

OCC Pre-Budget Submission 2017

The Ontario Caregiver Coalition (OCC) thanks the Standing Committee on Finance and Economic Affairs for the opportunity to provide our suggested priorities and recommendations for the 2017 Ontario Budget on behalf of Ontario's caregivers.

The OCC is the provincial advocacy body that supports unpaid caregivers in Ontario. We are comprised of over 100 individuals and organizations who actively work together to increase awareness of the important role unpaid caregivers play in the long-term sustainability of Ontario's health care system, and advocates for improved supports for caregivers.



The OCC is particularly focused on:

- The growing need for improved respite care
- Supports that address caregiver needs apart from the care recipient
- Caregiver involvement in patient engagement initiatives
- Recognizing the caregiver contribution to the Ontario health care system

OCC is currently working with all parties to seek action on the passage of *Bill 66, An Act to Proclaim Family Caregiver Day*, to formally recognize the role of unpaid caregivers in Ontario. As Members of Provincial Parliament, we ask that you will also join us in recognizing the value of caregivers by supporting Bill 66.

Today in Ontario, there are 3.3 million unpaid caregivers, which accounts for nearly 30% of Ontario's total population. 76% of Ontario's caregivers are juggling their caregiving responsibilities with paid employment, and 35,000 have reported being fired or having to quit their paid employment due to caregiving duties. This results in significant loss of skills and talent from the labour market as well as negative social, health and financial outcomes for caregivers and the economy. The estimated value of unpaid caregivers to Ontario's economy is \$25 -31 billion and that only relates to caring for those with dementia. Supporting caregivers is good public policy, not only for Ontario's families and economy, but for Ontario's health care system as well.

The growing trend towards providing more complex care in the community and reducing the length of stay in hospital has depended on the ability of unpaid caregivers to devote more of their time and energies to caregiving. This is due to the fact that there is an insufficient amount of additional home care to support people outside of the hospital or in other institutional settings. Deficiencies in the health care system are landing on the backs of caregivers. As evidenced by the Health Quality Ontario (2016) report, 35 per cent of people who care for loved ones at home reported feeling distress, anger or depression in 2014-15, up from 16 per cent in 2008-09. In order to ensure their continued ability to take on this rewarding, but extremely challenging role, we must ensure that caregiver needs are being

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sufficiently acknowledged and supported. We cannot take for granted the pressure caregivers in Ontario are under or their ability to continue in this role long-term.

Respite

As the provincial advocacy body for unpaid caregivers, the OCC urges the Committee to allocate funds to improving respite care by supporting new approaches to eligibility and decision-making for care recipients and caregivers, along with discovering and promoting innovative respite models. We'd like to start by acknowledging the allocation of respite funds put forward by Minister Hoskins, which have been earmarked for caregivers of Community Care Access Centre clients. This is a good start and we encourage this focus on respite to go further. More specifically, OCC supports the direction put forward by one of our member organizations, Alzheimer Society of Ontario, which is "New Directions in Respite Care". Therefore, OCC's recommendation is:

The Ontario Government invest \$20 million dollars over two years to improve respite services and delivery of these services for Ontario caregivers.

The total funds will be targeted toward four sub-categories of services or supports: caregiver accounts, in-home respite, day programs and overnight respite. The investment will provide approximately 4,000 caregivers with improved access and availability to high quality respite services.

The goal of "New Directions" is to:

1. Improve caregiver experience – reduce stress, maintain health, maintain labour force participation
2. Enable the care receiver to live in their preferred community location for as long as possible
3. Facilitate community care evolution to more patient and caregiver- centred care
4. Reduce pressure on the health care system

The cost of health care is growing at an accelerated rate. Better respite will improve patient and caregiver experiences and enable people to live in their community of choice for longer. Adverse outcomes like caregiver stress, anti-psychotic use and crisis admission to hospital or long-term care can be expected to decrease with excellence in respite care. In the absence of supporting innovative ideas and a recognition of the needs of caregivers, Ontario simply will not be able to keep pace with spending.

Dementia

Using the example of dementia (as one condition that many caregivers are managing with their family member or friend), 1 in 10 Ontarians over the age of 65 is living with this condition – the majority are living in the community. Many Ontarians are living with conditions wherein dementia is one component that adds immensely to the complexity of their care. For example, 30 per cent of Ontarians with Parkinson's disease also have a dementia diagnosis. Individuals caring for someone with dementia provide 75 per cent more care hours than other caregivers and experience 20 per cent greater stress -

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many of whom are working people. Health Quality Ontario (2016), reported a 20 per cent increase over the last 6 years in feelings of distress, anger and depression among people providing unpaid care.

Several OCC partners have been engaged in shaping the development of the Ontario Dementia Strategy, and are hopeful that it will be implemented with a focus on supporting not only the care recipient, but the caregiver as well. OCC supports the Alzheimer Society of Ontario's recommendation to **fund the Ontario Dementia Strategy at \$100 million over two years.**

Compassionate Care Benefit (CCB)

Many caregivers find themselves struggling to cope with the competing pressures of work and providing care. When these competing demands become too much, caregivers commonly opt to modify their employment to meet the demands of providing care. This results in absenteeism, reductions to employment hours from full- to part time, or premature exit from the labour force.

Such care-related employment consequences have negative impacts not only to the economic security of the caregiver, but also negatively impacts employers, labour market sustainability and the health of the economy in general. At a time when society is faced with significant demographic shifts and projected future labour market shortages, these implications cannot be ignored.

The OCC recognizes the efforts of the Ontario government to better support Ontario caregivers with the implementation of the Family Caregiver Leave Act, giving caregivers eight weeks of job security to provide care without the need for the person they are caring for to be near death or dying. However, currently the CCB is not as flexible and stipulates that a person “can receive compassionate care benefits for up to a maximum of 26 weeks if you have to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks”.

Ontario has shown leadership with the Family Caregiver Leave Act, by not adding a “near death or dying” criteria. It is unfortunate that caregivers can be eligible for this time, but not eligible for CCB during their leave unless the person they are caring for is near death. Many caregivers are already challenged financially making the number of caregivers able to access an unpaid job protected leave very low.

Furthermore, there is a disconnection between the weeks of EI funding through the CCB and the current amount of job secured time that is offered in Ontario. OCC is asking that Ontarians have the benefit of 26 weeks of job secured time that is EI covered to care for family member or friend where death is not necessarily foreseeable.

OCC calls on the Minister of Labour and the Minister of Finance to work with their federal counterparts to expand the eligibility of the CCB beyond only those caring for someone who is gravely ill and at risk of dying in order to ensure that job protected time is not taken at the financial expense of caregivers and families, and to make available 26 weeks of job protected and EI covered time.

The Caring Experience Project

The OCC recently partnered with The Change Foundation on The Caring Experience Project (referred to herein as “the Project”). The purpose of the Project was to better understand the interactions and experiences that Ontario caregivers have in the health care system. The Project met with nearly 300 caregivers across Ontario through various engagement methods including caregiver workshops, one-on-one interviews, and journey mapping activities. In addition, the Foundation also reached out to caregivers using short online surveys to broaden our reach provincially. The project shined an important spotlight on caregivers that are often left behind in the caregiving discussion: young carers and indigenous carers.

Young carers are children, youth and young adults, who are in a caregiving role for a family member who needs assistance with their daily lived experience due to illness or disability. Some of the concerns of young carers: financial stability, more care closer to home, more understanding, time to be a kid and play with their family members, and a wish that being a carer “wasn’t stressful”. The needs are the same, but these young people often fall through the cracks because of their age. As a society we assume they would not be placed in a caregiving role – unfortunately they are given no choice.

Indigenous caregivers report no access to services and the lack of a system that recognizes caregivers. Caregivers are placed in challenging positions with health care providers when their cultural practices and treatment methods are not recognized resulting in their values and needs not being met. The lack of “culturally appropriate programming” to help with loneliness in seniors was identified as a gap area.

Overall the Project discovered the following key themes from Ontario caregivers:

- Recognizing the caregiver and their role;
- communicating and exchanging information clearly;
- assessing caregiver abilities and knowledge; and
- providing the right kinds of support and education at the right time.

These all emerged as pathways that could lead to improved experiences for family caregivers. In conclusion the Project determined that addressing these themes in partnership with stakeholders, such as Ontario health providers and family caregivers, it is possible to transform the health and community care sectors in meaningful ways that benefit everyone.

OCC looks forward to working with our partners in government to explore ways to implement the findings of this project to ensure caregivers are receiving a full range of supports to meet their needs.

In conclusion, OCC is requesting:

- **Invest \$20 million dollars over two years to improve respite services and delivery of these services for Ontario caregivers.**
- **Fund the Ontario Dementia Strategy at \$100 million over two years.**
- **OCC calls on the Minister of Labour and the Minister of Finance to work with their federal counterparts to expand the eligibility of the CCB beyond only those caring for someone who is gravely ill and at risk of dying in order to ensure that job protected time is not taken at the financial expense of caregivers and families, and to make available 26 weeks of job protected and EI covered time.**

Thank you for your time and consideration.