

# We should care more about caregivers

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Every day, about 28% of Canadians provide care for a family member, friend or neighbour, and nearly half will do so at some point.<sup>1</sup> Although many Canadians with chronic conditions and disabilities need care, the most common needs requiring caregiver help are age related.<sup>1</sup> With 93% of older Canadians living at home, unpaid or informal caregivers provide up to 75% of care services, which equates to about \$24–\$31 billion in unpaid work annually.<sup>2</sup> We must and can do more to acknowledge and support informal caregivers in bearing this burden.

Over the next 20 years, the number of older Canadians requiring assistance will double, yet there is a shrinking pool of informal caregivers.<sup>3,4</sup> Changes in demographics and family structures are reducing the ratio of caregivers to older adults, and many potential caregivers are unwilling to assume responsibilities or are exiting the role early.

While caregiving for older adults can be rewarding, it is increasingly demanding, complex and stressful. The average informal caregiver spends 19 hours a week on caregiving duties, and 1 in 10 provides more than 30 hours of care per week.<sup>1,2</sup> Despite little to no training, they are expected to provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers.<sup>3</sup> Many Canadian caregivers report distress, including 26% of those caring for older adults and 45% of those caring for people with dementia.<sup>5</sup> Distressed caregivers experience a myriad of adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death.<sup>3</sup>

Although bolstering home care and respite care is essential for supporting both caregivers and care recipients, most Canadian caregivers do not have access to caregiver-specific education and supports despite evidence that these can improve their well-being and that of the care recipient. Most effective interventions are multidimensional and involve assessment of caregivers' risks and needs, education and skills training, and counselling and self-care.<sup>3</sup> The Reitman Centre CARERS (Coaching, Advocacy, Respite, Education, Relationship, Simulation) Program at the Sinai Health System in Toronto, an exemplary intervention supporting those looking after people with dementia, includes group psychotherapy, problem-solving techniques and experiential learning through use of simulated patients for caregivers, while providing respite with an arts-based group for care recipients. Participants show improved caregiving competence, ability to cope with stress, and mental well-being.<sup>6</sup>

However, supporting Canada's caregivers also means protecting them from economic and retirement insecurity.<sup>3</sup> To supplement limited publicly funded home and community care services, many caregivers incur substantial costs for transportation, equipment and professional help. Caregivers may forgo wages and benefits, with many reducing their hours, missing work, turning down advancement opportunities or exiting the workforce altogether.<sup>4</sup> Currently, 35% of the Canadian workforce is balancing employment with caregiving responsibilities; women are most vulnerable to financial consequences as they are more likely to assume caregiving roles and spend more time on caregiving tasks.<sup>1,7</sup>

The most common form of financial support for Canadian caregivers is tax relief, yet only a small minority receive tax credits.<sup>1</sup> Many caregivers are unaware of available financial assistance, and government portals for tax information are often difficult to navigate.<sup>4</sup> Eligibility for federal and provincial tax credits is generally restricted to caregiving relatives; Manitoba is notable for supporting anyone who assumes unpaid caregiving responsibilities.<sup>4</sup> Most caregiver tax credits are also nonrefundable (provincial credits in Quebec and Manitoba are exceptions), meaning that caregivers must be earning sufficient income to claim the credit as a deduction.<sup>4</sup> In general, existing tax relief programs do little to support low-income caregivers; Nova Scotia stands out for providing low-income caregivers with a monthly benefit.

We should and can do a much better job of supporting informal caregivers in the workplace. Governments and employers should develop more flexible workplaces that accommodate caregiving duties and provide better access to paid leave and benefits.<sup>3</sup> In 2015, the federal government extended the compassionate care benefit to 6 months to provide Employment Insurance for caregivers looking after critically ill or dying family members. While welcome, this benefit supports caregiving only for those at imminent risk of death, neglecting recurrent exacerbations of chronic illness, which is more typical of age-related caregiving needs.<sup>4</sup> Worthy alternatives exist in European countries such as Sweden, where some municipalities provide informal caregivers with direct allowances or reimbursements for caregiving activities.<sup>8</sup>

Addressing this pressing health care and societal issue is undoubtedly complex, but innovative, effective and potentially scalable programs and policies already exist in pockets across the country. It's time Canada cared more about its caregivers.

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