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# **Caring for the Carers**

*by*

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*This paper is the text of a speech delivered at the opening plenary “A Care Work Force in Crisis” at the International Conference on Caregiving held June 5-8, 2011, in Toronto. The Conference was part of the Festival of International Conferences on Caregiving, Disability, Aging and Technology.*

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## ***Introduction***

I would like to thank the organizers of this conference for the invitation to participate in this keynote session. It is a special honour to share the stage with Professors Eva Kittay and Michael Fine.<sup>1</sup>

I work for a national policy organization, the Caledon Institute of Social Policy, which has focused for close to 20 years on a wide range of public policy issues, including supports for caregivers. I would like to share a brief personal story before talking about policy.

About 25 years ago, I was a caregiver for my mother who was dying of cancer. I also happened to be working at the time for a Parliamentary Committee of the Government of Canada. It was the Parliamentary Committee on Child Care which, quite frankly, had limited understanding of the pressures of taking care of young children.

They would hold sessions early in the day and would reconvene after dinner if the public hearings had not finished by 5:00 p.m. We had a meeting that was held one day at 7.30 in the morning. The purpose of this gathering was – I kid you not – to talk about how *employers could be more responsive* to the needs of employees with young children. Child care centres didn't even open until 7:30 in the morning. I was told to “get there when you get there.”

Given the context, you can understand why I never breathed a word to *anyone* about my circumstances as the caregiver of a dying parent. The fact that I was a mother of two young children was, from their perspective, bad enough.

Times certainly have changed dramatically since those days. But I know that there are still far too many caregivers who minimize or even hide their caregiving responsibilities as though these were deep dark secrets. They keep these pressures to themselves – and they get there when they get there.

Conferences like this are invaluable in that they enable us to share our personal experiences. They provide those of us who are, have been or will be caregivers – virtually every human being – an opportunity to *turn our private troubles into public issues*.

Fortunately, there are some positive shifts in the wind right now that are the result of several factors. Employers *are* paying more attention to caregiver needs. It is thanks to the work of many of you who are here today that we have been able to move the yardstick in this area.

A major Caregiving and Work Workplace Survey is under way in Canada with close to 200 employers participating in the first group. Several major companies are now offering elder care services. We still face a challenge around small and medium enterprises that find it difficult to provide these benefits, as in other areas like sick leave and child care.

And the penny is finally dropping with policy-makers: *Real health care reform is impossible unless we take into account the needs of those who provide the bulk of care – the informal caregivers.*

There is a growing movement in the health field around patient- and family-centred care. This shift means listening *genuinely* to the voice of patients and their caregivers.

Caregiving has also assumed prominence on the public agenda as policy-makers grapple with the costs of an aging society. The International Monetary Fund has estimated that the toll of aging on G20 nations will be 10 times higher than the recent financial crisis – and will be even greater in Canada. By 2036, the number of seniors in this country is projected to reach between 10 and 11 million, more than double their 4.7 million in 2009.

We know from evidence that it is multiple chronic conditions and not aging *per se* that is driving up costs. Whatever the cause, rising expenditures are a concern in light of the pending expiry in 2014 of the health care transfer from Ottawa to the provinces and territories. Home-based options are being finally being understood as a key part of the puzzle – pushing caregiving to the heart of the public policy agenda.

We have *finally* found a place on the public radar screen. How do we capture this potentially golden policy moment?

### ***What do we say from a policy perspective?***

The first step is to reinforce the reality that caregivers comprise a formidable and essential workforce.

Caregivers provide more than 80 percent of care needed by individuals with long-term conditions and contribute more than \$5 billion of unpaid labour annually to the health care system. A more recent report pegged this figure at closer to \$25 billion if all caregiving is included.

As a ***workforce*** that provides an ***essential*** service, *I would argue that we need the same provisions as the workforce in any other field: financial compensation, decent working conditions, and training and support to do our jobs well.* Let's briefly look at each area.

#### ***a. Financial compensation***

Money is part of any work equation. Policy-makers need to understand that caregivers experience financial stresses that arise from three factors.

I called these factors the “three ghosts of poverty” in an op ed published several years ago on Hallowe’en. They are *ghosts* of poverty because these stresses haunt caregivers throughout their caregiving careers. The spectre of poverty is ever-present in a caregiving relationship.

The three ghosts relate to the income security of the care receiver, the vulnerable employment status of the caregiver and the cost of health- and disability-related goods and services.

Far too many people with severe disabilities and seniors in Canada live in poverty. Their caregivers often spend much of their own money paying for basic food and rent for the care receiver.

We need to shore up the disability and retirement income systems in our respective countries. *No one* should have to live in poverty because they have a disability or because they are elderly.

At Caledon, we have put forward over the years various proposals for both incremental and comprehensive reform of the disability and the retirement income systems. Unless we make significant shifts in these various programs of income support, the *poverty* of the care receiver effectively becomes the *poverty* of the caregiver.

Second, caregivers’ own employment status can be jeopardized by the pressures of their caregiving responsibilities. Many caregivers must reduce their hours or leave work altogether in order to carry out their caring role. We put at risk our current income and our future pensions. I will discuss policy remedies in a moment as part of good working conditions.

The third financial strain derives from additional expenses linked directly to age or to disability. More than one-third of caregivers report extra expenses due to their caregiving responsibilities. These include home care, transportation for medical appointments, drug dispensing fees, technical aids and equipment, and structural modifications to a vehicle or residence. Two-thirds of these caregivers spend more than \$100 per month on caregiving.

Our federal government offers various tax credits in respect of these costs. In fact, the Finance Minister is introducing a new federal Budget *today* that will include an additional caregiver tax credit worth an estimated expenditure of \$160 million a year.

The good news is that caregiving is now part of the public agenda and the government is acknowledging these additional costs. This is a positive development and should be publicly recognized.

The bad news is the problematic delivery of this assistance. *Beware* of governments bearing tax gifts. What you see is *not* what you get. In Canada, this aid is worth only 15 percent of the amounts designated in federal Budgets, so the caregiver allowance announced as \$2,000 is *actually worth only \$300*.

Moreover, these ‘amounts’ are not paid as a direct benefit. They simply allow you to reduce the taxes you owe. If you are a higher-income household, you will enjoy the full value of this tax credit. If you are a modest- or lower-income household, you will derive little or no benefit from this highly touted new measure.

At Caledon, we have argued that turning these measures into refundable tax credits would ensure that all households receive some money in respect of their caregiving costs. The province of Manitoba, for example, recently introduced a refundable Primary Caregiver Tax Credit. Its latest Budget included a 25 percent increase to the maximum annual value of this credit, from \$1,020 to \$1,275 per care recipient.

Alternatively, a small direct payment could be made to help offset these additional expenses. The UK and Australia, along with other countries, already do this. They pay a cash benefit to the family caregiver of persons requiring chronic at-home care, with supplements for households that incur especially high costs. These measures act as important policy precedents upon which we can all build in our respective countries.

Here at home, the province of Nova Scotia has brought in a \$400 per month caregiver allowance. Throughout the country, the federal government pays 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 and the benefit extended to low-income households caring for adults over age 18 with severe disabilities.

From a policy perspective, there is a clear agenda with respect to financial compensation. There are also policy precedents on which to build to help bolster the income security of the care receiver and offset the extra cost of health- and disability-related goods and services.

### ***b. Working conditions***

But financial compensation is not enough. A workforce that provides an *essential service* must also have good working conditions that respond to its needs.

Flexibility at paid employment is one of the most important responses. Flexibility is especially helpful for caregivers involved with elder care. The needs of the elderly are often unpredictable, and require adaptability on the part of the caregiver.

The same can be said for someone with an episodic condition, such as multiple sclerosis, where symptoms recur and remit. Companies are beginning to recognize that certain employees may need more than personal or vacation time to deal with family-related emergencies.

We need to explore new practices as well. There are groups of voluntary organizations in the US, for example, which have pooled their sick leave and family leave. Employees tap into a

larger bank of days rather than be limited to the days that their own employers are able to provide.

This type of co-op arrangement holds promise for the future – especially since so many of us work for smaller enterprises that find it difficult to make available these benefits. It is an example of a collective response in which employees basically take care of each other.

There are also important policy precedents at the international level regarding flexibility at work. As part of the Carer Strategy in the UK, wide-ranging employment measures have been introduced. In 2007, for example, the *Work and Families Act* was amended to allow caregivers the right to request flexible work.

In New Zealand, caregivers who have worked with their employer for at least six months have the right to request flexible arrangements, such as compressed work weeks, flex-time and work from home.

These rights do not guarantee that the employer will say yes. But at least they protect the security of employees who ask for flexibility. The legislative provisions also help raise employer awareness about this important need.

Paid leave is another important working condition. Here at home, some practicable changes can be made. We currently have Compassionate Care Leave as part of our Employment Insurance program. This measure allows up to six weeks' paid leave to care for a gravely ill relative who is likely to die within 26 weeks.

We are *fortunate* to have such a measure in place. But the eligibility criteria are too stringent to provide meaningful help to most caregivers. This provision can be expanded to permit leave for other caregiving circumstances, not just terminal illness, and extended with respect to the duration of the caregiving period.

Finally, future income can be affected when caregivers must drop out of the workforce due to their caregiving responsibilities. It is essential to find ways to protect the value of pensions in future. Here at home, one possible remedy is to expand the general drop-out or child care drop-out provisions of our national pension program – the Canada Pension Plan.

The latter provisions allow workers to discount from the calculation of their pensions the years during which they were caring for a child under age 7. These measures could be expanded to apply not only to child care but also to caregiving responsibilities, thereby helping to protect the value of pensions for caregivers.

Several other countries including Australia, the UK and Norway – to name just a few – have in place a special pension intended specifically for caregivers. Others make pension



contributions on behalf of caregivers so that they are not penalized later in life for lost employment time during their working years.

We need to ensure that adequate policies cover workplace flexibility, paid leave and pension protection. But good working conditions at paid employment must be supplemented by training and support at home.

### *c. Training and support*

All workers, regardless of employment or sector, require training and support in order to do a good job. So do caregivers. We need high-quality and up-to-date information about the various conditions with which we are dealing and advice on how best to handle them.

Like any essential service, the caregiving workforce must learn the skills to administer certain treatments or deal with complex or degenerative conditions. Despite some good models, there is insufficient training – especially for caregivers looking after someone with a mental health problem, episodic disability or dementia.

A significant development in the caregiving field involves the use of new social technologies that create networks among caregivers, care receivers and formal services. These networks provide information, emergency intervention and day-to-day assistance with caregiving tasks. In Canada, Vickie Cammack and colleagues from the PLAN Institute, for example, have established the online Tyze personal networks program.

A trained workforce in any sector also needs good information about suppliers. As caregivers, we need to know the supports that are available in the community and the associated financial assistance for health- and disability-related goods and services.

A related challenge is to find our way through this maze of supports. Every program has its own unique eligibility criteria and requires independent assessment and screening. Surely, we can think in terms of ‘gateway programs’ – such as the federal disability tax credit. Qualifying for this benefit automatically should open up eligibility for a range of similar programs.

But information and improved access are only part of the equation. Caregivers would be greatly helped by improvements in both the *quantity* and *quality* of the formal service system, particularly in relation to home care, homemaker services, respite and long-term care.

So policy work around training and supports for a care work force in crisis must include improved provision of information, more and better formal services, and easier access to these programs.

## ***Conclusion***

Clearly, there is a robust policy agenda related to compensation, working conditions, and training and support.

Policy measures to assist a care work force in crisis must bolster the income security of care receivers and help offset health- and disability-related costs. Relevant policies must include workplace flexibility, paid leave and pension protection. They also must involve information and training about various conditions and improved community services in both quality and supply.

But governments can't do it all. A resilient voluntary sector, which includes a strong caregiver voice, is crucial to helping caregivers carry out our caregiving responsibilities.

Engaging with employers around a range of work-related conditions is also essential. There are precedents throughout the world that align the work of various sectors. Several countries, including the UK, Australia and New Zealand, have in place national strategies that bring together the diverse players and integrate the component parts into a coherent whole.

But caregiving is not just a policy issue. Policy measures with respect to financial compensation, working conditions, and training and support seek to achieve a common end: *nurturing* caregivers. The purpose of these measures is to help caregivers – this essential workforce – do the best possible job that we can.

So we need to nurture caregivers. But we also need to celebrate them and to *celebrate caregiving* as the most precious gift that human beings can give to one another. It is through caregiving that we express and strengthen our humanity.

## **Endnote**

1. Dr. Eva Kittay is Distinguished Professor of Philosophy, Stony Brook University in New York. Dr. Kittay's books include *Cognitive Disability and Its Challenge to Moral Philosophy*, co-edited with Licia Carlson (Blackwell, 2010). Dr. Michael Fine is Associate Professor at Macquarie University, Sydney, Australia, where he is Head of the Department of Sociology and Deputy Director of the Centre for Research on Social Inclusion.

## **References**

- Battle, K. and S. Torjman. (2011). *When Is \$500 not \$500?* Ottawa: Caledon Institute of Social Policy, April.
- Battle, K., S. Torjman, M. Mendelson and B. Baldwin. (2011). *Pension Tension*. Ottawa: Caledon Institute of Social Policy, forthcoming.

- Canadian Institute for Health Information (CIHI). (2010). *Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions?* Ottawa.
- Canadian Institute for Health Information (CIHI). (2008). *Health Care in Canada 2008*. Ottawa.
- Cranswick, K. (2003). *General Social Survey Cycle 16: caring for an aging society*. Ottawa: Statistics Canada, Housing, Family and Social Statistics Division.
- Fast, J., L. Niehaus, J. Eales and N. Keating. 2002. *A profile of Canadian Chronic Care Providers*. Research on Aging, Policies and Practice. Edmonton: Department of Human Ecology, University of Alberta.
- Health Canada. 2002. *National Profile of Family Caregivers in Canada – Final Report*. Ottawa.
- Hollander, M., G. Lui and N. Chappell. (2009). “Who Cares and How Much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly.” *Healthcare Quarterly* 12(2): 42-49.
- Mendelson, M., K. Battle, S. Torjman and E. Lightman. (2010). *A Basic Income Plan for Canadians with Severe Disabilities*. Ottawa: Caledon Institute of Social Policy, November.
- Milner, B. and H. Scoffield. (2009). “The growing cost of an aging world.” *Globe and Mail*, July 8.
- Statistics Canada. (2010). *Population Projections for Canada, Provinces and Territories, 2009 to 2036*. Ottawa.
- Torjman, S. (2009a). *Talking Turkey on Taxes*. Ottawa: Caledon Institute of Social Policy, October.
- Torjman, S. (2009b). *The Three Ghosts of Poverty*. Ottawa: Caledon Institute of Social Policy, October.
- Torjman, S. and A. Makhoul. (2008). *Caregivers and Dementia*. Ottawa: Caledon Institute of Social Policy, June.