



*Soci t  Alzheimer Society*  
OTTAWA AND RENFREW COUNTY



**Champlain Dementia Network**

# **Caregivers and Dementia**

*by*

**Sherri Torjman and Anne Makhoul**

**June 2008**

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Finally, the authors wish to acknowledge the late Katharine Pearson who worked tirelessly at the J.W. McConnell Family Foundation to support local projects, pan-Canadian research and national policy development around the unique needs of caregivers.

## *Executive Summary*

### *Purpose of study*

This report presents the results of a study carried out on behalf of the Alzheimer Society of Ottawa and Renfrew County in collaboration with the Champlain Dementia Network. The purpose of the study was to identify the needs of caregivers of persons with Alzheimer’s disease and related dementia.

More specifically, this work focuses upon the availability and quality of respite for caregivers and the supports currently in place to provide relief from their ongoing caregiving responsibilities. The paper puts forward a range of policy and program recommendations in response to these identified needs.

While the focus of the study was upon respite for caregivers, it also explores services intended for care receivers – in this case, persons with some form of dementia. The latter component was included because the availability of appropriate supports and services for care receivers effectively acts as a type of relief for caregivers. In this sense, the provision of appropriate and timely supports for care receivers is a direct form of respite.

The analysis of the current system of services and supports for both caregivers and care receivers is based on the results of an extensive survey conducted in Champlain Region, which includes Ottawa, Renfrew County and the Eastern Counties. Information from Lanark and North Grenville was not available at the time this survey was undertaken.

The findings derive as well from meetings with caregivers and interviews with selected care providers. While the results of this work apply to Champlain Region in particular, the concerns related to service gaps are consistent with the results of respite studies conducted by the Caledon Institute and many other organizations. The policy and program recommendations are therefore relevant not only to this locale but to other regions of the province and indeed the country.

This study was based on the premise that respite should be understood as the outcome derived by caregivers as a result of time off from caregiving duties, relief from caregiving pressures or direct support for their specific needs. The assumption speaks clearly to the importance of flexible and responsive forms of assistance, determined primarily by caregivers themselves.

### *Dementia-related challenges*

While the concerns of caregivers of persons with Alzheimer's disease or related dementia are similar to other caregivers, there are also specific challenges that are unique to dementia. Alzheimer's disease and related dementia are progressively degenerative conditions that can last up to ten years or more. The symptoms gradually become more debilitating as individuals with dementia experience loss of short-term memory and the cognitive skills needed for daily decision-making.

As the disease progresses, persons with dementia typically are affected by gradual loss in their ability to perform the personal activities of daily living such as bathing, dressing, eating or toileting, and instrumental activities such as preparing meals, managing medication or attending to finances.

Because of the progressively debilitating nature of the condition, caregivers of persons with Alzheimer's disease or related dementia face unique challenges. The burden of physical care increases over time. Many caregivers report that they are virtually on call around the clock. The roles of caregivers continue to evolve and expand without the associated training or enhancement of supports. Of the total 168 hours in the "24/7" week for which caregivers must be available, only a weekly maximum 15 hours of home care is provided by the formal system of services (the number of hours of service may be extended in exceptional cases). While the care receiver may also be eligible for other services, such as a day program, the actual extent of in-home care is minimal compared to the number of hours for which assistance potentially may be required.

In addition to the loss of physical capacity, progressive mental deterioration means that caregivers must make more decisions on behalf of care receivers. There is typically a deep sense of loss, which often is linked to depression for both caregivers and care receivers. Cost pressures arise from additional expenses and financial insecurities related to frequent absences from work.

In recognition of these challenges, the Government of Ontario introduced in September 1999 its province-wide *Strategy for Alzheimer Disease and Related Dementias*. This effort was the first comprehensive Alzheimer Strategy in Canada. The province made a commitment to invest \$68.4 million over five years in ten major initiatives to improve the quality of life for Ontarians affected by Alzheimer's disease and related dementia.

Investments at the time included annual training for staff of community care access centres (described below), adult day programs and long-term care. A modest amount was allocated for physician training for early detection and awareness. One public education coordinator was hired for each of the local 39 Alzheimer Societies across the province to raise awareness of the disease and to recruit volunteers for various events. Perhaps most significant from the perspective of this study was the allocation of an initial \$3 million, rising to \$7 million per year as of 2000-01, for the creation of new Alzheimer day spaces. The Strategy also increased by an additional \$551 million the annual spending on long-term community care.

More recently in August 2007, the Government of Ontario announced its Aging at Home Strategy. While the Ministry of Health and Long-Term Care assumes primary responsibility for this strategy, it is clear that the consequences of dementia have implications for other ministries as well including Transportation and Justice at the provincial level and Human Resources and Social Development Canada at the federal level.

Under the Aging at Home Strategy, the province plans to expand dramatically the community living options for seniors, with a wider range of home care and support services to enable independent living at home. More than \$700 million in funding over three years will be invested in home care, community support services, assistive devices, assisted living services and supportive housing, long-term care beds and end-of-life care.

The Aging at Home Strategy also has a strong focus on innovation. Each Local Health Integration Network, described below, is required to allocate a minimum of 20 percent of funding over the three years for innovative approaches, such as non-traditional service provision and new preventive wellness services. The Alzheimer Society of Cornwall and District has entered into a partnership agreement and received a grant for the first year of a three-year project testing a model of self-directed care. Caregivers will be able to devise their own care plans and have access to subsidies in order to support their role of caring at home for persons with Alzheimer's disease or related dementia.

The proposals put forward in this study ideally will help guide the development of the Aging at Home Strategy as it unfolds over the next few years.



## *Policy and program recommendations*

This study gave rise to a wide range of recommendations for improving respite options for caregivers of persons with dementia. While these proposals touched on many different areas, they were grouped for the purposes of this paper into three main clusters.

- recognition of caregiver needs and support for their significant role
- improvement in the quantity and quality of services for individuals with Alzheimer's disease and related dementia and for their families
- reduction in the costs and financial pressures associated with caregiving.

Each of these themes is described more fully below. Within each theme, the proposals were classified even further into two major types: policy and program recommendations. Those related to policy are directed toward government in particular because they require some sort of legislative shift or deliberate decision that can be made only by government.

The recommendations put forward in the first two themes are intended primarily for the Government of Ontario and dovetail well with its Aging at Home Strategy. The recommendations in the third cluster related to home modification assistance, tax credits, the Employment Insurance regime and Canada Pension Plan are directed to the federal government.

The program recommendations, by contrast, are intended for service providers and for the Alzheimer Society. They involve important shifts in direction but do not necessarily require a legislative change or government decision for implementation.

### *Summary of key themes*

#### *Recognition of caregiver needs and support for their significant role*

The concerns raised in this cluster of issues focus upon the fact that caregiver needs are linked to – but are significantly different from – those of care receivers. The first area of need relates to the recognition of caregivers and their engagement in the planning process for care receivers. The second group of concerns involves the information and training required to effectively carry out the caregiving role. The third set of issues speaks to the fact that caregivers themselves may experience a range of stresses and associated mental health problems. Their unique needs should be addressed.

The following policy and program recommendations respond to the importance of recognizing caregiver needs and supporting their significant role:

#### *Policy*

- Separate the eligibility for respite for caregivers from the need for services for care receivers.

- Formalize the recognition of caregivers’ significant role through a National Caregiver Strategy similar to those already in place in the United Kingdom, Sweden, Australia and New Zealand.

### *Program*

- Increase broad-based delivery of education programs and individualized training for both family and professional caregivers around the physical needs of care receivers with dementia, and its legal and financial implications.
- Enhance access to support and interventions for family caregivers through such means as support groups, and telephone and online support.
- Recognize and address the changing roles that place demands on caregivers including the stress and impact on their physical and mental health.
- Develop and implement a Caregiver Burden Index to monitor caregiver relief.

### *Improvement in the quantity and quality of services*

The concerns raised in this cluster of issues focus upon the fact that caregivers experience two major types of problems around the delivery of supports and services for Alzheimer’s disease and related dementia. The first has to do with the quantity of available services, including the number of hours for in-home support and the waiting time for services like day programs and long-term care. The second group of issues in this cluster is rooted in the quality of service provision – i.e., the flexibility of current arrangements, their appropriateness relative to the needs of care receivers and caregivers, and the quality of staff training. A unique set of challenges is raised about the gaps in service in rural areas and the problems arising from travel distances and associated costs.

The following policy and program recommendations respond to the need to improve the quantity and quality of services for persons with dementia and their caregivers:

### *Policy*

- Extend the maximum number of hours available for in-home services and change the formula for assigning hours to include – as part of the eligibility assessment – caregiver and care receiver needs, disease progression, change in roles and caregiver coping.
- Introduce greater flexibility in the provision of supports at home, including the availability of individualized funding and self-directed care to enhance responsiveness to the needs of caregivers and care receivers, and programs like the successful Veterans Independence Program (VIP).
- Introduce greater flexibility in the eligibility criteria to ensure service availability for those with dementia under the age of 65.

### *Program*

- Ensure that professionals and service providers receive improved and ongoing training for addressing the continually changing needs of persons with dementia. Training should be culturally sensitive and linguistically appropriate.
- Ensure caregivers be involved in the development, implementation and evaluation of the services provided to them.
- Encourage home care providers to carry out basic animation with care receivers, where feasible, rather than only friendly visiting.
- Analyze and address gaps in the underutilization of services.

### *Reduction in the costs and financial pressures associated with caregiving*

The concerns raised in this cluster focus upon the fact that caregivers typically experience financial stresses that arise from two sources. The first involves the additional expenses associated directly with the condition and includes fees for home care services, transportation costs for medical appointments, drug dispensing fees, technical aids and equipment, and home modification. The second set of financial pressures derives from insecurity related to employment circumstances for caregivers who are active in the paid labour market. Many must reduce their hours of employment or leave jobs altogether in order to carry out their caregiving responsibilities. Those without leave, insurance coverage or pension protection risk their economic security.

The following policy and program recommendations respond to concerns associated with the costs of caregiving and the economic security of caregivers:

### *Policy*

- Renew the Home Adaptations for Seniors' Independence program when the funding commitment expires in 2009.
- Expand the leave provisions in federal and provincial labour codes.
- Extend the compassionate care leave provisions under the Employment Insurance Act to allow special leave for care for persons with progressively degenerative conditions, such as dementia.
- Extend the drop-out provisions of the Canada Pension Plan to cover caregiving for persons with moderate- and late-stage dementia.
- Consolidate the application for government funded subsidies into one centralized access point.

### *Program*

- Research the allowances and other supports for caregivers available elsewhere in the world, such as the National Strategy for Carers in the UK.

## *Methodology*

This report presents the results of a study carried out on behalf of the Alzheimer Society of Ottawa and Renfrew County in collaboration with the Champlain Dementia Network. The purpose of the study was to identify the needs of caregivers of persons with Alzheimer's disease or related dementia. More specifically, this work focuses upon the availability and quality of respite for caregivers and the supports in place to provide relief from ongoing caregiving responsibilities.

The methodology employed for this study included several major steps. The first involved the development of a survey questionnaire related to five streams of service, described below, for persons with Alzheimer's disease or related dementia.

The survey was then sent electronically to 83 organizations throughout Champlain Region – i.e., Ottawa, Renfrew County and the Eastern Counties.<sup>1</sup> Follow-up telephone calls were made to non-respondents in order to ensure a robust sample size. The final response rate was 72 percent. The survey results comprise an important part of the evidence base for the findings and associated recommendations put forward in this report.

Telephone interviews were also held with key informants from the Champlain Community Care Access Centre. The purpose of these conversations was to gain an understanding of caregiver needs from the perspective of the major referral agents in the region.

Another component of the methodology involved discussions with caregivers of persons with Alzheimer's disease or related dementia. Caledon staff participated in four meetings of support groups for caregivers. Two of these meetings were in Ottawa, one was in Arnprior and the fourth in Rockland. The latter two are considered rural areas and the meeting in Rockland was held in French. It should be noted that those who participate in support groups may be more confident and 'better connected' than others who do not attend these sessions. The concerns of many caregivers who are isolated or not linked to formal or even informal supports may actually be more acute than those expressed here.

In-depth interviews were carried out with selected caregivers. Caledon staff attended several public sessions in which panels of caregivers and professionals made presentations about respite and other caregiving needs. A search of relevant literature was also conducted. Key findings were incorporated in the discussion and associated policy proposals presented below.

Finally, conversations were held throughout the course of the study with representatives from the two major Alzheimer Society organizations that comprise Champlain Region. These discussions helped ensure that the study remained consistent with the original intent and specific questions posed by the sponsoring organizations.

## *Who are the caregivers?*

An estimated three million Canadians are unpaid or informal caregivers. The economic value of caregivers' unpaid work to the Canadian economy has been pegged at more than \$5 billion [Fast, Eales and Keating 2001].

According to the Canadian Caregiver Coalition, caregivers are individuals who provide care and assistance for family members and friends in need of support because of physical, cognitive or mental health conditions. The Coalition considers 'family' to include both biological members and family of choice in which the caregiver is deemed part of the family, whether legally related or not.

The Ontario government definition of caregiver refers to individuals with primary responsibility for the care of an applicant for homemaking or personal support services or of a person who receives such services, and who provide that care without remuneration. In this case, the caregiver is defined by the formal services delivered to the care receiver.

The 2002 General Social Survey defines 'care providers' as Canadians 45 years and over who reported providing assistance, in the past 12 months, with at least one task because of a long-term health problem of the care receiver.<sup>2</sup> It should be noted that caregiving is not restricted to persons of this age. However, the vast majority of Canadians who are considered active caregivers fall into this category.

Caregiving tasks include duties inside the house such as meal preparation and clean-up, house cleaning, laundry and sewing; house maintenance and outside work like snow removal; transportation; shopping for groceries or other necessities; banking and bill paying; and personal care such as bathing, dressing, toileting, care of toenails and fingernails, brushing teeth, and shampooing and hair care. Many caregivers play an important brokerage role. They act as coordinators of the myriad services that care receivers may require.

Caregivers assist individuals with a wide range of conditions, including Alzheimer's disease and other forms of dementia. They also help those who require palliative care at the final stages of their lives, and both children and adults with severe disabilities. Because persons with disabilities typically object to their designation as care receivers, the term 'caregiver' generally is used to refer only to the parents of children with severe disabilities.

Caregivers take care of seniors – persons over age 65 and the frail elderly. Clearly, not all seniors over 65 require care. Most remain active and healthy, and may need only minor or modest assistance with some functions of daily living, the care of their home or transportation. Many require eyeglasses or an assistive hearing device or may need help with home maintenance. However, Canada's aging population includes a growing proportion of very old and frail seniors. A distinction increasingly is being made between the 'young elderly' and the 'old elderly,' whose needs are wide-ranging in scope.

The caregivers of persons with Alzheimer's disease or related dementia, in particular, represent a subset of the total population of caregivers. Alzheimer's disease is the most common form of dementia, accounting for 64 percent of all types. In 2008, about 97,000 Canadians are expected to develop some form of dementia. An estimated 450,000 Canadians over 65 currently have Alzheimer's disease or related dementia, which means that there are an equal or even greater number of Canadians involved in caring for these individuals.

In Champlain Region, in particular, about 14,000 individuals are affected by some form of dementia. The numbers are expected to double in the next few years with some 2,800 new cases identified annually. The growing numbers are a concern, given current pressures on existing services and supports. Persons with Alzheimer's disease or related dementia, for example, comprise about 80 percent of the residents in long-term care.

While the caregivers of persons with dementia face unique challenges, caring at home for persons with some form of dementia is not new. Spouses, children, other relatives and friends have always assumed this role well before the presence of formal, publicly funded services. What is new is the context – i.e., the fact that social and economic circumstances have changed significantly over time.

The majority of Canadian women now participate in the paid labour market and may have to reduce their hours or leave work entirely in order to accommodate their caregiving responsibilities. Many are raising children at the same time as they are caring for aging parents, creating a double stress. Families are smaller than they used to be with fewer 'built in' caregivers. Moreover, family members are increasingly dispersed, which means that caregivers have less emotional support and fewer opportunities for a physical break. The depopulation of rural areas has meant the loss of young family members and community volunteers.

Overall, Canada is a rapidly aging society with growing demand for caregivers and diminishing supply. It is also an increasingly diverse country in terms of language and cultural practices. The provision of many supports and services has not kept pace with these changing demographics.

Finally, there is a heavy economic burden on caregivers, which includes additional expenses, lost income and reduced pensions from being out of the workforce. But while many caregivers are overworked and under-supported, most are not seeking to be relieved of their care responsibilities. Rather, they just need occasional reprieve so that they can sustain this crucial role. They require some form of relief from their caregiving responsibilities, generally known as respite.

### *What is respite?*

The term 'respite' often is used to refer to a service in which paid employees come to the home of care receivers in order to give caregivers a break by allowing them some time off from



their caregiving responsibilities. Typically, respite providers are sent for a few hours by a community agency, such as visiting homemaker association, to the residence of persons with dementia. The presence of respite providers enables primary caregivers, usually a spouse or daughter, to take a few hours to carry out essential household tasks or to look after their own health and personal needs, such as exercising, visiting friends or attending the school events of their children or grandchildren.

While formal services comprise an essential component of the respite package, they are by no means the only form of support that provides relief for caregivers. These at-home services are now understood as a necessary – but not sufficient – part of the respite equation.

For some caregivers, respite or a sense of relief derives from information from a qualified provider that helps better meet the needs of the care receiver. It is possible that the individual wanders at night or inadvertently risks causing a fire through unsupervised use of the stove. Advice on how to minimize the likelihood of these potentially dangerous behaviours can provide significant relief.

Other caregivers experience respite when they are able to have a free night, weekend or even a week. A 24-hour break allows many to get the badly needed rest that they may be missing. A weekend or week allows caregivers to take a break or even a brief holiday if they are able to afford the time and cost. The physical rest allows them to “recharge their batteries” in order to carry on with their caregiving responsibilities.

For some, respite stems from knowing that there is a 24-hour call line in the event of a health-related or behavioural emergency. Caregivers of individuals with dementia or mental health problem point out that they are often unsure of how to cope with challenges, such as verbally or physically abusive behaviour. This conduct can be especially acute for those with late-stage dementia who may hallucinate or experience delusions, such as mistaking the caregiver for a stranger or attacker.

While caregivers want to do everything possible to protect the care receiver, they must look after their own well-being and that of other family members, such as young grandchildren. The Alzheimer Society of Canada has established an online support forum on its website where questions are responded to by other caregivers who have experience dealing with the behavioural and care challenges associated with dementia. As more seniors become comfortable with computers and Internet technology, use of this site is expected to increase.

Caregivers may also require legal advice. It is difficult to know when to have care receivers deemed mentally incompetent. In some cases, it may be necessary to apply for a change in legal status in order to gain access to certain benefits. (In fact, even when it is not required, some caregivers believe this to be a requirement – effectively making it a condition in their view.) Some caregivers are reluctant to take the step of declaring a spouse or relative to be mentally incompetent. It is usually seen as the final stage in a long progression of loss and a sign that any hope for recovery is gone.

Many caregivers face financial pressures related to their caregiving responsibilities. Most households incur extra costs, such as technical aids and equipment to enable independent living outside of a hospital or residential care facility, or modification of a primary residence such as the addition of an elevator or ramp. Caregiving responsibilities may also include the purchase of other supports for respite – e.g., a friendly visitor for the care receiver for a short period of time. In this case, financial assistance for the purchase of these supports may provide the necessary relief.

In addition to extra costs, caregivers may have had to leave their job or reduce the number of hours of paid work in order to make time for the care receiver. The insecurity may interfere with their continued contribution to a pension plan or otherwise affect their ability to save for the future. Both current and future financial security may be jeopardized.

In response to this wide range of needs, a new and broader interpretation of respite has been developed in recent years, which recognizes that there are many different interventions which potentially create a sense of respite for caregivers. These various forms are being tested in practice through a major national initiative called Care Renewal, coordinated by VON Canada and supported by the J.W. McConnell Family Foundation.

The Canadian Association for Community Care first proposed the concept of respite as outcome ten years ago in the Final Report of the National Respite Project in 1998. While the concept has been substantially developed through the Care Renewal initiative, the notion of respite as outcome has not yet been widely translated into policies and programs. The concept is based on the idea that respite should be understood not as a single service but rather as an outcome experienced by caregivers. Respite refers to caregivers' experiences of relief or renewal, which can be physical, emotional, psychological, social or spiritual.

The notion of respite as outcome implies far more than temporary removal from a caregiving role. A sense of reprieve for caregivers derives from a number of possible supports delivered within or outside the home including temporary breaks, personal emergency system, information and training with respect to care receiver needs, adequate programs and supports for the care receiver, housekeeping, outdoor home maintenance, counselling and peer support. Even the ability to work for a few hours or days a week is a relief for some caregivers who may worry about financial circumstances or the security of their employment [Torjman 2003].

Caregivers of persons with chronic degenerative conditions, debilitating illnesses or severe disabilities have similar requirements for support and relief. However, persons caring for individuals with Alzheimer's disease or related dementia face additional stresses that need to be taken into account in determining their need for respite [Smale and Dupuis 2004].

Dementia-related conditions typically advance through several stages, each with increased loss of functional capacity and greater use of formal services. The early stage involves mild impairment with no major impact on cognitive functions or basic activities of daily living.



The symptoms gradually become more debilitating as individuals with dementia experience loss of short-term memory and the cognitive skills needed for daily decision-making. There is a steady change in memory and at least one other cognitive function, such as language or judgment. There may be a need for minimal assistance (every two to three days) with basic personal or housekeeping activities.

Individuals at the moderate stage of dementia become increasingly less able to manage for themselves. At least one personal activity of daily living, such as dressing, toileting or bathing, typically is affected. At this stage, some individuals develop behavioural symptoms such as wandering, being verbally or physically abusive, resisting care or experiencing mood disruptions including persistent anger or perceived fears.

Many care receivers feel frustration at this point as they recognize that “there is something happening to them” or that they are unable to carry out even the most basic household routines, such as using the TV remote or remembering to add the local area code when using the phone. Those at the moderate phase of the disease usually need some form of assistance once every 4- to 12-hour period. It is at this stage that families often begin to consider the need for relocation to a supervised setting in the form of a retirement home or long-term care facility.

The late stage of dementia involves significant impairment in the ability to carry out the activities of daily living. Memory loss is severe and behavioural symptoms can present serious challenges for caregivers. Some form of assistance generally is required once every four hours and most persons at this phase of the illness are placed in long-term care homes. At the end-of-life or palliative stage, affected individuals tend to be bedridden and need assistance with all the activities of daily living. Their expected lifespan is between three and six months.

Because symptoms at the early stages may be barely noticeable, there is often a delay of up to three years in recognizing the condition. More than 50 percent of cases are diagnosed beyond the mild stage, which means that there may already be significant need for some form of support by the time a precise diagnosis has been made [Champlain Dementia Network 2007a]. Care receivers may have to be placed on a waiting list and caregivers may struggle with managing the assistance on their own for a substantial period before they receive formal help.

The physical demands alone are exhausting in that care receivers gradually lose functioning and become partially or totally dependent on the caregiver for all aspects of daily living. Lack of sleep is another serious issue. As dementia progresses, nightly sleep patterns become severely disrupted for both care receivers and caregivers. It is common for care receivers to be awake throughout the night and sleep during the day. Caregivers, meanwhile, must continue to look after daily living routines, gradually experiencing a significant sleep deficit.

Perhaps even more difficult for caregivers are the emotional dimensions of the disease [Smale and Dupuis 2004]. Many caregivers talked about the fact that they “lose the soul” of the person whom they love. The care receiver no longer acts as a partner, parent or friend, and is

virtually unrecognizable from their former self. Many wives reported that they have become mothers again – this time, to spouses with the same basic needs as young children.

Unlike persons struggling with conditions that affect physical function, many caregivers of persons with dementia noted that they are unable to communicate with care receivers other than through superficial conversation about meaningless subjects. Many persons with dementia lose their capacity to speak in sentences or at all. Some “talk nonsense” or repeat incessantly certain words or questions, and caregivers must refrain from showing their exasperation. Several respondents reported being patient for a long time and then blowing up when the pressure became overwhelming. After an outburst, care receivers are often remorseful and caregivers feel tremendous guilt.

In some cases, caregivers need help managing abusive or violent situations. Care receivers sometimes get angry if their routines are upset or if they sense that parts of their independence and control are “slipping away” – as in the medically required withdrawal of a driver’s licence. At later stages of the illness, some care receivers have moments or even periods of lucidity when they are aware of the fact that “things are not well with them” – a realization that contributes to their emotional vulnerability.

Caregivers also reported that persons with dementia often struggle with depression – sometimes in response to their diagnosis and the prospects that they face a deteriorating condition when diagnosed at an early or mild stage. Others appear to have mood swings or dips, frequently as a result of medications that may have been prescribed for physical symptoms, such as tremors. Several caregivers made reference to the fact that the symptoms of the condition may be exacerbated by medications that interfere with the capacity to speak or that even cause problems, such as hallucinations. A profile of Ontario’s home care clients found that, compared to other care receivers, people with dementia exhibited greater impairment of short-term memory and cognitive skills for daily decision-making, ten times more defensive behaviours and higher rates of mood disturbance.

Stigma was identified as another burden. Dementia is a condition not well understood by the public, with many believing that the illness is inherited or communicable. The challenge for caregivers is that there are usually few people with whom they can discuss their own mental health needs. Some caregivers reported seeing a doctor for this purpose. Others stated that they had family members who could provide support but that they did not want to continually burden them. Still others noted that their children or siblings lived out of town and were not readily available for providing assistance or occasional respite.

Some caregivers pointed to the supportive role of friends but noted that they did not want to alienate them by talking about the illness all the time. Others indicated how hard it was to maintain friendships. Because of the lack of respite supports in the evenings and on weekends, it is difficult to participate in meetings held after dinner or even to see friends at a time other than when respite is offered.

Not surprisingly, many caregivers of persons with dementia feel isolated through geography, transportation or communication barriers. The social isolation stems from the demanding nature of the caregiving role and the loss of companionship that most caregivers experience as the condition evolves through its progressively debilitating phases.

Finally, while all participants in the support groups were women, there are expected to be more male caregivers in future. In fact, recent figures show that men increasingly are assuming this role. Census 2006 found that more men are involved in carrying out unpaid work – though women still assume the bulk of this responsibility [Pearce 2008: L3]. Special attention should be paid to the needs of male caregivers who may be less likely to ask for help or to reach out for support. Moreover, they may not feel comfortable assuming the ‘parenting role’ to which many of the female caregivers referred.

The net result of this combination of factors is that caregivers of persons with dementia typically experience more stress than other caregivers. They tend to provide longer informal unpaid hours. As noted, of the total 168 hours in the week for which caregivers must be available around the clock, only a weekly maximum 15 hours of respite is provided by the formal service system (which may be increased in exceptional circumstances). One could even conclude that the maximum number of hours of respite provided relative to the number of hours of caregiving work represents a violation of labour standards.

The compromise of caregiver health and safety clearly jeopardizes their productivity over time. They have little time to renew themselves due to the continuous vigilance required to ensure the well-being, safety and security of the person with dementia. The time interval during which care receivers can be left unattended becomes very short as the disease progresses, if they can be left alone at all.

The Alzheimer Society summarizes the three major components of stress that caregivers experience. There are primary stressors such as the disease-related changes in functioning and behaviour that place demands on caregivers. They may have feelings of overload in which they believe that the scope of tasks is greater than their capacity. They also face the strain of performing tasks that are emotionally difficult or feel trapped by the demands of care with little support. Secondary stressors, such as work-related pressures, financial strain and loss of identity, result from the effect of primary stressors. The combination of primary and secondary stressors creates a third stress – the impact on the physical and mental health of caregivers in the form of higher rates of depression, less physical activity and rest, increased medication use and exacerbation of their own health conditions.

### ***Current respite system***

The services and supports for persons with Alzheimer’s disease or related dementia fall primarily within provincial jurisdiction – in the case of Champlain Region, the Ontario Ministry of Health and Long-Term Care. In 2006, the Government of Ontario introduced the *Local Health*

*System Integration Act* that introduced a significant change in the delivery of health care services through 14 Local Health Integration Networks (LHINs) across the province. While the networks do not directly provide health care services, they are responsible for planning, integrating and funding health care services including hospitals, community care access centres, community health centres and support services, long-term care, and mental health and addiction services.

There are several ways in which individuals with Alzheimer's disease or related dementia are referred to various services. The most frequent route is through community care access centres (CCACs) at the moderate stage, which act as the key information and referral agents for long-term care provided in each of the 14 Local Health Integration Networks. In January 2007, the four previously existing community care access centres merged into the Champlain community care access centre. There is a CCAC head office in Ottawa and ten branch offices spread throughout Champlain Region.

The role of community care access centres is to assess the type and extent of need, and to arrange for the provision of homemaking services, personal support services and professional services in response to that need. The centres are intended to act as a 'one-stop shop' so that caregivers and care receivers themselves do not have to negotiate the entire range of supports on their own.

A case manager is assigned to take primary responsibility for conducting the needs assessment and referring the household to the appropriate resources. The CCAC branch offices in Renfrew County and the Eastern Counties are linked to local geriatric teams, a relatively new innovation, instead of requiring care receivers to travel to geriatric assessment units in Ottawa.

A related CCAC role involves discharge planning. Case managers are placed in hospital emergency and ward floors to assist discharged patients who may require some form of placement or at-home assistance. The case managers are part of the hospital's multidisciplinary team. They act as connectors and navigators – e.g., contacting general practitioners to discuss client needs or make links to appropriate community services.

While the survey of service providers carried out for this study confirmed the role of community care access centres as the primary referral agent at the moderate stage, a smaller but significant percentage of individuals access services on their own or through retirement homes. Referrals to community support agencies are also made by First Link, a collaborative program of the Champlain Dementia Network led by the Alzheimer Societies. Designed for individuals newly diagnosed with dementia and their families throughout the continuum of the disease, First Link offers education courses and peer support in the form of caregiver groups.

There are also professional points of entry to various services through general practitioners and psychogeriatric services, though it seems that the latter typically direct clients to the CCAC as the primary gatekeeper. Specialized services, such as neuropsychologists, play a relatively minor role in the referral process but were identified by service providers as the first point of contact when they are trying to cope with an emergency or behavioural challenge.

While a range of services comprise the system of care for persons with dementia and for their caregivers, these supports effectively can be grouped into five major categories: regulated services, home support services, in-home respite, day programs and out-of-home respite.

*Regulated services* consist of services that require professional training and certification. They include personal health care – e.g., bathing; catheterization; various forms of nursing care and professional foot care. Other regulated services involve psychogeriatric services, physical therapy, occupational therapy and the provision of technical aids and assistance.

*Home support services* focus primarily upon care of the home. Home help is available to assist with routine household activities, such as light housekeeping, laundry, meal preparation and delivery, snow shovelling or yard maintenance, and friendly visits. These services are important because they help ensure that care receivers are able to remain in their own residences for as long as possible. Home support services seek to prevent or delay institutional care. In that sense, they contribute significantly to the quality of life of persons with dementia and their caregivers.

*In-home respite* delivers primary assistance to caregivers, through providing one-on-one support, companionship and temporary replacement care, where required, to care receivers. Telephone assurance helps verify well-being and security. Transportation may be made available for medical appointments or essential shopping. In-home respite also includes referral for financial support or other forms of community assistance.

For caregivers, the benefits of sustained in-home respite have been linked with improved mood, reduced emotional distress, less time spent helping with the activities of daily living, and a moderating effect on depression and other health conditions. Problems with in-home respite that affect both persons with dementia and caregivers include the fact that in-home staff may be poorly trained and unreliable; families prefer to have a say in the selection of in-home staff; and fluctuating and inflexible hours of service are determined by the agency without input from caregivers.

*Day programs* are group activities for seniors that include meals, supervision, personal care and counselling. Alzheimer day programs, in particular, organize recreational and activation activities for persons with dementia. There are two basic models of activation employed by these programs: a health model which includes nursing services, and a social model that provides custodial care, social interaction and exercise.

There is clear evidence of the benefit of adult day services to caregivers, in particular, if used regularly and for an extended period. These benefits include less overload and strain, reduced levels of depression and anger, a sense of freedom and ability to participate in personal activities, and high levels of satisfaction. There are also anecdotal reports of benefits to adult day program participants, such as improved mood and participation in activities, enhanced cognitive functioning for people in the early stages, and fewer agitation and sleep problems [Dupuis, Epp and Smale 2004: 40-41].

Out-of-home respite provides care outside of the home – for 24 hours or more in some cases – in order to allow caregivers to take a break. Overnight respite can take place in short-term beds of a long-term home or in specially-built respite homes. The latter accept people with early to mid-stage dementia; those in the later stages of the illness would go to a long-term care home. In either case, the number of available overnight respite beds is limited.

For caregivers, in particular, the primary benefit of overnight respite is that it enables them to attend to essential personal details of their own lives. Reclaiming the calm and quiet of their homes, while temporarily free of the burden of care, is a powerful restorative. Out-of-home respite also enables caregivers to travel out of town for brief periods to visit relatives or friends. Some caregivers may need to attend a special event, such as a university graduation or provide care to a relative who lives in a different city.

Studies indicate, however, that the benefits of reduced stress may be short-lived. While caregivers experience relief during the period of overnight respite, they return to prior stress levels once the person returns home. The evidence with respect to persons with dementia is mixed. Some studies suggest that overnight respite actually can be disruptive to care receivers while, for others, a therapeutically designed short-term stay program can have significant beneficial effects [Dupuis, Epp and Smale 2004].

### ***Guiding principles***

The Aging at Home Strategy, earlier described, means that a framework is already in place in Ontario upon which to build an improved system of supports for caregivers. However, the scope and range of issues identified in the course of this study speak clearly to the fact that substantial work remains. Any changes to be introduced should be shaped by the guiding principles that caregivers themselves have articulated.

The Care Renewal initiative provides important guidance in this regard. Its work speaks to the need for caregiver voice and choice. Caregiver voice means that caregivers should be involved in developing, implementing and evaluating programs and policies that affect them. Caregiver choice refers to the importance of ensuring that caregivers have access to a range of options that meet their identified needs.

These principles are applicable to caregivers of persons with Alzheimer's disease or related dementia. Caring at home for someone with dementia is a continuous and evolving process that varies with the stages of the disease and the personal characteristics of both the person with dementia and caregivers. The same strategies will not work for all.

Caregivers must be actively engaged in identifying the specific interventions that will result in respite. Some caregivers will find it helpful to choose from a range of existing options while others may prefer to design their own package of supports. In seeking to improve the measures that comprise the Aging-at-Home Strategy, these guiding principles mean that



caregivers require services and supports that are sufficiently flexible to accommodate their changing needs.

### ***Key concerns***

This section summarizes the wide range of concerns that caregivers raised in the support groups in which we participated as well as in relevant studies carried out by the Alzheimer Society, and other groups and researchers.

#### ***i. Recognition of caregiver needs and support for their significant role***

##### ***Caregiver recognition***

A focus on the caregiver as a partner in care means that caregivers should be recognized and respected as individuals who are entitled to support from the community and the formal health system, regardless of whether the person for whom they provide care is receiving formal home care services. As partners with health care providers, caregivers should be involved – to the extent that they wish – in the planning, delivery and evaluation of programs and services that affect them directly or indirectly. There is a Caregiver Burden Index that is currently, though not consistently, employed by community care access centre branch offices in Champlain Region.

Research on caregiving under way in the country has been calling for an assessment process for caregivers as separate clients [Guberman et al. 2001]. Their needs should be identified and addressed separately from those of care receivers. It is possible that caregivers themselves have some form of physical or mental condition that requires intervention. A good assessment tool should include outcome indicators in order to monitor whether or not the caregivers are experiencing relief or renewal. Research has also been undertaken on an assessment process to enable caregivers to identify their goals relative to a core basket of community services.

As a result of this view of distinct caregiver needs, proposals have been made to assign a specially trained worker to spend time in the home with both caregivers and care receivers on a weekly or biweekly basis. These workers would be in a position to provide up-to-date information on disease management; suggestions for adapting or modifying routines; ideas for helping care receivers engage in activities that provide relaxation or a sense of routine; and relevant information on nutrition, toileting and bathing – all within a context that encourages caregivers to build their own understanding of the disease. Most important, caregivers would be helped to adopt a healthy emotional perspective. They would learn to recognize their own signs of stress – anger, vivid dreams, depression, hopelessness – and respond to them as signals for action.

It may take some time before such an individualized support system can be put in place. In the meantime, the Alzheimer Society, its First Link program and other services in Champlain Region continue to offer helpful courses and informal training sessions on various aspects of care at home. These educational sessions should be supported and extended where possible. An investment of resources in more telephone support should also be considered. This form of assistance could move beyond the provision of advice only in the event of emergencies. Telephone assurance could include active outreach to caregivers to help monitor the status of the caregiving arrangement.

### *Education about care at home*

Despite exemplary work in this area, there appears to be insufficient training for caregivers on how to care at home for persons with dementia. As care receivers gradually lose their functional capacity, education is required particularly around role reversals, skills needed to assume new roles, how to communicate with someone suffering from a degenerative brain disease and how to assist with activities of daily living – i.e., bathing, toileting, grooming and feeding. There is also a need to help caregivers deliver more medically complex interventions at home and to coach them on ways of providing care for other chronic or medical conditions.

Changes in disease progression and associated “responsive” behaviours also need to be taught to caregivers. If caregivers try to help with bathing, for instance, care receivers may feel violated and may respond by striking out. Care receivers effectively are reacting to circumstances that they perceive as threats. Understanding the motivation and framing it appropriately can help caregivers respond appropriately to the circumstances.

Households experience pressures related not only to physical care but also to legal uncertainties – particularly around individual competence and power of attorney. As noted, caregivers often wonder whether and when they should apply for changes to legal competence. Some believe (incorrectly) that this is a necessary action in order to receive benefits and services. Others fear that they could lose property or enter into a legal quagmire related to joint property and other assets if they initiate this step. Even when it is the appropriate avenue, caregivers often hesitate to seek the status of legal incompetence for care receivers because it is such a significant step in their ongoing story of loss.

### *Information about formal services*

A major challenge for caregivers is to gain access to accurate and timely information about the range of available services for both care receivers and caregivers. The related obstacle is to find their way through this maze of supports. Some caregivers indicated that they did not know where to begin to seek guidance about available supports, had difficulty navigating among different providers or did not obtain services appropriate to the needs of the care receivers.



Entry into the system must be made as easy and transparent as possible. It is also important for caregivers to have ready access to information on how to handle concerns, emergency or crisis situations related to their own needs and to those of care receivers. If too much information is presented at one time, caregivers will retain only what is immediately relevant.

Part of the problem embedded in the navigational maze appears to arise from the inconsistent entry point to various services. Community care access centres, for example, are the gatekeepers for all day programs in the region. While the CCAC conducts assessments for day programs and maintains a centralized waiting list, the specific exclusion policies of individual day programs mean that the ultimate placement decision varies on the basis of those exclusions. Someone may be first on the list, for example, but may have to wait longer for a day program because of toileting or feeding issues.

Similarly, while most service providers indicated that referrals came through the community care access centre, this referral point was not always the case. As noted, many households enter the care system through self-referral or referral through general practitioners.

Another problem arises from the fact that community care access centres see people who are in the moderate to severe stages of dementia. They are not in contact at earlier stages, when symptoms are often not recognized or when care receivers do not yet require help. This relatively later-stage intervention means that care receivers and caregivers are generally hard-pressed for help and already under significant stress by the time they come into contact with the formal system of services and supports. As a result, care planning tends to be crisis driven rather than proactive, systematic and supportive.

Service providers themselves identified problems in the information and referral process. Case managers who work in community care access centres have a heavy caseload of about 120, making it difficult to spend sufficient time or maintain regular phone contact with individual households. Clients themselves must be proactive in seeking help, which usually happens in crisis situations when a problem is extreme or intolerable. Even then, they often must wait for assistance. In one case, for example, it took three weeks before the CCAC case worker was able to get help for a care receiver whose circumstances had taken a turn for the worse.

However, community care access centres face their own staff shortages. Case managers serve a broader group of clients than strictly those with dementia, and are spread thinly across a wide geographic area and range of care needs. One participant noted that the CCAC predecessor unit – the Cog (Cognition) team – appeared to be generally better informed about dementia and available services, and tended to have deep and durable relationships with clients. Their greater depth of knowledge may be linked to the fact that they specialized in dementia-related conditions. However, this unit's orientation is no longer in line with more recent changes that favour continuity of care over care receivers' lifetime and circumstances.

Heavy caseloads also make it difficult to share information between case managers and other service providers involved with a given household. The result is that people must tell their stories repeatedly to a variety of medical and social service providers. Caregivers often feel that the helping process effectively boils down to the continual assessment of needs with insufficient time for the actual provision of assistance to address those concerns.

Overlap and confusion also arise from lack of coordination among different services. An example was cited involving the duplication of efforts from federal Veterans Affairs and the provincially funded community care access centres. The latter maintain vacancy lists but there are gaps in the system. Just under half of the surveyed day programs, for example, reported functioning under capacity while caregivers were noting long wait times to access those same day programs. Improved training of staff in handling various ‘problem’ behavioural responses may help modify the exclusionary practices currently in place and address the underutilization challenge.

General practitioners play a significant role in terms of referral to community agencies. They are often the first line of defense in that they can identify and assess signs of dementia. The problem is that they typically do not recognize dementia until the moderate to later stages of the condition. As a result, the links to specialized services are made at a later time in the disease progression when caregivers may already be dealing with difficult symptoms. Moreover, early detection is the best defense because drugs can slow the process of deterioration that is typical of all forms of dementia.

The challenge of early diagnosis is made more difficult by the shortage of general practitioners. It is possible that patients are not seeing GPs regularly enough to allow them to notice changes in the patient. (It should be noted that this problem is not unique to Champlain Region.) If they are seeing a physician, it may not be a consistent person but rather a practitioner in a group practice, walk-in clinic or emergency department of a hospital.

There is also a serious shortage of geriatric specialists; medical schools graduate only five such specialists a year. There are currently 180 geriatric specialists in Canada and an estimated 1,000 currently are required.<sup>3</sup> The Government of Ontario’s Strategy for Alzheimer Disease and Related Dementia announced in 1999 had pointed to the need to bolster psychogeriatric services throughout the province. But the modest investment clearly has not responded to the fundamental lack of supply of this specialized resource.

Access to information about community resources can alleviate caregiver stress – provided it leads to supports and services. Otherwise, the information can simply add to caregivers’ sense of frustration and isolation. Caregivers need information on how systems work and how to use them in light of the complex array of agencies and funding sources. Information about resources, supports and services must be presented in ways that are culturally sensitive and linguistically appropriate.

### *Eligibility for formal services*

Some services require medical certification to attest to the presence of Alzheimer's disease or related dementia. They also involve an assessment of functional capacity in the activities of daily living, such as walking, feeding oneself and the ability to use the toilet independently. With respect to respite, in particular, the guidelines are based on the needs of care receivers, who must qualify for some form of personal care service before any form of support for the caregivers is considered.

The Resident Assessment Instrument – Home Care (RAI-HC) is the common assessment instrument used by the CCAC branch offices for adults requiring a comprehensive assessment for longer-term home care services or access to a long-term care facility. As noted, RAI-HC's Caregiver Burden Index is used in parts of Champlain Region to help quantify needs. RAI-HC also includes other instruments that provide information about the care receiver – e.g., cognitive performance scale, depression rating scale and pain algorithm.

Community care access centres may further restrict eligibility based on capacity within the system – i.e., the size of the client caseload and the associated available services. For example, the community care access centre might receive a two percent increase in budget but have a 10 percent rise in numbers of clients. It must then determine whether to provide more services to fewer people or less service to more people. One CCAC branch office noted that it engaged an ethicist to help balance the many competing demands.

Legislation and regulations determine how much service to allocate and who is eligible. Regulations pursuant to the *Long Term Care Act*, 1994 outline eligibility criteria for homemaking services as well as maximum time allocations for homemaking and nursing services. The regulations state that care receivers are eligible for homemaking services if they require personal support services along with the homemaking services; if care receivers get personal support and homemaking services from caregivers who require assistance with homemaking services in order to continue providing the required care; or the person requires constant supervision as a result of a cognitive impairment or acquired brain injury and the person's caregiver requires assistance with homemaking services.

The regulations note that community care access centres shall not provide a person with homemaking and personal support services for more than 80 hours in the first 30 days that follow the first day of service or 60 hours in any subsequent 30-day period – i.e., a maximum 15 hours a week. However, a community care access centre may provide more than the maximum number of hours of homemaking and personal support services for a period of up to 30 days if extraordinary circumstances justify their provision.

The regulations for the delivery of nursing services, in particular, are almost unintelligible. Community care access centres “shall not provide a person with more than the lesser of the following amounts of nursing services: 28 visits from a registered nurse or a registered practical nurse in a seven-day period, and the following number of hours of service in

a seven-day period: 43 hours of service if provided by registered nurses, 53 hours of service if services are provided by registered practical nurses or 48 hours of service if the services are provided by both registered nurses and registered practical nurses.” How any case manager – let alone caregiver – can ascertain their eligibility for nursing services is beyond comprehension.

There are no precise formulas, however, for allocating respite for caregivers. The only criterion for in-home respite is that care receivers for whom they are responsible must require assistance for bathing. The latter implies that there has been considerable loss of function because in-home supports for personal care are required. By implication, caregivers must need some form of relief. Some service providers also use their own assessment, which supplements the information from the community care access centre.

Current eligibility conditions set out in Ministry Regulations effectively mean that personal support workers may choose to interpret their mandate very narrowly and stay close to the books. We heard, for example, that some in-home support workers will not put in an extra load of laundry if required or help start a meal if the assessment does not say “meal preparation.” CCAC staff are seeking ways to introduce more flexibility in light of the regulatory constraints within which they must work. The pilot project being undertaken in the Eastern Counties in partnership with the Alzheimer Society of Cornwall and District that provides caregivers at home with self-directed options is demonstrating one way to tackle these barriers.

There are other problems created by inflexible rules in the system. In some cases, caregivers are unable to have their needs met, such as overnight respite, without the signed consent of care receivers. Clearly, this requirement presents serious difficulties when care receivers are either unable or unwilling to sign the required papers.

If the need for respite is assessed separately from the supports for care receivers, then eligibility for respite would be de-linked from the provision of formal services. This de-linking would help advance the notion that respite is not necessarily a formal service. Respite can derive, as noted, from a number of interventions and should not be predicated only upon the type and extent of care receiver need.

### *Caregiver support*

Caregivers in the support groups expressed appreciation for the Alzheimer Society and the critical role played by these groups. Meeting with peers who can offer practical guidance, affirm that they are moving in the right direction and validate their experience was vital to their mental health and ability to cope. There is no replacement for this kind of support. It is invaluable for caregivers to share their concerns in a safe space with others facing similar problems and who understand the challenges.

A poignant moment arose in one support meeting when several caregivers told a participant that the aggressive behaviour of which she was a victim was not her fault. She

appeared to be doing everything humanly possible under the circumstances. Group members also provided advice for her personal safety and protection. It was clear that they had saved her mental health, if not her life.

Many caregivers were grateful to have the Alzheimer Society as their primary contact at the point of diagnosis and found that it was the most helpful link to the range of community programs and information. Several participants, however, were unaware of the possible forms of home assistance despite regular participation in Alzheimer support groups. While physiotherapy that had been arranged by a case manager was deemed to be very good, for instance, at least two members of the support groups were not aware that the CCAC actually could prescribe this service. Another woman whose husband had not bathed in more than two weeks had no knowledge about in-home assistance until her peers mentioned its availability and suggested how she might make the appropriate contact.

Of course, many caregivers and care receivers are reluctant to ask for or accept help because they feel that it represents a loss of independence. In this case, members of the support group provide encouragement to care for their own needs and generally encourage peers to use the available supports, where possible. Despite the scope of resources, caregivers often try to postpone using them in the hope of maintaining a normal environment for as long as possible. Until caregivers really need help, they often do not look for it until they face a crisis.

It was evident that caregivers themselves are often the best source of support and of respite. Many are very knowledgeable when it comes to coping strategies, personal care assistance for care receivers and formal services including various day programs, out-of-home respite and long-term care. The challenge arises from the fact that the voluntary sector capacity to run these groups is limited. Current meetings are organized on a monthly basis only because staff of the Alzheimer Society have heavy caseloads and a wide range of responsibilities. Additional resources should be made available to bolster the frequency of these groups or to train volunteers to help run them.

### *Recommendations*

In summary, the concerns raised in this cluster of issues focused upon the fact that caregivers have needs that are linked to – but significantly different from – those of care receivers. The first need has to do with recognition of the value of caregivers and including them as an integral part of the planning process for care receivers. The second involves the information and training required to effectively carry out the caregiving role. The third relates to the fact that caregivers themselves may experience a range of stresses and associated mental health concerns. Their unique needs should be addressed.

The following policy and program recommendations respond to the importance of recognizing caregiver needs and supporting their significant role:

## *Policy*

- Separate the eligibility for respite for caregivers from the need for services for care receivers.
- Formalize the recognition of caregivers' significant role through a National Caregiver Strategy similar to those already in place in the United Kingdom, Sweden, Australia and New Zealand.

## *Program*

- Increase broad-based delivery of education programs and individualized training for both family and professional caregivers around the physical needs of care receivers with dementia, and its legal and financial implications.
- Enhance access to support and interventions for family caregivers through such means as support groups, and telephone and online support.
- Recognize and address the changing roles that place demands on caregivers including the stress and impact on their physical and mental health.
- Develop and implement a Caregiver Burden Index to monitor caregiver relief.

### *ii. Improvements to the quantity and quality of services*

Despite the wide range of identified concerns, it is important to note that many caregivers expressed positive comments about the system of care in Champlain Region. Some were very pleased with the support they received and felt that the respite providers were trying hard, within the context of their own constraints, to provide good service. While the sample size is too small to conclude that these statements are representative views, they nonetheless should be acknowledged.<sup>4</sup>

#### *Quantity of available services*

Caregivers expressed concern about the lack of services and supports – or in many cases, the limited number of hours of service to which they were entitled. Others noted the pressing need for more services at home if informal caregivers are expected to provide over the long term the bulk of care.

A related problem had to do with sufficient hours for in-home supports. Some caregivers stated that they received one or two hours of assistance a week and that it was simply not enough. One hour rarely provides enough time to do anything; all they could reasonably manage was a fast trip for a few groceries and medications for the care receiver. Another woman from a rural area had received only two hours of in-home help, despite the fact that it took 90 minutes for a return ride for a medical appointment in Ottawa.



Other caregivers noted that they may qualify on paper for a certain numbers of hours of support but in practice receive only half that amount. In the case of one family, only nine of the allocated hours actually were delivered. The caregiver maintains a counselling business and has private insurance to help pay for care beyond the 15 hours a week allotted by the community care access centre.

There is also a shortage of services for younger persons (between ages 40 and 59) with early-stage dementia. The existing supports generally are intended for seniors among whom dementia is most prevalent. Those who develop the disease at young ages face additional barriers in finding appropriate supports that are not linked to programs for the elderly.

Long waiting lists for service, particularly long-term care, were also identified as a serious pressure in the formal care system. One woman reported that it took her case manager a year to get the care receiver into a day program. Caregivers must plan well in advance to ensure that the availability of a respite bed corresponds with the time that they need the support. Ironically, there is a general sense that in a crisis situation, action happens quickly.

In some cases, long waiting lists were the result of the shortage of services. Caregivers expressed a general sense of lack of supports relative to need. This experience ‘on the ground’ is significant in light of the responses to the survey conducted for this study. All categories indicated that their services are underutilized and, in some cases, there is a big gap. More specifically, the following rates of underutilization were reported: 75 percent for regulated services, 55 percent for home support services, 59 percent for in-home respite, 46 percent for day programs and 73 percent for out-of-home respite.

Several reasons were identified for this underutilization including the lack of client and referral agency awareness, caregiver reluctance, the lack of intensive case management to ensure that information is communicated in a timely fashion, service unsuitable for the client’s current stage of dementia, staff shortages and cost. The most commonly cited reason for underutilization was lack of client awareness.

Regulated services reported lack of awareness among clients and referral agents, staff shortages and cost as major reasons for underutilization. For home support services, cost, lack of client and referral agency awareness, and staff shortages were cited as major factors. In-home respite for caregivers identified cost, staff shortages and lack of client awareness as key reasons for underutilization. Day programs made reference to caregiver reluctance and lack of client awareness as factors preventing full usage. Similarly, overnight respite providers identified lack of client awareness, caregiver reluctance and cost as major barriers.

Clearly, there is a need to explore the gap between the perceived lack of services and long waiting lists reported by caregivers and the apparent underutilization cited by service providers. It appears that both caregivers and referral agents are unaware of the range of services in the region or, more specifically, the availability of vacancies when these arise.

There is a need for an improved information and referral service as well as general information for the public. As a way to meet this demand, the Champlain Dementia Network's bilingual website launched a mapping inventory in April 2008 which lists dementia-related services operating in Ottawa, Renfrew County and the Eastern Counties. Services in Lanark County and North Grenville will be added in a second phase of the work. It is hoped that these website materials will help individuals, family members and professionals find and link with appropriate dementia-related services.

The Champlain Region CCAC currently tracks long-term care home beds for the Ministry of Health. A time-limited research project might be initiated to test the value of measures to maintain a better balance between available supply and current demand.

It is possible that there will always be a certain level of underutilization – a natural gap between the posting of a vacancy and the filling of that opening. But even if the service underutilization gap is addressed, there is still a need for investment in the supply of the range of services and supports. The aging of the population and expected increase in the percentage of the population that will experience some form of dementia speaks clearly to the need for an adequate supply of services. Some communities, such as St-Michel in Montréal, are responding to this pressing need by converting a local school that had been identified for closure into a long-term care residence located in the heart of the neighbourhood.

The present scope of services in Champlain Region will in no way be able to respond to the coming rise in demand that invariably will present itself in light of the population shift under way. As noted, an estimated 14,000 individuals in Champlain region currently are affected by some form of dementia and the total numbers are expected to double within the next few years. An investment in supply is essential if the objectives of the provincial Aging at Home Strategy are to be met.

### *Lack of flexibility*

The survey results show that providers in Champlain Region deliver a wide range of services, especially in regulated and at-home categories. On paper, the system looks like a rich and robust package. In practice, the problem arises from the fact that the services which actually are delivered are predetermined in advance. Someone who comes to do laundry usually will not help with basic meal preparation or shopping if those are required.

Rigid job categories or descriptions can prevent a personal support worker from doing anything more than turning on the water, for example, when providing bathing assistance. Lending a strong arm to help climb into or out of the tub or cleaning the floor may be interpreted as going beyond the strict job description. CCAC Champlain staff is working to figure out how to be more flexible in the face of legislation, which is basically too restrictive.



Caregivers frequently made reference to the need to have someone come to the home who could provide a broader range of assistance. While they recognize the importance of respecting the limits and demands on the service provider, most would prefer to direct the assistance as required. In fact, several said that they would like to hire their own support worker and develop the job description. This arrangement would also help ensure consistency in the service.

Clearly, there are costs associated with this option that few can afford. However, there may be possibilities of individualized funding in which the provincial government provides households with the option of going through an agency or receiving a designated amount of funds to help them hire their own service provider for several hours a week.

As noted, the Eastern Counties Caregiver Respite and Relief Project – recently approved by the Champlain Local Health Integration Network – will provide clients and caregivers just such an opportunity. For the next three years, early- and middle-stage dementia patients and their caregivers will be helped to develop care plans which take into account existing needs and then provided up to \$5,000 per year to purchase required supports. The pilot project will afford an opportunity to experiment with greater flexibility in the range of available services. It will also enable caregivers to gain access to relatively modest forms of assistance that support personal dignity and provide respite.

Another example of this kind of individualized approach is the Ontario Special Services at Home program for the parents of dependants with severe disabilities. The program provides funding directly to families to enable them to purchase services for personal development and relief support to child or adult with a developmental disability or a child with a physical disability. Families use the funds to purchase supports that they normally could not provide on their own and are not available elsewhere in the community. For example, families can hire an individualized support worker to focus on specific therapeutic goals with their child or provide respite for the family.

This flexible method of financing is used by several provinces for different purposes. Manitoba offers individualized funds for home care while Alberta and BC support various forms of disability-related assistance in this way.

There are also rigid models of service delivery – e.g., day programs with fixed hours and respite beds available only on weeknights and not weekends. Out-of-home options tend to be institutional, even when they are not long-term care facilities. One caregiver pointed out, for example, that a short-term respite facility did not have a telephone or a television in the room. The caregiver felt that the lack of ‘at home’ features would disorient his wife and he decided to give up the respite option altogether. It was suggested that short-term respite facilities should provide some ‘getting to know you’ opportunities. Care receivers should be allowed to visit for several hours or days before they feel comfortable for longer periods of respite.

The Ottawa Guest House located on the grounds of the Perley and Rideau Veterans’ Health Centre, for instance, is a 12-bedroom bungalow that opened in 2007 and provides short- and

long-term (up to 90 days) respite for people with early- to moderate-stage dementia. Planners at the respite bungalow have addressed virtually all of the identified concerns. Despite their efforts, the Guest House reports functioning at 50 percent capacity since opening in April 2007. In an effort to address this problem, the Guest House is expanding its referral process for six months to include direct referrals from regional geriatric teams and other services.

It is likely that many caregivers are still unaware of this service. It is also possible, however, that some caregivers need to be encouraged to make use of the facility for their own physical and mental health. A study published by the Alzheimer Society cited “growing evidence that the uptake of respite is greater when it is combined with other caregiver initiatives such as education, case management and supportive counselling. These strategies foster a readiness to utilize respite care among caregivers who had not previously considered it an option” [LeDuc and Lennox 2001: 6].

It was noted that there are no long-term (i.e., a week or more) respite options provided at home. The longer-term options would enable caregivers to feel more comfortable taking a holiday, knowing that the care receiver was able to remain at home. Caregivers who wish to care for late-stage dementia patients would not be pressured to opt for placement in a long-term care facility. Rather, they would be provided with the supports they identify as critical to continuing home-based care.

In one group, it was pointed out that Québec is currently experimenting with this model of longer-term respite at home in which a respite provider moves into the home for several days or weeks rather than moving the care receiver, which can be physically and emotionally disruptive for some. Baluchon Alzheimer, for example, is an in-home respite project pioneered in 1998 at the Research Centre of the University Geriatric Institute of Montréal. The respite provider or ‘baluchonneuse’ completes a personality and preferences inventory, compiles a list of difficult situations the care receiver and caregiver have faced, and visits the household for a 24-hour period to learn the precise details of their daily habits. Caregivers may use the service for between 7 and 14 days at a cost of \$100 per day plus travel expenses. The organization receives corporate and private donations to cover additional costs [Gendron and Adam 2005].

### *Inappropriate services*

Day programs were generally seen positively though there were problems, in some cases, with lack of streaming relative to capacity. Some day programs mix old and young people, and dementia patients with persons with developmental disabilities. As a result, many earlier stage dementia clients see themselves as not belonging to the group and refuse to attend. More help is needed to overcome client resistance to attending day programs or to having a stranger come to the house.

One caregiver spoke about the fact that her husband did not want to continue in a day program because he was not as “sick” as the others. His observation was true; because the day

program is based in a rural setting, there are not sufficient numbers of participants to provide a streamed approach in which care receivers are grouped on the basis of type and extent of care. They are together in the same program regardless of capacity – though the fact of qualification means that they all had a certain level of functional loss.

In fact, there is a more general concern about the issue of activation or stimulation. There is a need to build more activation into existing services – particularly those delivered at home. Several caregivers noted that even when respite workers are sent to the home to provide care, they may sit with the care receiver but do nothing more than that. Clearly, it is impossible to generalize; there are many home visitors who do make an effort to engage in more active mental stimulation and whose work was deeply appreciated.

It is also possible to consider a variation on the current method of service provision. In South Australia, for example, there are several ‘home clubs’ in which a trained homemaker looks after three or four individuals with dementia. It is a more personalized service than a larger centre-based day program and has been found to work particularly well in rural settings in which there may not be sufficient people to create a program that is relevant to need.

In addition to actual or perceived shortages, there appear to be many inappropriate placements – especially in long-term care facilities, where applicants are required to take the first available bed. When considering placement for long-term care, caregivers are asked to identify their top three choices in the region. If any one of these choices becomes available, applicants are not permitted to wait for a bed in the other two facilities. The need to be ready to radically change life circumstances “at a moment’s notice” creates considerable stress and anxiety. If care recipients do not avail themselves of the opportunity, their names are put at the bottom of the list and they have to start the waiting process all over again.

One caregiver told the story of the placement of her husband at the Royal Ottawa Hospital, a local psychiatric facility. It was the only available bed to which he could move after a stay for treatment at a local hospital where he was deemed to be the proverbial “bed blocker.” The other patients in the psychiatric facility were functioning at a capacity well below that of the individual in question and his wife feared that he would deteriorate rapidly in the absence of active communication and mental stimulation.

### *Personnel issues*

Caregivers and care receivers want to have access to and support from the same providers on a consistent basis. While this factor is important for all households, it is crucial for persons with Alzheimer’s disease or related dementia whose condition often generates fear or paranoia. Consistency and routine can help with this uncertainty.

Problems frequently arise on the weekend, in particular, when caregivers take time off to be with their own families. Caregivers often do not know who will come to the home or whether

they will get service at all. One respondent noted that it was the responsibility of the service providers to call clients and to make their own time arrangements on the weekends. A provider who consistently called late on Friday evening would say that she had available only very early morning appointments, which were not appropriate for this particular care receiver.

The majority of service providers indicated that providing continuity of person (same employee visits the care receiver each time) was not an issue. The community care access centre strives for continuity when assigning care – in fact, it is a goal against which it measures service provider performance. However, agencies also reported difficulty in attracting and retaining staff, particularly nurses and personal support workers. This discrepancy indicates a human resources supply difficulty: Though agencies clearly strive to ensure continuity, the current training and employment system is unable to keep up with demand. This issue must be addressed across the board, not by single agencies alone.

Perhaps even more important than consistency is the fact that service providers must be both technically competent and responsive to the preferences of caregivers and care receivers. Ideally, service providers become like trusted family members who are partners in providing care rather than solely professionals determining the type and quantity of care to be delivered. Caregivers will not achieve respite as an outcome unless they trust that the care receiver is content, well cared for and supported.

The need for improved training at all stages in the care process was noted by caregivers and in relevant literature produced by the Alzheimer Society of Ottawa and Renfrew County. General practitioners are often identified as the first line of dementia identification. In Renfrew County, for example, general practitioners are generally the entry point for patients who need diagnosis and referral to geriatric assessment teams.

While ongoing training sessions on geriatrics and dementia are offered to doctors and nurses in long-term care facilities in Champlain Region, these programs typically attract the same small group of committed health professionals. Family physicians are invited to these sessions, but they are generally held in the evening – adding to an already heavy workload. The problem of lack of training is exacerbated by the short supply of general practitioners in the Region.

Home support workers must also have thorough knowledge of dementia. Though virtually all surveyed agencies reported providing training for their staff, there are wide variations in the amount, quality and application of the information. Similarly, agencies reported communicating with families about care recipients, but the quality and frequency of those interactions are not monitored or documented.

Cultural diversity must be considered along with barriers arising from the relative lack of services in French. Supports and services should respect cultural attitudes towards health and sharing of personal information. One positive example identified in terms of cultural appropriateness was the long-term care facility in Ottawa's Glebe neighbourhood that has a unit for Chinese-speaking residents.

Sometimes care receivers and caregivers have preferences around their comfort with persons from different cultural backgrounds. The community care access centre sends the preference information to the agency supervisor who attempts to make a suitable match. Clients or assigned workers who are uncomfortable may request a review of the arrangement.

Finally, recruiting and retaining workers in rural and remote communities can be difficult and expensive because of travel distances. But this problem is by no means the only issue relevant to rural and remote areas.

### *Challenges in rural areas*

Special considerations were identified with respect to smaller towns and rural areas in particular. On the one hand, their small town character is positive in that people know each other and tend to look out for each other with a “neighbourhood watch” atmosphere. The Legion and church groups are also supportive though they generally do not provide badly needed transportation (discussed below).

On the negative side, there may be fewer formal and informal supports. At the formal level, rural areas lack the economies of scale to set up full services. This reality has led, in some cases, to inappropriate services, earlier described, in which people at different levels of functioning and with diverse needs, for example, are grouped together into a single program.

Caregivers in rural and remote communities often find that services and supports are few and far between, geographically distant or even nonexistent. Transportation services are expensive and do not provide accompaniment – it can cost \$150 to get to an appointment in Ottawa. The isolation of caregivers can be especially acute in these communities.

The lack of informal supports is particularly difficult to resolve in rural areas because of several complex demographic factors. Many retired and elderly Canadians are returning to rural areas where they grew up. At the same time, young people are moving increasingly to cities. As a result, the population ratios point to the fact that rural areas appear to be aging more rapidly than the rest of the country.

Many young people leave rural and remote areas for larger centres and are unavailable to provide primary care or even secondary support or relief. Caregivers in rural areas are often asked to assume care responsibilities well beyond reasonable expectations. The ‘young old’ are caring for the 85-plus group – the fastest growing segment of the population. There are 70-year-old volunteers, for example, who are delivering Meals on Wheels. These respite providers themselves are tired and in need of relief.

## *Recommendations*

In summary, the concerns raised in this cluster of issues focused upon the fact that caregivers experience two major types of problems around the delivery of supports and services for Alzheimer's disease and related dementia. The first has to do with the quantity of available services, including the number of hours for in-home support and the waiting time for services like day programs and long-term care. The second group of issues in this cluster is rooted in the quality of service provision – i.e., the flexibility of current arrangements, their appropriateness relative to the needs of care receivers and caregivers, and the quality of staff training. A unique set of concerns was raised about the gaps in service in rural areas and the challenges arising from travel distances and associated costs.

The following policy and program recommendations respond to the wide-ranging concerns regarding the quantity and quality of services:

### *Policy*

- Extend the maximum number of hours available for in-home services and change the formula for assigning hours to include – as part of the eligibility assessment – caregiver and care receiver needs, disease progression, change in roles and caregiver coping.
- Introduce greater flexibility in the provision of supports at home, including the availability of individualized funding and self-directed care to enhance responsiveness to the needs of caregivers and care receivers, and programs like the successful Veterans Independence Program (VIP).
- Introduce greater flexibility in the eligibility criteria to ensure service availability for those with dementia under the age of 65.

### *Program*

- Ensure that professionals and service providers receive improved and ongoing training for addressing the continually changing needs of persons with dementia. Training should be culturally sensitive and linguistically appropriate.
- Ensure caregivers be involved in the development, implementation and evaluation of the services provided to them.
- Encourage home care providers to carry out basic animation with care receivers, where feasible, rather than only friendly visiting.
- Analyze and address gaps in the underutilization of services.

### ***iii. Reduction in the costs and financial pressures associated with caregiving***

While financial pressures and economic security were not the focus of this study, the economic aspects of caregiving were identified as a concern by members of the support groups in



which we participated as well as in related research. Caregivers who are trying to balance their personal responsibilities with paid employment may find that their financial circumstances are affected, both in the short- and long term.

### *Additional costs*

At the very least, most households incur additional costs related to caregiving whether in the form of home modification, purchase of technical aids and equipment, fees for professional services or miscellaneous costs, such as hiring a sitter even for short outings because care receivers no longer can be left safely alone. Two-thirds of caregivers spend more than \$100 per month on caregiving, such as home modification, drugs and other supplies.

For example, a new treatment for Alzheimer's disease, the Exelon Patch, has just been approved by Health Canada for use in this country. However, its cost is not covered under any public formularies. At \$4.29 per day, caregivers would have to pay \$128.70 a month or \$1,544 a year – a considerable expenditure, particularly for households on fixed income.

The survey of organizations providing respite indicated a wide range of hourly costs associated with care provision (depending on service and geographic area) – from a maximum hourly rate of \$35 for regulated services, \$30 for home support services, \$24.36 for in-home respite services, and \$30 for day programs. Out-of-home respite services range from \$32.37 an hour and up.

Many agencies report providing subsidies, but the levels of support and determination of need are wide-ranging and tend to rely on the personal judgment of agency representatives. In-home respite – the preferred choice of families that feel more at ease leaving the care receiver in the comfort of their home environment – is an expensive option. Economies of scale are possible in a long-term care home. Studies have found that in-home respite can be twice as expensive as day centre respite and that in-home overnight respite is more expensive than facility-based respite [Leduc and Lennox 2001: 6].

With respect to immediate costs, there is a grant program and two major federal tax credits relevant to caregivers of persons with Alzheimer's disease or related dementia.

The costs of home modification, in particular, may be partly offset through the federal Home Adaptations for Seniors' Independence, which helps homeowners and landlords pay for minor home adaptations to extend the time low-income citizens can live independently in their own homes. Assistance of up to \$3,500 is provided as a forgivable loan.

Homeowners and landlords may qualify for this assistance as long as the occupant of the dwelling in which the adaptations will be made is 65 or over; has age-related difficulty with daily living activities; and has total household income at or below a specified limit for the area of residence. The dwelling must be a permanent home, and adaptations should be minor items

that meet the needs of seniors with an age-related disability – e.g., handrails, easy-to-reach storage areas in the kitchen, lever handles on doors and walk-in showers with grab bars and seats.

The two federal tax credits – the caregiver and infirm dependent credit – are not linked to specific costs *per se*. Rather, they are ballpark amounts which recognize that caregivers taking care of individuals with severe impairment in function likely will incur a range of additional costs. The credits effectively acknowledge the extra costs of caregiving – though these measures provide relatively limited financial assistance.

The caregiver credit allows a federal tax reduction of up to a maximum \$655 in 2008 – calculated as 16 percent of \$4,095. Average provincial and territorial tax credits are worth an estimated 50 percent of that amount for an additional \$328 in tax savings. Income taxes can be reduced by a total maximum \$983. Eligible claimants must be providing care in their own home for a dependant whose net income for the year is \$13,986 or less and who is the caregiver’s or spouse’s parent or grandparent aged 65 or adult infirm dependent relative aged 18 or over. A partial claim may be made if the relative’s income is between \$13,986 and \$18,081.

The infirm dependant credit also allows a federal tax reduction up to a maximum \$655 in 2008 – calculated as 16 percent of \$4,019. Average provincial and territorial tax credits are worth an estimated 50 percent of that amount for an additional \$328. Income taxes can be reduced by a total maximum \$983. The infirm dependant credit provides a tax reduction for individuals supporting an infirm dependant aged 18 or older who is a relative living in Canada and whose net income for the year is less than \$5,811. A partial claim may be made if the relative’s income is between \$5,811 and \$9,906.

While these modest amounts are important, they are limited in scope. The tax reductions permitted through these tax credits are not delivered to households as cash payments. Rather, these reductions are the amounts that can be deducted from tax owing. Therein lies the catch. Many households are not in the taxpaying threshold that allows them to benefit from these credits. Tax credits are therefore not helpful to many Canadians, notably lower- and modest-income households that derive little or no benefit from current measures.

After studying the effectiveness of these provisions, the Technical Advisory Committee on Tax Measures for Persons with Disabilities had pointed to the need to make these credits “refundable.” The proposed change means that even households which fall below the required taxpaying threshold would receive a payment of cash if they otherwise qualify on the basis of the definition.

The medical expense tax credit also provides modest assistance for costs. Unlike the caregiver credit and the infirm dependant credit, the medical expense tax credit is intended for costs that can be listed or itemized. Medical expenses for the taxpayer, the taxpayer’s spouse or common-law partner, and dependent children under 18 may be claimed. Only expenses in excess of the lesser of \$1,925 (in 2007) and 3 percent of net income can be claimed.



The problem with the medical expense tax credit is that few Canadians would know the long list of items that are included as a claimable medical expense. Second, the expenses must exceed a certain level in order for them to be claimed. Finally, as in the case of the other tax credits, households' income must be higher than the taxpaying threshold in order to benefit from this measure. As a result of these features, many households are unable to take advantage of this tax credit.

A response that helps address these limitations involves the direct payment of a designated amount to households that qualify on the basis of designated circumstances – e.g., a veteran in the family, a child with a severe disability or in this case a person with dementia. As noted, the Caregiver Respite and Relief Project currently is testing this type of initiative under the Innovations Stream of the provincial Aging at Home Strategy.

The Multiple Sclerosis Society of Canada has experimented with the provision of a small amount of cash to help caregivers offset some of the additional costs. The Caregiver Wellness Funding Pilot Project made available funds up to a maximum \$300 which caregivers could use for activities, services or supports that would provide them with respite – including a holiday, household help and use of fitness facilities. An evaluation of the initiative found that the great majority of caregivers reported satisfaction with the personalized nature of these funds. The most common benefits reported by caregivers were relaxation, stress reduction, peace of mind and time for caregivers to be by themselves. Other results included overall contribution to health and well-being, positive effect on care receivers and caregiver recognition.

Veterans Affairs Canada provides individualized funding in the form of small grants to be spent on self-determined caregiver needs. The Veterans Independence Program was introduced in 1981 as an alternative model of care for aging World War II veterans. It serves an estimated 103,000 clients nationally.

The Veterans Affairs program is based on the principles of dignity and independence. It seeks to create a comprehensive continuum of care that includes early intervention, home support, self-managed care and chronic long-term home care. Under the program, care receivers and caregivers have access to a wide range of supports and services including dental benefits, prosthetics and orthotics, technical aids and equipment, physiotherapy, medications, massage, health-related transportation, homemaker services and time off for respite – virtually anything that the family requires. Needs are assessed by a caseworker and they are all considered acceptable within reason. Identified needs are then translated into a designated amount of funds for the purchase of goods and services.

An evaluation of the program published in 2004 found that it is highly valued and appreciated. Individual providers are perceived to offer greater flexibility, enhanced security and better quality service than agency providers. However, lengthy delays in reimbursement were identified as a major source of frustration. Provider shortages in rural areas were also found to hinder access to the program.<sup>5</sup>

In addition to the burden for households, there are significant societal costs – about \$5.5 billion a year – associated with Alzheimer’s disease and related dementia. These costs were estimated on the basis of the use of nursing home care, medications, community support services by caregivers and unpaid caregiver time. The annual societal cost of care per individual with Alzheimer’s disease is an estimated \$36,794 for those at the advanced stage of the disease, \$25,724 for persons at the moderate stage, \$16,054 for those with mild to moderate disease and \$9,451 for mild disease [Alzheimer Society nd].

### *Economic security*

In addition to immediate costs, the economic security of caregivers is affected in other ways – e.g., refusing a job offer, promotion or transfer; changing or resigning from a position to accommodate caregiving responsibilities; reducing the number of hours worked; or being absent from work because of caregiving responsibilities. Employed caregivers often lose income, benefits and pension in the attempt to balance their work and family responsibilities.

Holding a job and providing elder care at the same time frequently cause stress, depression and burnout that can lead to absenteeism and turnover. Employees with elder care responsibilities tend to be more overworked than employees without these responsibilities [Galinsky et al. 2005]. The *Wall Street Journal* reported in 2001 that elder care was becoming as big an issue in the United States as child care, and likely will loom even larger in near future, with close to two-thirds of employees younger than age 60 believing that they will have elder care responsibilities within the next 10 years [Greene 2001].

The cost to US business from lost productivity of employees caring for elderly family members is estimated at more than \$33 billion per year, according to a MetLife Caregiving Cost Study conducted in 2006. The average caregiver costs an employer \$2,110 per year in absenteeism, turnover and lost productivity [Dobkin 2008].

With greater numbers of workers expected to be caring for elderly relatives in the future, employers can play an important role in enabling employees to cope with these demands. Greater flexibility in work schedules and periods of leave can help accommodate caregiving responsibilities. Up-to-date information about community resources and services can ease the arduous navigational journey. Some companies make available financial assistance to offset the additional costs of caregiving.

In recognition of the fact that many employees face child care and elder care responsibilities at the same time, several US companies have begun to expand their child care facilities to include day programs for the elderly, where appropriate. Employers are starting to consider an innovative work-family benefit called intergenerational care, in which children and elders go to the same facility [Matthes 1993].

In order to find effective solutions, employers and unions must partner to enhance current leave provisions and institute flexible work arrangements for caregivers. The federal and provincial labour codes need to support and promote family-friendly workplaces by expanding eligibility requirements and flexibility around provisions for those with dependent care responsibilities.

Research on caregiving has also called for enhancements to the Employment Insurance compassionate care leave provisions. Compassionate care benefits may be paid up to a maximum of six weeks to a person who must be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks.

Unemployed persons on Employment Insurance can also apply for this leave. To be eligible for compassionate care benefits, applicants must show that their regular weekly earnings from work have dropped by more than 40 percent. Applicants must also have accumulated 600 insured hours in the last 52 weeks or since the start of the last claim.

In response to proposals to improve the reach of the compassionate care leave provisions, the federal government has expanded the definition of “family.” Other possible changes include the provision of benefits for chronic but not necessarily palliative conditions and increasing the length of benefit beyond six weeks to include other crisis times during the caregiving career.

Additional proposals include an expansion of the drop-out provisions within the Canada Pension Plan to permit periods for caregiving, similar to the drop-out periods allowed for children. The Canada Pension Plan is a social insurance scheme that is attached to workforce participation and is based on average earnings between the ages of 18 and 65. It does not provide support during the time an employee is off work. Individuals who leave the paid workforce or who are employed part time are reducing their average employment income and limiting their eligibility for disability benefits.

The Canada Pension Plan currently permits workers to exclude from calculation of pensionable earnings the years when they stopped work or had lower earnings while they had a child under age 7. Caregiver studies in Canada have proposed an expansion of the drop-out provisions in respect of care for children to include care for an infirm relative.

Finally, it is of interest that several countries throughout the world have taken significant steps to recognize the economic burden of caregiving. In the United Kingdom, for example, the National Strategy for Carers has been in place since 1999, along with three separate Acts of Parliament: the *Carers Recognition and Services Act* (1995), the *Carers and Disabled Children’s Act* (2000) and the *Carers Equal Opportunity Act* (2004). Carers now have the right to an assessment of their need. The 1999 National Strategy for Carers has been updated with a package of reforms introduced in June 2008 as part of a New Deal for Carers. Support is provided directly to caregivers, who are also eligible for social security, sick days and vacation.

Sweden offers direct payment options and pension credit accrual as well as a comprehensive leave policy. The Carers Allowance is equivalent to the rates charged by formal home help service providers. Under the terms of the *Care Leave Act*, carers of terminally ill family members are eligible for 60 days of leave paid at 80 percent of salary. Those deemed eligible by a home care assessor can receive cash to hire external care or pay a person from home – though the municipality is the employer and not the care receiver.

Australia introduced carer policies more than ten years ago. Financial support is provided through direct compensation, and a home care and respite care package. A motion calling on all levels of government, businesses and schools to consider adopting carer-friendly work and learning practices was unanimously supported in the federal Parliament in October 2006.

In April 2008, New Zealand launched a national Carers' Strategy to achieve improved recognition and support for New Zealand's carers. In partnership with the Carers Alliance, the Strategy sets a strategic direction for developing policies and services for New Zealand's carers over a ten-year period, starting with a five-year action plan.

### *Recommendations*

In summary, the concerns raised in this cluster focused upon the fact that caregivers typically experience financial stresses that arise from two sources. The first relates to the additional costs associated directly with dementia and include fees for home care services, transportation costs for medical appointments, drug dispensing fees, technical aids and equipment, and home modification. The second set of financial pressures derives from the insecurity related to employment circumstances for caregivers who may be active in the labour market. Many reduce the number of hours of paid work or leave their jobs entirely in order to carry out their caregiving responsibilities. Those without leave, insurance coverage or pension protection risk their economic security.

The following policy and program recommendations respond to the wide-ranging concerns related to the costs and financial pressures associated with caregiving:

### *Policy*

- Renew the Home Adaptations for Seniors' Independence program when the funding commitment expires in 2009.
- Expand the leave provisions in federal and provincial labour codes.
- Extend the compassionate care leave provisions under the Employment Insurance Act to allow special leave for care for persons with progressively degenerative conditions, such as dementia.
- Extend the drop-out provisions of the Canada Pension Plan to cover caregiving for persons with moderate- and late-stage dementia.

- Consolidate the application for government funded subsidies into one centralized access point.

### *Program*

- Research the allowances and other supports for caregivers available elsewhere in the world, such as the National Strategy for Carers in the UK.

### **Conclusion**

The individual measures proposed in this study would improve significantly the delivery of supports and services to the caregivers of persons with Alzheimer’s disease or related dementia. However, the proposals are simply that: a set of disparate measures. Ideally, governments will consider a series of linked actions as part of a broader caregiving strategy.

The Ontario government has taken important steps in this regard through its earlier Alzheimer Strategy and more recent Aging at Home Strategy. The challenge at this time is to develop further the many components that comprise these initiatives and to ensure their integration. Perhaps most important is to pay special attention to the voice and choice of caregivers so that they can identify their unique needs and design the most appropriate responses that together provide an authentic sense of respite.

### **Endnotes**

1. All appendices to this study are available on the Caledon Institute website. Follow this link: [www.caledoninst.org/Publications/PDF/679ENG.pdf](http://www.caledoninst.org/Publications/PDF/679ENG.pdf)
2. Statistics Canada. (2003). *General Social Survey Cycle 16: Caring for an aging society*. Ottawa, Catalogue no. 89-582-XIE.
3. Presentation by Dr. Bill Dalziel, Chief, Regional Geriatric Program of Eastern Ontario, on Early Screening and Diagnosis for Dementia, Ottawa, January 16, 2008.
4. Caregivers generally reported a good relationship with their case manager from the community care access centre. Many caregivers had positive things to say about the local long-term facilities and simply want more of them. The Memory Loss Clinic and Drug Trials Unit at the Bruyère Centre were identified as exemplary programs. Visiting these clinics helped to reduce tension – the care recipient was in the hands of experienced professionals who could put medical terminology and ‘normalcy’ around the patient’s current behaviours. The foot clinics at Carefor health and community services – even though people had to go out of the home to access them – were seen as a critically important service.

Visiting home care workers were positively reviewed – caregivers reported being able to request the same worker and good relationships had developed with the care receiver. Service providers coming into the home to provide hair washing, nursing care or visiting were chatty and related well to the care receiver, which gave the caregiver time to go out or do other housework. Caregivers expressed appreciation for Safely Home, the

bracelet identification program initiated by the Alzheimer Society. The Department of Veterans Affairs also makes available an identification bracelet, which was found to be important for protecting people who wander. Handicapped parking permits made it easier to assist with visits for medical and other appointments.

5. [www.vac-acc.gc.ca/general/sub.cfm?source=department/reports/deptaudrep/vip\\_baseline#exsummary](http://www.vac-acc.gc.ca/general/sub.cfm?source=department/reports/deptaudrep/vip_baseline#exsummary)

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