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**Submission to the Parliamentary Committee on  
Palliative and Compassionate Care**

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**October 26, 2010**

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## *Caregivers in Canada*

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. About 2.85 million Canadians are unpaid or informal caregivers. Because this figure derives from 1997 data, the Canadian Caregiver Coalition estimates that the actual number of caregivers is likely between 4 and 5 million.

Caregivers provide more than 80 percent of care needed by individuals with long-term conditions. The economic value of caregivers' unpaid work to the Canadian economy is pegged at more than \$5 billion.

## *Caregiving tasks*

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

In addition to these wide-ranging tasks, there are caregiving pressures that are unique to progressively degenerative conditions, such as multiple sclerosis or Alzheimer's disease and related dementia. Persons with these conditions experience 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 these conditions, the burden of care increases over time. Many caregivers report that they are virtually on call around the clock.

In addition to the loss of physical capacity, mental deterioration in particular 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 expenditures and the financial insecurities related to frequent absences from work.

Caregivers may also require formal legal advice. It is often difficult to know when to deem care receivers as 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. Yet many 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.

## *Support for caregivers*

Caregiver needs are linked to – but significantly different from – those of care receivers. The first need involves the explicit recognition of caregivers and their engagement in the planning process for care receivers. The second entails 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 problems.

Caregivers would be greatly helped by improvements in the formal care system, particularly in relation to home care, attendant services and homemaker services. The first area of improvement involves the *quantity* of available services, including the number of hours for in-home support and reductions in the waiting time for services like day programs and long-term care.

The second improvement is rooted 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 effectiveness of staff training. It would also be helpful if there were greater flexibility in the provision of supports at home, including the availability of individualized funding, to enhance responsiveness to the needs of both caregivers and care receivers.

The supply of long-term care options, including care at home, must be expanded as well. This change is important not just for caregivers but also for reform of the acute health care system, which is suffering due to the lack of long-term care.

Improvements to formal services would go a long way toward providing respite or relief to caregivers. But while formal respite services comprise an essential component of the respite package, they are by no means the only form of support that offer relief. These at-home services are now understood as a necessary – but not sufficient – part of the respite equation.

The term ‘respite’ often is used to refer to a service in which paid employees come to the home of care receivers 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 the care receiver. 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.

In addition to formal respite services, a new and broader interpretation of the notion of respite has emerged in recent years, which recognizes that many different interventions can potentially create a sense of respite for caregivers. The assumption speaks clearly to the importance of flexible and responsive forms of assistance, determined primarily by caregivers themselves.

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

For some, respite stems from knowing that there is around-the-clock tele-help in the event of a health-related or behavioural emergency. Caregivers of individuals with various forms of dementia or other mental health problem, in particular, point out that they are often unsure of how to cope with presenting 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.

### *Financial pressures*

The caregiving role can create serious financial strains. Many persons with disabilities and seniors live on low income and, as a result, caregivers spend much of their own money for basic food, heat and shelter for the care receiver. Caregivers’ own employment status and income can be jeopardized by the pressures of their caregiving responsibilities. Moreover, caregivers often pay the additional costs of disability-related goods and services not covered by medicare or private insurance.

The first problem is that persons with disabilities, regardless of condition, have on average significantly lower and more sporadic participation in the labour force. They often have no choice but to rely on income security programs, which virtually guarantee a life of poverty.

At last count in 2007, 538,396 Canadians with severe disabilities received provincial or territorial welfare for their income. Welfare was designed as a last-resort safety net. It never was intended as a lifetime guarantee [Mendelson, Battle, Torjman and Lightman 2010].

The solutions lie in shoring up and reforming the disability income system. If nothing else, welfare benefits for persons with severe and prolonged disabilities should be bolstered and indexed to ensure that welfare does not equal poverty.

Better still, persons with disabilities would not rely on welfare at all but would qualify for a separate income program, ideally run by the federal government. Provincial and territorial

savings would be reinvested in disability supports to enable independent living [Mendelson, Battle, Torjman and Lightman 2010].

There are many Canadians with severe and prolonged disabilities who actually are employed – but they need to leave work occasionally because of episodic conditions, such as multiple sclerosis, AIDS or cancer. These conditions involve both remission, during which individuals function well, and recurrence which can be debilitating. Current income programs make no provision for these up's and down's – or in's and out's as the case may be. Possible reforms include changes to the Employment Insurance sickness benefit or to the Canada Pension Plan disability benefit to allow more flexible workforce participation [Prince 2008].

The second financial pressure arises from employment-related insecurities for the caregivers. Many Canadians must reduce their hours or leave jobs altogether in order to carry out their caregiving responsibilities. They jeopardize their current income and future pension.

Reform options include expanding the Compassionate Care Leave provisions under Employment Insurance that allow up to six weeks' paid leave to provide care to a gravely ill relative at risk of dying within 26 weeks. This measure can be expanded to permit leave for other caregiving circumstances, not just terminal illness, and extended with respect to the duration of the caregiver period.

Another possibility is a modest caregiver allowance. The UK and Australia, for example, pay a cash benefit to the family caregiver of persons requiring chronic at-home care. Nova Scotia recently brought in a \$400 per month caregiver allowance for those providing 20 or more hours of assistance per week for care receivers with a high level of disability or impairment and low income.

Ottawa currently provides a Child Disability Benefit, which delivers an annual maximum \$2,470 to low-income parents with children with severe disabilities. This amount could be raised in recognition of the higher real costs of care. The benefit could also be extended to low-income households caring for adults over age 18 with severe disabilities.

Another possible remedy is to expand the child-rearing drop-out provisions of the Canada Pension Plan to allow the measure to apply not only to child care but also to caregiving responsibilities. These changes would help protect the value of pensions.

The third economic strain derives from additional expenses linked directly to age or disability. These include charges for home care services, transportation costs for medical appointments, drug dispensing fees, technical aids and equipment, and structural modifications to a vehicle or residence.

There are both direct costs and hidden costs. Direct costs are readily itemizable. In some cases, they are offset by provinces or may be partially claimed under the federal medical

expense tax credit. But households must be in a secure enough financial position to afford these upfront costs in the first place.

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 additional supports for respite – e.g., a friendly visitor for the care receiver for a short period of time.

Hidden costs, by contrast, cannot be easily measured though they are very real – the out-of-the-way trip to the accessible store or the wear-and-tear on clothing. In recognition of the additional hidden costs of caregiving and other financial pressures, Ottawa provides some relief through two income tax measures – the caregiver credit and the infirm dependent credit. These measures are intended to help caregivers by reducing their federal income taxes.

The problem is that these provisions afford no assistance to Canadians too poor to pay income tax. Turning these measures into refundable tax credits would ensure that all households receive some money in respect of their caregiving costs. Manitoba has just introduced a refundable Primary Caregiver Tax Credit. Alternatively, a small direct payment could be made to help offset additional expenses.

The federal and provincial governments could also invest in the supply of disability supports and thereby reduce the costs incurred by individual households. There are several ways to effect such an investment, including a federal-provincial commitment similar to the Early Childhood Development Agreement signed in 2000 [Torjman 2000].

Another option, as noted, is a National Child Benefit-type arrangement in which the federal government would assume responsibility for income security for persons with disabilities currently on welfare. Under a negotiated agreement, provinces and territories would direct the resulting savings toward the supply of disability supports [Mendelson, Battle, Torjman and Lightman 2010].

Investment in a wide range of disability supports is essential not just for persons with disabilities but also for Canada's aging population. Many seniors will also require a range of technical aids and support services in order to participate actively in the economy and society. At the end of the day, this discussion of caregiving and disability is really a conversation about citizenship.

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