



2022 Ontario Election Caregiver Manifesto

May 2022

Caregivers are the unsung heroes of our health care system. Sacrificing their own mental, physical, and financial wellbeing, caregivers provide an irreplaceable amount of care to their family members, friends, and neighbours—saving health care systems across Canada an estimated \$30-40 billion annually.

Around 3.3 million Ontarians are unpaid caregivers, nearly 30% of the province's population. Of these, 850,000 provide over ten hours of care per week. They are not getting the support they need: one-in-three caregivers in Ontario say they need additional help, more than in any other province.

Ontario can't afford to replace caregivers, so must do all it can to support them. The Ontario Caregiver Coalition has three recommendations to do just that:

- 1. Include caregivers** in policy decisions affecting them.
- 2. Address financial distress** among caregivers.
- 3. Expand care options** at home and in the community.



ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health care system. We are a not-for-profit organization, whose membership includes both unpaid caregivers and organizations that support them.

INCLUDE CAREGIVERS IN POLICY DECISIONS AFFECTING THEM.

Caregivers, along with those they support, are experts in their own right. Their insights should be incorporated not only into individual care plans but also into system-level planning. The province's commitment to include patient and caregiver representation in the governance structure of every Ontario Health Team is a welcome step in this direction.

To build on this progress, the Ontario Caregiver Coalition is calling on the next provincial government to:

- ◆ Continue to include caregiver representation as an equal partner at leadership tables for local health care delivery, including home and community care.
- ◆ Consider the needs and experiences of caregivers in policy proposals relating to health care reforms as well as to labour market reforms, gender equity, social security, and other policy areas not directly tied to health care.
- ◆ Provide funding for a dedicated person to work with families and caregivers in every long-term care home, as recommended by AdvantAge Ontario.

ADDRESS FINANCIAL DISTRESS AMONG CAREGIVERS.

In a 2020 survey conducted by the OCC, the number one challenge expressed by caregivers was financial distress. Caregivers are not only paying to provide care for their loved ones, but they are forgoing future income in benefits to be able to care for their loved ones. Today's caregivers will not be able to afford their own care as their needs become more complex.

Financial distress is the main factor reported by caregivers who have been forced to prematurely admit their supported person to long-term care. Care decisions should be made based on the needs and wishes of the individual and their families, not based on the financial need of the caregivers. Draining the financial resources of caregivers first, before providing adequate support in long-term care, is a tremendously inefficient burden on the health and long-term care system—which must now provide round-the-clock care and support to someone who does not want or need to be in long-term care.

Despite the distress faced by caregivers, and the value in alleviating this distress, governments across the country have been slow to act. Over two-thirds of caregivers across Canada say they need more financial help, with just 6% receiving money from existing government programs.

This is not a sustainable situation. Caregivers are past their breaking point, and the OCC urgently calls for the following actions:

- ◆ Implement a direct financial support program, administered and funded by the Government of Ontario, for the province's caregivers. This could take the form of a refundable tax credit, as in Manitoba, or a monthly payment, as in Nova Scotia.
- ◆ Expand access to take-home cancer drugs by filling gaps in public coverage, as recommended by the Canadian Cancer Society.
- ◆ Reevaluate public reimbursement policies for off-label use of pharmaceutical interventions that have high efficacy, proven safety, and demand amongst people living with dementia, as recommended by the Alzheimer Society of Ontario.
- ◆ Act on treatment optimisation recommendations from the MS Society of Canada's 2020 working group.

EXPAND CARE OPTIONS AT HOME AND IN THE COMMUNITY.

Unpaid caregivers are providing work that, in the Canadian consciousness, is meant to be provided by the health care system: meeting the care needs of someone who has lost the ability to care for themselves. Canadians assume there will be professional home care available to support them when needed—not that care will be provided, for the most part, by unpaid, untrained, unprepared caregivers. Yet that is where we are today: about 70% of home care hours in Ontario are provided by unpaid caregivers.

This downloading of care must stop. It is hurting families, patients, and the economy, forcing caregivers—mostly women—to withdraw from the labour market during their peak earning years. The best way to support caregivers is to stop forcing them to care beyond their limits—and that means restoring home and community care options:

- ◆ Expand eligibility criteria for self-directed care programs, such as the Ministry of Health Direct Funding Program, to include caregivers, and eliminate administrative and navigation barriers that make it difficult for caregivers to use these programs.
- ◆ Increase funding for community support services to help keep Ontarians living at home as they age, as recommended by AdvantAge Ontario, the Alzheimer Society of Ontario, and the Ontario Community Support Association.

ENDORSED BY:



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