

The Dementia Respite Bungalow

Caring for caregivers

The 1994 Canadian Study of Health and Aging¹ estimated that in 2001, 365,000 Canadians would be affected by Alzheimer Disease and related dementias, and that by 2031 that number would rise to 725,000. This figure, combined with Canada's declining birth rate, will create an enormous burden of care for a proportionately smaller younger generation. As caregiver supply is outstripped by demand, home care and respite will become vitally important commodities. Even now, these services and supports are in short supply.

Earlier diagnosis of Alzheimer Disease and new medications are improving treatment and management options for those living with the disease. Alzheimer generally lasts between 10 and 14 years, but medication can help the individual maintain a certain level of functioning for a number of years.

The cost of caring for someone in the early stages of Alzheimer Disease is approximately \$9,500 per year, but if the individual lives long enough to become more severely affected by the disease and requires placement in a long-term care

facility, that figure rises to \$37,000 [Hux et al. 1998]. Besides assuming some of the expenses of care, there is a human cost being paid by caregivers. Each of them represents another potential casualty of the disease as their physical and emotional reserves become drained.

Dementia is experienced as a progressive, severe decline in intellectual abilities which results in memory loss, personality changes and poor reasoning. The most common forms of irreversible dementia are: Alzheimer Disease, mixed Alzheimer Disease, vascular dementia (caused by stroke), Lewy Body and Fronto-temporal dementia. Less common forms are Pick's Disease, Parkinson's dementia and Huntington's dementia.

Placement in a long-term health care facility is appropriate for those in the later stages of Alzheimer and related dementias, but it is generally in the early and middle stages that care providers (most often spouses and children) begin to suffer the strain of providing ever greater levels of care. As the illness progresses, people are able to do fewer things for themselves (e.g., bathing, shaving, dressing and cooking) and their behaviour becomes more unpredictable. They may wander from home,

become extremely agitated, turn day into night and, in some cases, experience severe behavioural changes. Caring for such a person becomes a progressively heavier burden and it is not uncommon for caregivers themselves to become physically or psychologically ill. In fact, caregivers of people with dementia are twice as likely to experience depression, if employed, they are absent 50 percent more often than their colleagues, and as a group, they are more likely to develop chronic health problems [Canadian Study of Health and Aging 1994b].

Respite can be understood as “anything that contributes to caregivers’ emotional, spiritual, physical, and/or social rejuvenation enabling them to have the reserves and resources they need to care for their family member or friend” [Meredith 2003]. Respite might include having the care receiver attend a day program, hiring a home care provider to help with grooming, using a cleaning service or allowing someone else to look after the care receiver while the caregiver attends support group functions. By extending a caregiver’s physical and psychological resources, respite may extend the amount of time a person may be cared for at home.

The Dementia Respite Bungalow Project

The Perley and Rideau Veterans’ Health Centre (PRVHC), the Alzheimer Society of Ottawa and the Victorian Order of Nurses, Ottawa Branch, are planning the construction of a 12-bed respite bungalow for those with dementia and their caregivers. This dwelling will be a temporary home away from home for people experiencing mild to moderate levels of dementia, and will provide their caregivers with breaks ranging from several hours during the day or night to three weeks of continuous care, for a maximum of 60 days each year. It is hoped that emergency and flexible placements will be possible.

The dementia respite bungalow will be situated on the PRVHC site, which itself is in a residential Ottawa neighbourhood. A registered nurse will oversee admissions, plans of care and the administering of medications, and a minimum of two staff members will be on site at all times. A client care worker will manage each person’s physical, social, emotional and spiritual care.

The bungalow will have the look and feel of a home and will be set up to encourage people to carry on normal household routines (e.g., cooking, gardening, grooming and cleaning). Each single bedroom will be equipped with a washroom and shower. The facility will be fully secured but also will include an enclosed garden and pathway to allow visitors the chance to enjoy the outdoors. Common spaces (i.e., kitchen, dining room, study and living room) will support the 24-hour activity patterns common among those with dementia.

Life at the bungalow will offer a variety of activities, given the easy access visitors will have to PRVHC services. These include hairdressing and foot care, craft and recreation rooms, pub, gift shop, dental facilities, training room, auditorium and library. The Alzheimer Society of Ottawa office (which offers family support and education programs) and a VON day program also are located at the PRVHC. Trained volunteers, including high school students who are accumulating community service hours, will improve the client-to-staff ratio and provide an interesting mixture of personalities and capabilities.

The cost of building the respite bungalow will be \$2 million. Its annual operating budget will be approximately \$500,000, a portion of which will be paid by the families using the facility. The three partner organizations have submitted a proposal to the provincial Ministry of Health and Long-term Care to transfer the operating license of 11 beds from another long-term care facility to the bungalow project. The beds will be purchased at a cost of

\$132,000 (\$12,000 per bed) and will include the same level of provincial funding as would be available for beds in long-term care facilities. The initial purchase expense and building costs will be raised through a public capital campaign; no funding is being requested from the provincial government. A twelfth bed will be funded by another, as yet undetermined, sponsor. Once ministry requirements are satisfied and approval for the project is granted, the bungalow will be ready to open within 18 months.

The impetus for the bungalow project came from a 2001 City of Ottawa research study that identified dementia respite as a number one priority [LeDuc and Lennox 2001]. The Ottawa bungalow project underlines the fact that support for caregivers of people with dementia is lacking, and there is a great need for respite alternatives. The current practice of using long-term care facilities as short-stay respite facilities has met with resistance from care recipients and their caregivers for a variety of reasons. Associating with late stage sufferers is often frightening to those in the early and middle stages of the disease. Institutional facilities do not offer the ‘cues’ of a home-like environment. Moreover, respite patients pose administrative and care challenges to long-term care staff where employee-to-client ratios typically are ten to one. Most significantly, using long-term facilities for respite care forces caregivers and recipients to prematurely forge a connection with the later-stage reality of long-term care – a link which caregivers are often unready and unwilling to make.

There are 10,000 people in Ottawa with dementia; half of that number already are in long-term care facilities. The remaining 5,000 have only three secure beds available to them for respite; these are located in long-term care facilities and so are inappropriate respite options for those with mild to moderate stages of dementia. By 2005, there will be 12,000 people with dementia in Ottawa; half will need community supports of some kind [Hopkins 2000].



Care and courage – Phyllis Laroque

After six years of looking after her husband, Ken, an Alzheimer patient, Phyllis Laroque realized she needed a rest. Her social worker helped her find a day program for Ken, and the experience was positive for both husband and wife. A short stay at a long-term care facility was equally successful, and because of similar respite experiences, Phyllis was able to continue caring for Ken at home for another four years. Handing over the caregiving reins was difficult at first, but Phyllis soon saw how important it was for her to have time to do things for herself. Says Phyllis: “I felt guilty about getting some time off to garden or visit with friends, that I was a traitor and being selfish. I wasn’t aware of generally how well people tolerate respite programs and services. I would recommend to all caregivers that they take a break – the sooner, the better.”

Transitional programming like the bungalow project will provide important results in the area of best models of care for the individual and the caregiver. The cost to families using the bungalow will be \$30 per day, compared with \$49 charged each day to clients in a long-term care facility. The partner organizations are investigating payment solutions for low-income families that are unable to afford the daily fee.

Changing the way we look at caregiving

Despite the difficulties of looking after an individual with dementia, a research study undertaken by the City of Ottawa discovered that caregivers are extremely reluctant to give up care of their family member at any point in the illness [LeDuc and Lennox 2001: 27]. A strong sense of duty, combined with the belief that a short-term placement will hasten the transition to long-term care, has made it difficult to convince caregivers that respite options should be exercised early and regularly.

“Our work has shown that people who access respite services and supports are very pleased with both the assistance and its impact on their state of mind,” says Kathy Wright, Executive Director of the Alzheimer Society of Ottawa. “Often, however, caregivers may not recognize the signs of their own increasing stress until a crisis occurs, and then it may be too late in the illness for respite to be the appropriate care solution.”

Canada’s health care system traditionally focuses upon patients rather than caregivers. Recognizing caregivers’ role as primary care provider and encouraging them to see themselves as valuable members of a health care team is the key to changing this attitude. Health care professionals receive regular training and time off. Many caregivers have been worn out by what is described as the “36-hour day” of caring for a person with dementia.

The success of the dementia respite bungalow will be determined partly by its ability to overcome this perception and be seen as a life-enriching resource, supportive of caregiver and care recipient alike.

Anne Makhoul

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Endnote

1. The Canadian Study of Health and Aging (CSHA) was a population-based, cohort study of the epidemiology of dementia in Canada. It involved 10,263 participants aged 65 or over. A team of more than 60 investigators (i.e., clinicians, epidemiologists, social scientists, psychologists and others) collaborated in 18 study centres across Canada. Data were collected at 5-year intervals: CSHA-1 in 1991, CSHA-2 in 1996 and CSHA-3 in 2001. (For more information on the study, visit: <http://www.csha.ca>)

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