

## Caring for the Caregivers\*

In a world in which credentials count more than ever, even so-called McJobs involve skills and training. The majority of new jobs in this country call for some form of postsecondary education and at least 25 percent of these positions require a university degree. Fast-paced advances in knowledge mean that it is not just nice – but indeed essential – to have access to continual opportunities for skills upgrading.

So how is it possible, in an era in which knowledge and training are vital for virtually every job, that millions of Canadians carry out their work with little information or preparation – and practically no support? Yet that is exactly what happens when it comes to family caregivers.

Caregivers assist individuals with a wide range of conditions, including Alzheimer's disease and other forms of dementia. Caregivers deliver palliative care at the final stages of life, and assist both children and adults with severe disabilities. They

also take care of individuals over age 65 and the frail elderly.

Clearly, not all seniors require care. Most remain active and healthy, and may need only minor or modest help with some functions of daily living, care of their home or transportation. However, Canada's aging population includes a growing proportion of very old and frail seniors. The concern is that the incidence of cognitive impairment, commonly known as 'dementia,' rises dramatically with age.

Caregiver tasks include duties inside the house such as meal preparation, housecleaning, laundry and sewing; home maintenance and outdoor work like snow removal; transportation; grocery shopping; banking and bill paying; and personal care such as bathing, dressing, toileting and grooming. Many caregivers also play an important brokerage role by coordinating the various services that care receivers may require.

\* *January is Alzheimer Awareness Month. A full report on this issue entitled Caregivers and Dementia by Sherri Torjman and Anne Makhoul was published in June 2008 by the Caledon Institute of Social Policy and is available at [www.caledoninst.org](http://www.caledoninst.org)*

While the concerns of caregivers of persons with dementia are similar to other caregivers, there are also unique challenges. Alzheimer's disease and related dementia are progressively degenerative conditions that can last up to ten years or more. Symptoms gradually become more debilitating as those affected 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 ongoing impairment in their ability to perform personal activities 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 dementia-related conditions, the burden of physical care increases over time. Many caregivers report that they are virtually on call around the clock.

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.

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 personal activities. There is also a need to help caregivers provide more medically complex interventions at home and to

coach them on ways to deliver care for other chronic conditions.

Changes in disease progression and associated behaviours should also be taught. When caregivers try to help with bathing, for instance, some care receivers may feel violated and may respond by striking out. But these care receivers simply may be reacting to circumstances that they perceive as threats. Understanding the motivation and framing it appropriately can help caregivers respond more suitably to these tough situations.

Households experience pressures related not only to physical and emotional care but also to legal uncertainties – particularly around individual competence and power of attorney. Caregivers often wonder whether they should apply for changes to legal competence.

Some believe (incorrectly) that a declaration of incompetence is necessary in order to receive benefits and services. Others fear that they could lose property or enter into a legal predicament related to joint assets if they initiate this action. Even when appropriate, caregivers often hesitate to seek legal incompetence status for care receivers because it is such a significant step in their ongoing story of loss.

In a world in which education, training and support are in place for virtually everything from burger flipping to rocket science, how have we managed to overlook the need for ongoing information, personalized instruction and continual upgrading for caregivers? As in any other job or profession, their roles change with added pressures. Their need for information and guidance shift constantly in relation to these new demands.

Why have we not done more to help caregivers face the challenges embedded in their demanding and complex role? Would we send nurses to work in hospitals with no training? Would we send paramedics to provide emergency care with no prior instruction?

In the case of dementia, in particular, there are literally hundreds of thousands of Canadians who would benefit from enhanced knowledge of this condition, its early warning signs and symptoms, various forms of activation and mental stimulation, effective ways to handle difficult and potentially dangerous behaviours, and the grief and loss that caregivers invariably experience as their loved one slips away. The occasional information session run by stretched-far-too-thin voluntary organizations is simply not enough.

Essential support for caregivers involves the provision of relief so that they can take some time to recharge. But another equally important part of the equation is to

equip them to do the difficult and invaluable work that they carry out on a round-the-clock basis at no cost (other than to their own health) – and in fact, at substantial savings to society. The least we can do is pay more attention to this precious resource – the family caregivers who provide so much yet get so little recognition and support in return.

*Sherri Torjman*

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Caledon Institute of Social Policy

401-1390 Prince of Wales Drive  
Ottawa, ON K2C 3N6  
CANADA

Phone: (613) 729-3340  
Fax: (613) 729-3896  
E-mail: [caledon@caledoninst.org](mailto:caledon@caledoninst.org)  
Website: [www.caledoninst.org](http://www.caledoninst.org)