Impairment Protocol which was developed by the Regional Director, Client Services in the Ontario Regional Office.

With varying ideas and beliefs on case management, as well as a low number of dementia clients with active case plans, a number of clients with dementia are not being followed up with on a frequent basis. In order to give VAC staff guidance, and to help ensure a more consistent and standardized approach to case management, VAC should consider developing a tool or strategy based on the key areas of case management listed above.

R5 It is recommended that the Director General, Service Delivery Management in consultation with the Director General, Policy and Programs, consider developing a tool or strategy to ensure standardized and successful case management for persons with dementia living at home. (Essential)

Management Response:

Service Delivery Management (SDM) - Management agrees with this recommendation.

Policy and Programs (P&P) - Under the auspices of the Case Management Review, the Department's service delivery model is being enhanced through investment in business tools, staff training, clinical supervision and enhanced decision-making.

The enhanced Case Management Review implementation under way will focus on ensuring that staff are supported to provide the full spectrum of case management services to all vulnerable clients based on their individual needs.

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[51] The FAST-ACT © 1997 by D. Macdonald Connolly B.N.

<u>Management Action Plan</u>:

Corrective Actions to be taken	OPI (Office of Primary Interest)	Target Date
SDM In collaboration with PPP Branch, develop a strategic approach on how to meet the needs of these clients and caregivers to ensure that our extremely limited specialists are used effectively and efficiently.	DG, Service Delivery Management	
- Discussions with PPP.		June 30, 2009
- Strategy in place.		October 9, 2009
- Detailed Implementation Plan.		December 31, 2009
- Implement and educate district staff on their respective roles in case management for persons with dementia living at home.		March 2010
P&P Through the implementation of the Case Management Review, the Director General, Policy and Programs and the Director General, Service Delivery Management will work to ensure that all vulnerable clients, including those with dementia, will receive the full spectrum of Case Management services based on their individual needs.	Director General, Policy and Programs and the Director General, Service Delivery Management	November 30, 2009

Client Service Agent Screening

There was a desire among DO staff for additional tools to guide CSAs on the care and identification of persons with dementia; particularly when speaking with them on the phone. It was also felt that the CSA could play a greater role in client interactions. CSAs conduct annual reviews for low risk VIP clients, and can approve housekeeping, groundskeeping and social transportation within their delegated authority. Several CSAs interviewed felt it would be useful to have a set of questions to ask the client or specific behaviours to listen for in order to determine if the client was experiencing cognitive impairment. This would help VAC ensure that clients are assessed early and supports are put in place. One must recall that early intervention is very important for persons with dementia. VAC has cues for referral and a screening tool; however, enhancements could be made to include questions or prompts regarding change in mental state.

As the CSA is often the first point of contact for clients, it would be useful for them to have additional information to assist in identifying any changes in cognitive abilities as early as possible.

R6 It is recommended that the Director General, Service Delivery Management in consultation with the Policy and Programs, consider developing a tool to assist Client Service Agents in identifying dementia. (Important)

Management Response:

Service Delivery Management (SDM) - Management agrees with this recommendation.

Policy and Programs (P&P) - With the implementation of the Case Management Review, it would be timely to review the screening tool and other issues relating to our supports to elderly Veterans, to ensure that the Department has a comprehensive approach to supporting clients with dementia, as well as their caregivers.

The Director General, Policy and Programs Division will strike a small working group with Service Delivery and Commemoration to review general screening and assessment tools with Departmental physicians, as well as experts in the psychogeriatric community through the Gerontological Advisory Council, to ensure that the Department has in place a holistic approach to support staff in responding to those clients with dementia, as well as their caregivers.

Management Action Plan:

Corrective Actions to be taken	OPI (Office of Primary Interest)	Target Date
SDM Develop a tool to assist Client Service Agents in identifying dementia.	DG, Service Delivery Management	
- Discussions with PPP.		June 30, 2009
- Terms of Reference for Working Group/ name members.		August 31, 2009
- Draft tool.		December 31, 2009
- Implement tool.		March 2010

Corrective Actions to be taken	OPI (Office of Primary Interest)	Target Date
P&P Policy and Programs will set up a small working group with Service Delivery and Commemoration to review general screening, assessment tools with Departmental physicians, as well as experts in the psychogeriatric community through the Gerontological Advisory Council, to ensure that the Department has in place a holistic approach to support staff in responding to those clients with dementia, as well as their caregivers.	DG, Policy and Programs	October 30, 2009

6.0 Other Observations

Over the course of the evaluation, there were a number of issues that were brought to the attention of the evaluation team. Although there was not sufficient evidence to make recommendations, it was felt that the issues were identified with sufficient frequency to warrant observation. The observations are described in Appendix G.

7.0 Distribution

Deputy Minister

Chief of Staff to the Minister

Chair, Veterans Review and Appeal Board

Senior Assistant Deputy Minister, Policy, Programs and Partnerships

Assistant Deputy Minister, Service Delivery and Commemoration Branch

Assistant Deputy Minister, Corporate Services Branch

Executive Director and Chief, Pensions Advocate, BPA

Director General, Policy and Programs

Director General, Service Delivery Management

Deputy Coordinator, Access to Information and Privacy

Program Analyst, Treasury Board of Canada Secretariat (TBS)

Comptrollership Branch (TBS)

Appendix A Significance of Recommendations

To assist management in determining the impact of the observations, the following definitions are used to classify recommendations presented in this report.

Critical: Relates to one or more significant weaknesses/gaps. These weaknesses/gaps could impact on the achievement of goals at the Departmental level.

Essential: Relates to one or more significant weaknesses/gaps. These weaknesses/gaps could impact on the achievement of goals at the Branch/Program level.

Important: Relates to one or more significant weaknesses/gaps. These weaknesses/gaps could impact on the achievement of goals at the Sub-Program level.

Appendix B Terms of Reference

Dementia Care Evaluation **ISO Project No. 8900-158**

Background:
Demographic trends in Canada, coupled with the notable incidence of dementia, are having a significant impact on health care facilities.

The Department has invested in strategies that will lead to new and enhanced approaches to dementia care. VAC has been working with contract facilities to ensure that staff are adequately prepared, trained and supervised in the long-term care model for the care of dementia residents. However, there is a segment of the Veteran population with dementia who are not in contract and departmental long-term care facilities. This evaluation will focus on these at home Veterans.

Rationale:
VAC wants to ensure that at home dementia clients are receiving adequate care.

Proposed Statement of Work:
To evaluate the capacity of informal caregivers and community-based services to effectively treat and care for clients with dementia.

Objectives:

1. To assess if VAC is effectively meeting needs of at home Veterans with dementia (e.g., quality of life, quality of care).
2. To assess community-based services for dementia care patients and extent of achievement of dementia care objectives.

Cost: 10 person months (2 people x 5 months)

Target Date: Fiscal Year 2008-09 **AEC Decision**: April 2, 2007

Risk Analysis: Overall rating = 12, Medium priority

Likelihood	Impact
Complexity Rating: 2 / 3 * • Moderate number and types of stakeholders • Moderately complex and integrated issues	Damage & Liability Rating: 3 / 3 * • Dealing with client mental health and quality of life • Substantial number of clients involved
Audit & Performance Information Rating: 3/ 3 * • Not audited or evaluated within last 3 years • Ministerial complaint about service	Operational Effects Rating: 1/ 3 * • Client service disruption < 1 day
* Rating Scale 3 = High 2 = Medium 1 = Low	Reputational Loss Rating: 3 / 3 * • Significant loss of trust from Veteran's organizations • Potential for unfavourable media attention

Overall rating = 12, Medium priority (Score: 5-8 = Low 9-12 = Medium 13-15 = High)

Appendix C Detailed Primary and Secondary Data Collection

1.1 Primary Data Collection

A team of four evaluators from the Audit and Evaluation Division of VAC made site visits to Saskatoon, Vancouver, Toronto, and Mississauga to conduct in-person interviews with internal and external representatives. A team of two evaluators also made a site visit to Sydney. Prior to the site visits the team conducted numerous in-person interviews with VAC Head Office personnel. The sites were chosen based on socio-economic status, client population density and geographic disbursement.

1.1.1 Interviews: In-Person

Table 1 outlines the in-person interviews conducted and the topics discussed with the interviewees.

Table 1 In-Person Interview Matrix

#	Category	Issues Covered	Location and Number of Persons Interviewed
1	VAC staff	• Services available provincially • Adequacy of VAC services and benefit in meeting needs of persons with dementia living at home • Adequacy of case management • Guidelines and/or strategies for VAC clients with dementia • Identification of gaps	Charlottetown, PE Total interviewed: 13
			Sydney, NS Total interviewed: 5
			Saskatoon, SK Total interviewed: 6
			Vancouver, BC Total interviewed: 11
			Toronto, ON Total interviewed: 10
			Mississauga, ON Total interviewed: 9
	Sub-total		*54*
2	Provincial/Health Authority Home Care Representatives	• Services available provincially • Challenges in coordinating care for persons with dementia living at home • Collaboration among organizations • Adequacy of VAC services and benefits • Identification of gaps	Sydney, NS Total interviewed: 4
			Saskatoon, SK Total interviewed: 8
			Toronto, ON Total interviewed: 1
	Sub-total		*13*
3	Alzheimer Society Representatives	• Services available provincially • Challenges in coordinating care for persons with dementia living at home • Collaboration among organizations • Adequacy of VAC services and benefits • Identification of gaps	Sydney, NS Total interviewed: 1
			Toronto, ON Total interviewed: 2

#	Category	Issues Covered	Location and Number of Persons Interviewed
	Sub-total		*3*
4	Geriatric/Dementia / Caregiver Specialists	- Services available provincially - Challenges in coordinating care for persons with dementia living at home - Collaboration among organizations - Adequacy of VAC services and benefits - Identification of gaps	Charlottetown, PE Total interviewed: 1
			Saskatoon, SK Total interviewed: 2
			Vancouver, BC Total interviewed: 2
			Toronto, ON Total interviewed: 5
	Sub-total		*10*
	TOTAL		**80**

1.1.2 Interviews: Telephone

In addition to the site visits the team held telephone interviews with various subject matter experts. Table 2 outlines the telephone interviews conducted and the topics discussed with the interviewees.

Table 2 Telephone Interview Matrix

#	Category	Issues Covered	Location and Number of Persons Interviewed
1	Provincial/Health Authority Home Care Representatives	• Services available provincially • Challenges in coordinating care for persons with dementia living at home • Collaboration among organizations • Adequacy of VAC services and benefits • Identification of gaps	Vancouver Island, BC Total Interviewed: 1
	Sub-total		*1*
2	Alzheimer Society Representatives	• Services available provincially • Challenges in coordinating care for persons with dementia living at home • Collaboration among organizations • Adequacy of VAC services and benefits • Identification of gaps	Regina, SK Total interviewed: 1
	Sub-total		*1*
3	Geriatric Specialists	• Services available provincially • Challenges in coordinating care for persons with dementia living at home • Collaboration among organizations • Adequacy of VAC services and benefits • Identification of gaps	Waterloo, ON Total interviewed: 1
			Halifax, NS Total interviewed: 1
			Victoria, BC Total interviewed: 1
	Sub-total		*3*
	TOTAL		**5**

1.1.3 Case File Review

A sample of 100 VAC clients was randomly selected from the group of clients who were in receipt of a dementia drug (Ebixa, Aricept, Reminyl and Exelon) through VAC benefits under POC 10 in the 2008 fiscal year. The evaluators conducted a review of the client information captured in CSDN to obtain additional information on clients with dementia living at home, and provided information on case management, assessments/follow-ups, informal caregivers, powers of attorney and client health.

1.2 Secondary Data

Various forms of secondary data were also used during this evaluation, including statistical information and a significant document/literature review. Further details are outlined below in sections 1.2.1 and 1.2.2.

1.2.1 Statistical Information

The Statistics Directorate of VAC was approached to provide statistical information on clients with dementia living at home. The data set was compiled from a variety of VAC Databases, including the Reporting Database (RDB), the Federal Health Claims Processing System (FHCPS) and the Residential Care Support System (RCSS). The statisticians identified the clients who were in receipt of a dementia drug in the 2008 fiscal year under POC 10. For the individuals identified, the number of transactions and dollar amounts provided for the 2008 fiscal year for the Health Care Program and VIP elements was gathered. The list of clients was then amalgamated with demographic information obtained from the RDB. In order to determine if clients were living at home, the selected clients were cross-referenced with the RCSS database to determine if VAC was paying for LTC. Clients who were captured in RCSS were deemed to not be living at home.

1.2.2 Document/Literature Review

As a first step toward the evaluation, a document/literature review was conducted. The document review provided a background and history on dementia, including current Canadian statistics and demographic future projections; current needs and issues relating to persons living at home with dementia; and future dementia service and benefit trends. The review also provided insight into a dementia caregiver’s perspective on the amount of support provided and coping mechanisms. The following documents were reviewed:

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Appendix D Services Available in Visited Sites

Sydney, Nova Scotia

Continuing Care Division, Nova Scotia Department of Health - Provincial Continuing Care Managers conduct assessments, provide assistance in navigating community services, and determine eligibility for provincial home care services.

Provincial Home Care Support and Professional Services - Direct services in the home care program are primarily provided by contracted agencies, although in some areas of the province, Department of Health employees provide some nursing services home support (e.g., personal care, respite, and light housekeeping) and nursing (e.g., dressing changes, catheter care, and intravenous therapy); and home oxygen. Subsidization is based on income (nursing services and palliative care never have a fee).

In-home Respite - A maximum of 40 hours per month can be provided for in-home respite and is determined by need and availability of home services (more than 95% of users do no pay fees, but it is based on a sliding scale and income). Demand is high. There is no 24 hour care or overnight respite.

Facility Based Respite - There are 91 respite beds in the province available for planned and emergency respite. The Department of Health is responsible for determining need and eligibility. Maximum eligibility is 60 days per 12-month period.

Day Programs - They are run by the voluntary sector. There is no formal provincial funding for these programs.

Provincial Caregiver InfoLine - The provincial InfoLine exists to provide people with a trained individual to talk and discuss their concerns with.

Alzheimer Society of Nova Scotia - Existing programs and services include:

- Alzheimer InfoLine;
- Public Education;
- Caregiver and Health Professional Education;
- Caregiver Support Groups;
- Resource Library;
- Provincial Library Partnership;
- Community Outreach; and
- Safely Home™ - Alzheimer Wandering Registry.

Dementia Network of Cape Breton - Includes service provider agencies, provincial departments, and stakeholders in the community who work together to identify and deliver services to families living with dementia.

Caregivers Nova Scotia - Services for caregivers take many forms, including workshops; newsletters; book and video lending library; telephone caregiver assistance; and community-based peer support groups. The Caregivers Forum Virtual Support Group allows people to search past posts, correspond with other members, and ask/answer questions to other members on their experience with dementia.

Saskatoon, Saskatchewan

Client/Patient Access Services (CPAS), Saskatoon Health Region - Department within the Saskatoon Health Region that exists to help people access health care services both in the community and in the hospital. CPAS has Client Care Coordinators that help individuals to navigate services and eligibility; they have three coordinators dedicated specifically to case loads of persons with dementia.

Provincial Home Care Support and Professional Services - Eligibility is determined by CPAS after an in-home assessment. Support services include: personal care, in-home respite, meal preparation, and home management. Professional services offered in the home include: nursing, physiotherapy, occupational therapy, social work, and nutrition counselling.

Community Day Programs - Helps to relieve social isolation; provides stimulating organized activities; and provides a respite break for caregivers. Days, times, and activities vary, but typical programs are available during the week and include a noon meal and subsidized transportation. In some instances there are restrictions for persons with cognitive impairment, wandering tendencies, and/or behavioural issues often due to staffing levels, staff training, and physical layout of the premise. Some may also need to be booked for a minimum number of days per week.

Planned Overnight Respite - Provides relief for the caregiver and reduced risk of family breakdown. Bookings are made through CPAS in advance of requested dates. Often bookings need to be made significantly in advance and for a minimum of seven days.

Unplanned Respite Programs - Various special care homes (nursing homes) offer unplanned respite programs. Beds cannot usually be booked in advance, are dependent on availability, and are available for up to seven days.

Community Volunteers Services - Provides services such as transportation, shopping/errands, and companionship during the week. This is basically a backup to other sources for support like friends and families, so it is eligible to those who aren't able to manage independently after exploring other available support (not specific to dementia).

Rural Memory Clinic - Stream-lined, integrated one-day weekly clinic that includes assessment by an interdisciplinary team for a full day, following an introductory tele-health meeting. The clinic takes a family-centred approach so the caregiver is always involved. Eligibility is for those at least 100 km outside urban centres.

Saskatchewan Geriatric Assessment Unit - Comprehensive geriatric assessment including assessment and treatment of: complicated medical issues, physical movement, cognitive ability, functional ability, the environment, social supports, mental health, and medication issues. In addition to the assessment clinic, there is a 10-bed in-patient clinic, a 20-bed out-patient clinic, a 20-bed rehabitation unit, community assessments, and a seniors mental health partnership.

Saskatoon Council on Aging Inc. - Offers a resource centre with information of interest to older adults as well as a caregivers centre with information on referrals and a network via mini forums (not specific to dementia).

Alzheimer Society of Saskatchewan -

- Public Education;
- First Link Learning Series;
- Enhancing Care - program for LTC that involves a Alzheimer Society staff; member assessing the level of caregiving skills in relation to the 'Guidelines for Care' established by the Alzheimer Society;
- Support Groups (for persons with early dementia and caregivers);
- Resource Centre;
- Safely Home Program; and
- Information and referrals.

Other - Church groups, volunteer groups, etc. sometimes offer assistance with transportation, companionship, and running errands.

Vancouver, British Columbia

BC Nurses Line (toll free) - Registered nurses are available 24/7 to answer people's questions and help identify health concerns, discuss treatment options and advise when to see a health professional.

Vancouver Community, Vancouver Coastal Health Authority - Community home and community care services are offered so that seniors, and adults with significant health problems, can live independently at home. Services include: home care, home support, assisted living, residential care, adult day centres, caregiver support programs, home hospice programs, meal programs, short-term assessment and treatment centre, and transitional care. (Personal care includes: grooming and hygiene, bath assistance, assistance with mobility lifts and transfers, assistance with medications, nutritional assistance and family and caregiver respite).

NOTE: There are multiple health authorities and the services offered in Vancouver might not necessarily be offered in another region.

Short-term Assessment and Treatment (STAT) Centre - Falls under Vancouver Community, but is housed in acute care. The centre includes 17 in-patient beds and 55 spots in a day program. All patients are over the age of 65 and have complex mental issues (40%) or cognitive issues (60%). They do not treat acute problems. The average stay is 44 days and the goal is to get the seniors back in their homes.

Provincial Geriatric Psychiatric Outreach Team - This interdisciplinary team assesses and treats seniors with psychiatric problems who are living in the community. The team links with the Vancouver Hospital STAT Centre for day hospital and in-patient care when needed.

GEM STAT Program - Vancouver Community program linked with the STAT Centre where geriatricians work on a sessional time in community health centres to do assessments, etc.

Home ViVE Program - Vancouver Community program linked with the STAT Centre where an interdisciplinary team visit in-home elderly that do not have the ability to make trips outside the home. The goal is to keep them in the home and avoid acute care visits.

Provincial Gerosychiatric Education Program and Services - Provides a full range of health care services ranging from hospital treatment to community-based residential, home health, mental health and public health services. They serve residents in the coastal mountain communities of Vancouver, North Vancouver, West Vancouver and Richmond. Senior services include: fall prevention, needs assessment, care planning, day programs, and caregiver support .

Independent Living BC - Offers a middle option to bridge the gap between home care and residential care for those who need some assistance, but don’t need 24 hour professional care. A referral is made from a health authority and an assessment is conducted for eligibility. The person will pay 70% of their after-tax income to live-in assisted living homes.

Choice in Supports for Independent Living - Alternative option (self-managed care) for eligible home support clients. The program is developed for persons with daily personal care needs to give them more flexibility in managing their home support services. The client receives funds and manages and coordinates their home support (they need to demonstrate their ability to do so). There are registered client support groups that can assist those not able to direct their own care. Immediate family members cannot be paid.

Alzheimer Society of British Columbia -

- The Dementia Education Series;
- Tele-workshops;
- Support groups (for caregivers and early stage dementia patients);
- Dementia Help Line;
- Starter Information Pack with brochures, fact sheets, and list of resources;
- Newsletters;
- Referrals;
- Resource Centres; and
- Safely Home wandering registry/BC Photo Registry.

Dementia Journey Web site - Web site that is currently being expanded into a provincial web-based resource that will connect the needs of individuals and caregivers, living with dementia, with the resources available locally. The site provides good resources and information for persons with dementia and their caregivers.

Caregivers Association of British Columbia - Provincial non-profit organization formed to support and educate caregivers in British Columbia. Provides an online searchable database for caregiver information including support groups and educational materials.

Society for the Arts in Dementia Care - Offers workshops, mainly for caregivers, in how to assess seniors ability to express themselves creatively and applying the creative arts into their care plan.

Toronto, Ontario

Client Care Access Centre (CCAC), Ontario Ministry of Health - Client Care Coordinators assist in navigating community and provincial services, provide case management, coordinate assessments, offer referrals, and determine need and eligibility for services. In-home services include nursing, personal support (bathing, dressing, etc.), physiotherapy, occupational therapy, speech-language therapy, social work, nutritional counselling, and medical supplies and equipment. Home care services are tendered out to contract home care service providers. Clients are allowed 15 hours per week of home care; however, service hours can extend as high as 22 hours per week for special situations.

Provincial Respite Services - Offer in-home or short stay (at an LTC) respite care for the caregiver . The respite ceiling allowance is also 15 hours per week. CCAC often makes recommendations to attend day programs. Restrictions for admittance into day programs and respite can apply if the person is severely cognitively impaired, wanders, and/or has behavioural issues.

Waiting at Home Program - Program that was piloted in another Ontario CCAC that assisted elderly who were admitted to acute care to return home and provide up to eight hours service as long as they are LTC eligible. The program proved that 40% of patients actually went back into the home and did not enter a LTC.

Alzheimer Society of Ontario (Toronto) -

- Counselling;
- Support Groups (for persons with dementia and family and friends);
- Public Education;
- Resource Centre (one of the largest dementia specific collections in Ontario);
- First Link Partnership – partners include family physicians, geriatric specialists, pharmacists, social service workers in health facilities and community agencies and staff working in family practice;
- Safely Home Wandering Registry;
- Information and Referrals; and
- Newsletters.

Toronto Dementia Network - Collects, organizes, and disseminates information about dementia and dementia services in Toronto. Their Web site offers information on dementia and a searchable database of dementia services in the Greater Toronto Area.

National

Home Adaptations for Seniors Independence Program - Canada Mortgage and Housing Corporation helps homeowners and landlords pay for minor home adaptations to extend the time low-income seniors can live in their own homes independently through a forgivable $3,500 loan.

Appendix E Detailed Tables

Table 1: VAC VIP contributions to dementia clients living at home and to all VIP clients by province for 2007-2008

	VIP Clients with dementia living at home				All VAC VIP Clients				Percentage of total VIP contribution to clients with dementia	Variation in percentage between VIP Clients with dementia and All VIP clients contributions
	Amount	Percentage of total contribution	Number of clients	VIP Contribution per client	Amount	Percentage of total contribution	Number of clients	VIP Contribution per client		
BC	$2,470,661	13.1%	653	$3,784	$49,915,525	16.5%	21,509	$2,321	4.9%	63.0%
ALB	$509,957	2.7%	199	$2,563	$13,185,561	4.4%	7,005	$1,882	3.9%	36.1%
SK	$373,670	2.0%	120	$3,114	$7,969,581	2.6%	4,333	$1,839	4.7%	69.3%
MAN	$338,718	1.8%	102	$3,321	$9,415,137	3.1%	4,975	$1,892	3.6%	75.5%
Total Prairies	$1,222,344	6.5%	421	$2,903	$30,570,279	10.1%	16,313	$1,874	4.0%	54.9%
ON	$7,868,072	41.8%	1,497	$5,256	$107,481,596	35.5%	36,255	$2,965	7.3%	77.3%
QC	$1,440,577	7.6%	282	$5,108	$29,036,549	9.6%	10,521	$2,760	5.0%	85.1%
NB	$1,241,807	6.6%	148	$8,391	$23,847,646	7.9%	6,091	$3,915	5.2%	114.3%
NS	$3,611,200	19.2%	262	$13,783	$44,878,585	14.8%	8,337	$5,383	8.0%	156.0%
PEI	$543,134	2.9%	34	$15,975	$5,989,428	2.0%	1,239	$4,834	9.1%	230.5%
NFLD	$413,541	2.2%	25	$16,542	$11,300,077	3.7%	1,899	$5,951	3.7%	178.0%
Total Atlantic	$5,809,682	30.8%	469	$12,387	$86,015,736	28.4%	17,566	$4,897	6.8%	153.0%
USA	$30,239	0.2%	6	$5,040	Not Available	Not Available	Not Available	Not Available	Not Available	Not Available
Total Canada	$18,841,576	100.0%	3,328	$5,662	$303,019,685	100.0%	102,164	$2,965	6.2%	90.9%

Table 2: VAC VIP contributions to dementia clients living at home and to all VIP clients by VIP type for 2007-2008

	Total VIP Expenditures for dementia VIP clients by VIP service	Number of dementia clients by VIP service	Percentage of dementia clients who received VIP contributions	Expenditures per client for all dementia VIP clients	Total Expenditures for all VIP clients per VIP service	Number of VAC clients by VIP service	Percentage of VIP clients who received VIP contributions	Expenditures per client for all VIP clients	VIP expenditures : Variation (in percentage) between dementia VIP clients and all VIP clients
Adult Residential Care	$39,184	4	0.1%	$9,796	$304,756	31	0.0%	$9,831	-0.4%
Nursing Home Care	$7,953,918	673	20.2%	$11,819	$54,381,306	6,407	6.3%	$8,488	39.2%
Ambulatory Care	$252,380	247	7.4%	$1,022	$913,939	1,251	1.2%	$731	39.8%
Nutrition	$362,170	409	12.3%	$886	$7,795,372	8,436	8.3%	$924	-4.2%
Direct Patient Care	$4,134	3	0.1%	$1,378	$90,280	68	0.1%	$1,328	3.5%
Personal Care	$2,316,659	602	18.1%	$3,848	$19,867,621	6,707	6.6%	$2,962	29.9%
Housekeeping	$6,593,100	2,628	79.0%	$2,509	$170,307,281	87,367	85.5%	$1,949	28.7%
Grounds keeping	$1,149,601	1,502	45.1%	$765	$46,210,585	60,990	59.7%	$758	1.0%
Social Transportation	$153,423	248	7.5%	$619	$2,711,310	4,649	4.6%	$583	6.1%
Home Adaptations	$17,009	25	0.8%	$680	$437,235	516	0.5%	$847	-19.7%
Total/Average	$18,841,576	6,341		$5,662	$303,019,685	176,422		$2,965	90.9%
Number of clients		3,328		1,91 elements/client		102,164		1,73 elements/client	10.4%

Table 3: VAC treatment expenditures to dementia clients living at home and to all clients by VIP type for 2007

	Veterans living at home with dementia						All VAC Clients					Average treatment expenditures per client by POC: Variation in percentage between Veterans with dementia living at home and all VAC clients
	Number of unique clients with dementia living at home by POC	Percentage of total unique clients with dementia at home using specific POC	Treatment expenditures by POC	Distribution in percentage of all treatment expenditures	Percentage of total treatment expenditures by POC	Average treatment Expenditures per client by POC	Number of Unique clients by POC	Percentage of total unique clients using specific POC	Treatment expenditures by POC	Distribution in percentage of all treatment expenditures	Average treatment expenditures per client by POC	
POC1	843	20.6%	$167,420	1.2%	5.5%	$199	15,312	13.7%	$3,065,420	1.1%	$200	-0.7%
POC2	702	17.2%	$51,320	0.4%	0.3%	$73	30,400	27.2%	$18,959,103	6.7%	$624	-88.3%
POC3	1,331	32.6%	$1,078,779	7.7%	2.7%	$811	48,435	43.4%	$39,462,892	13.9%	$815	-0.6%
POC4	1,586	38.8%	$857,507	6.1%	4.9%	$541	31,560	28.3%	$17,654,442	6.2%	$559	-3.3%
POC5	90	2.2%	$15,974	0.1%	0.7%	$177	1,926	1.7%	$2,241,501	0.8%	$1,164	-84.8%
POC6	41	1.0%	$1,589	0.0%	0.3%	$39	1,490	1.3%	$468,942	0.2%	$315	-87.7%
POC7	1,234	30.2%	$576,025	4.1%	8.5%	$467	18,994	17.0%	$6,763,399	2.4%	$356	31.1%
POC8	1,473	36.0%	$270,118	1.9%	3.2%	$183	23,426	21.0%	$8,413,653	3.0%	$359	-48.9%
POC9	44	1.1%	$76,272	0.5%	2.1%	$1,733	2,289	2.1%	$3,560,174	1.3%	$1,555	11.5%
POC10	3,767	92.1%	$9,104,811	64.7%	7.3%	$2,417	80,348	72.0%	$124,223,815	43.8%	$1,546	56.3%
POC11	163	4.0%	$60,587	0.4%	2.1%	$372	5,430	4.9%	$2,848,280	1.0%	$525	-29.2%
POC12	1,587	38.8%	$387,391	2.8%	1.8%	$244	36,016	32.3%	$21,400,735	7.5%	$594	-58.9%
POC13	1,411	34.5%	$1,268,412	9.0%	4.3%	$899	28,197	25.3%	$29,309,321	10.3%	$1,039	-13.5%
POC14	687	16.8%	$148,124	1.1%	2.8%	$216	19,137	17.1%	$5,233,635	1.8%	$273	-21.0%
Total	4,088		$14,064,328	100.0%	5.0%	$3,440	111,653		$283,605,312	100.0%	$2,540	35.4%

Appendix F Dementia Care in Canada and other Countries

This section draws on the findings of two studies that compared several countries on various aspects of care for older people affected by dementia[52].

With a world-wide growing elder population, many countries are developing and/or implementing strategies that will help people with dementia live with dignity and receive the best quality of care. It is hoped that the strategies will also alleviate the economic, psychological and social burden put on families and caregivers of persons with dementia. Many governments have made dementia care a priority and changed the policy focus from long-term care to community care.

Many countries have recognized that early detection of dementia is important. Health care strategies that stress the importance of early detection of dementia are becoming an important health policy issue at the national level in countries such as France, Spain, the United Kingdom (UK), but only at the sub-national level in other countries such as in Canada, Sweden and the United States.

The services provided to persons with dementia by the formal health care and social care systems vary greatly between countries. Health care systems in Australia and the UK have developed complex and detailed strategies and programs to meet the specific needs of persons with dementia, their families and caregivers. For example, in Australia, the Mobile respite team for dementia offer an innovative short-term service for people living with dementia and their carers in the form of dementia education and support in the home for those who wish to continue caring at home.

People in the late stages of dementia require continuous care, support and supervision. In Canada and worldwide, the three main determinants of admission to a long-term care institution for people with dementia are their level of impairment and care needs, the absence of an informal caregiver, and poor health[53]. In terms of admission to long-term care institutions *"for late-stage dementia sufferers, admission eligibility tends to be based on the amount of care services required with no specification as to type of disease, meaning dementia patients are assessed the same along with patients with other physical and mental disabilities. Faced with a shortage of eligible places [and long wait lists] in almost all countries, late-stage dementia patients, especially those with aggressive behaviours, have greater difficulty in finding places in long-term care*

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[52] Organization for Economic Co-operation and Development (OECD) of dementia services across nine countries (Australia, Canada, Germany, France, Spain, Great Britain, Japan, Sweden, USA) (Moise et al. 2004), and one by Knapp et al. (2007)

[53] Moise, Pierre, et al. Dementia Care in 9 OECD Countries: A Comparative Analysis. Organisation for Economic Co-operation and Development (OECD) Health Working Papers No.13 (42). DELSA/ELSA/WD/HEA (2004) 4.

facilities since facilities will tend to pick the least burdensome patients from those eligible for admission."[54]

The burden faced by informal caregivers that provide care and support to people with dementia is extremely important and was recognized in all countries. *"While most countries state they value the vital role informal caregivers play in the care of dementia, the lack of dementia-specific support programs [worldwide] belies this claim."*[55]. Many countries, such as Canada, Spain and the United States offer tax credits for informal caregivers, while other countries such as Australia, France and Sweden offer direct cash payments for people caring for a disable adult living at home. In Australia, we can find a large range of financial assistance programs for caregivers. With the exception of Australia, the problem with credits or payments to caregivers is that they are minimal in nature and are not dementia-specific.

Australia and the UK are well advanced in their dementia care strategies and programs. Canada has also had significant advances in dementia care; however, the Alzheimer's Society has been advocating for Canada to make dementia a national health care priority.

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[54] Moise, Pierre, et al. (44)

[55] Ibid.

Appendix G Other Observations

Training of Staff

VAC staff interviewed felt that the majority of recent training had been focussed around the New Veterans Charter (NVC). Dementia-specific training varied among DOs. Some district offices are co-located with health centres (such as Sunnybrook) or are in large urban areas, which can provide more opportunities for educational sessions and conferences than those less centrally located. Depending on their proximity to each other, some district offices also combined their training efforts. There is no set training program or policy in relation to dementia within VAC.

With differing backgrounds and experience in the district offices, the level of knowledge and understanding of dementia held by staff varies. Depending on their level of understanding, some staff felt they did not need additional training, while others felt it would be beneficial to their work. Specific education interests voiced by VAC staff included:

a) information on what kind of services are available for persons with dementia, specifically in their community;
b) information on how to better assist spouses and/or adult children that are providing care to persons with dementia (e.g., caregiving and respite); and
c) tips for how to look for initial symptoms of dementia.

There is no conclusive evidence to support a national training initiative on dementia and DOs have medical professionals on staff who have a good understanding of dementia. DOs may wish to make use of opportunities for dementia training, depending on the training needs identified in their respective office.

Veteran as Caregiver

Of the VAC DO staff interviewed, 17% identified a gap for Veteran clients who are caregivers to a spouse with dementia. With women accounting for 62% of all cases of dementia in Canada[56], and the majority of our senior Veteran population being male, there is a potential for a large group of Veterans caring for a spouse with dementia. VAC has no authority to provide care to a person who is not a client; however, VAC can provide housekeeping and grounds keeping to Veteran caregivers who are eligible for VIP. The hope is that the additional grounds keeping and housekeeping will provide some relief for the client caregiver. VAC currently defines the term ‘respite’ as “benefits, services or care provided to an eligible client for the purpose of giving relief to an informal caregiver who is the primary caregiver”.

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[56] Alzheimer Society of Canada, 2009.

A caregiver can only care for someone effectively if they themselves are healthy. As discussed earlier in the report, caring for someone with dementia is a burdensome task that can result in an increased risk of chronic health issues. Assistance in the form of respite (one of the most widely requested services) could help a Veteran caregiver and help in prolonging their ability to care for their spouse in the home. The estimated average age of traditional Veterans (World War II and Korean War Veterans) as of March 2008 was 81 years[57]. It is commonly known that as people age they require more assistance in day-to-day life and the instance or probability of injury and illness increases; therefore, visits to the emergency room and acute care generally rise. If a Veteran caregiver does not have the support and is not able to cope with the burden, or falls ill themselves, both the spouse and the Veteran could be admitted to acute care, or long-term care.

Collaboration with Outside Agencies

Various organizations such as regional dementia networks are currently trying to meet the need for additional dialogue and collaboration between agencies. Nevertheless, there continue to be gaps in cross-sectional integration.

VAC area counsellors (ACs) interviewed felt that the working relationship with provincial health authority representatives is generally good; however, it appears that some districts have stronger relationships than others. In some areas, ACs and provincial representatives correspond frequently regarding client situations whereas in other areas they may only communicate when an issue arises. Though the working relationship between provincial representatives and VAC is generally good, provincial representatives felt that VAC ACs can be hard to reach to relay information regarding clients or for questions regarding VAC programming and eligibility. As discussed earlier in the report, collaboration and communication among agencies is important and can help make sure clients receive services in a timely manner. Communication between VAC and the provinces could be improved by provincial representatives having direct access to ACs, rather than having to call VAC's toll-free number.

Because of staff turnover in both organizations, it can be difficult to maintain strong relationships, as well as a good knowledge base of the services and benefits offered by each agency. A suggestion by one provincial representative was the incorporation of an annual meeting between VAC's ACs and their provincial counterparts to share information regarding services and benefits, new initiatives, new policies, lessons learned, etc.

The relationship between VAC and physicians, and other health care professionals, could also be strengthened. In the Greater Toronto Area, hospitals discharge plans have a default question asking patients if they are Veteran's. The hospital will contact

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[57] General Statistics."Canada at War: Participation and Casualties". Veteran Affairs Canada.

VAC regarding a discharged Veteran client. This practice would be beneficial if incorporated into discharge plans in acute care facilities in other areas.

Transportation Services

Driving can have a positive effect on quality of life as it allows a person to maintain their familial and social relationships, participate in recreational activities and maintain independence. It has been shown that the loss of a drivers license has a direct health impact on the individual and the family. The individual can experience increased depression, isolation and loneliness. The family can feel stress by the additional responsibility. A person with dementia will lose their license as their dementia progresses. One of the challenges for persons with dementia is impaired judgement and they may not realize they are no longer able to drive safely. Planning ahead, for example, identifying alternative sources of transportation, can lessen the impact of the change[58].

The MAREP study found that caregivers felt a need for improvements to social transportation. Although their opinions were about social transportation in the province of Ontario, and were not specific to VAC, their opinions still point to a gap in services in the community which VAC could supplement to help our clients with dementia.

Social transportation is a benefit available under the VIP Program. Transportation services may be approved to allow clients to participate in social activities, in response to the client's basic social, recreational, or personal needs. When transportation is not otherwise available, services may include transportation to church services, or occasional visits to friends/relatives, community centres, banks, and grocery stores[59]. Social transportation is only available to clients in receipt of Home Care Service[60] or Ambulatory Health Care Service. In addition, Veteran pensioners, civilian pensioners and special duty area pensioners must be income qualified. Therefore, the intended recipient of social transportation are those who could not otherwise afford alternative modes of transportation. It is not intended for persons with moderate to severe dementia who may require assistance and supervision in order to access public transportation.

Transportation was identified by those interviewed as an area that should be enhanced. Concerns were raised about the lack of availability of social transportation in rural areas. In areas where social transportation was available, the maximum rates were felt to be

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[58] Hogan, David B. et al. “Management of Mild to Moderate Alzheimer’s Disease and Dementia”. The Alzheimer’s Association. Alzheimer’s & Dementia (2007) : Vol. 3 355-384.

[59] A Guide to Accessing VAC Health Benefits and the Veterans Independence Program, 2008. www.vac-acc.gc.ca/content/services/vip/vachealthvip_e.pdf.

[60] Home Care Service includes Health and Support Services, Personal Care Services, Housekeeping Services, Access to Nutrition Services and Grounds Maintenance Services. (Source: VPPM)

inadequate, particularly since persons with moderate to severe dementia often require an escort. There are also general issues with social transportation which are outside of VAC's control. For example, some organizations offering transportation will not accept persons with behavioural issues or severe dementia. VAC employees indicated that eligibility for social transportation was an issue.

There was not sufficient evidence to support any changes in social transportation.