



## **Family caregivers – the essential ingredient to successful health care transformation**

Family caregiving is not new – most families expect to provide support when a loved one needs care, recognizing that home is the preferred setting of care. With shifting demographics, family members will be called upon more frequently to support a loved one in a time of need. While most embrace the opportunity, the reality is that families are the mainstay of the home care system and family caregiving responsibilities can be demanding and challenging to manage. Home Care Ontario makes the following recommendations to build better support for family caregivers.

### *Education*

- Improve provider knowledge across the health system of all resources available to family caregivers.
- Provide clients and families with information about available public and private services in order to support their planning and ability to access the resources to support their care at home.

### *Service*

- Permit greater service provider organization (SPO) flexibility to use their staffs judgment in order to determine timing, length and frequency of visits that respond the real-time needs of the patient and family caregiver.
- Offer more and enhanced respite services to families with extraordinary caregiving responsibilities.
- Establish a schedule of investments in government funded home care so that as the population ages, the amount of publicly administered home care rises.

### *Incentives*

- Implement HST exemption on privately purchased home care services and a refundable tax credit for privately purchased home care to help offset cost and demonstrate the importance of the family contribution.
- Establish programs to motivate family caregiving friendly policy and behaviours amongst employers.

## **Home Care in Ontario**

The shift to home-based care is in large part based on the understanding that home is where patients and their families would prefer to be. In addition to improved quality of life, care at home decreases the risk of infection and increases the likelihood of ambulation and socialization – both of which are required to support recuperation.

Providing home care is not a requirement of the Canada Health Act, however, across the country publicly funded home care programs have been implemented. In Ontario, publicly funded home care falls under the jurisdiction of the Ministry of Health and Long-Term Care (MOHLTC). This government-funded program, which was first introduced in 1970, is now administered by 14 Community Care Access Centres (CCACs).

Home care services include nursing, personal support / homemaker, therapy (including physiotherapy, occupational therapy, speech language pathology, social work, nutrition/dietetics), medical supplies and equipment, and case management. Home care is delivered by service provider organizations (SPOs) that meet high standards of excellence, many of which are reported publicly by Health Quality Ontario.<sup>1</sup> These organizations are usually incorporated entities, and can be one of the following: a non-profit organization, a private corporation, a municipal government or an aboriginal organization.

## Family Caregivers

Families are, however, the mainstay of the home care system – only 2% of clients manage without a family caregiver<sup>2</sup>. Family caregivers provide 80% of care at home, supplementing the government-funded service. The average family caregiver spends twenty hours per week caring for a period of four years; one quarter of caregivers spends forty hours per

*Family caregiver is the term used to denote a family member, friend or family of choice who gives unpaid care to someone, either at home or in a facility, who has a physical or mental health condition, or is chronically ill, frail, or elderly<sup>5</sup>. The use of the term “informal caregiver” is discouraged because, to many caregivers, it diminishes and invalidates the role and the nature of the care they provide.<sup>6</sup>*

week.<sup>3</sup> Home Care Ontario estimates that the value of the care delivered by family caregivers in Ontario represents \$9.7B annually if family and friends were reimbursed as employees.<sup>4</sup> Without family caregivers, government funded home care, as it is currently configured, would not be a feasible option.

Caregiving tasks that families / friends undertake can include clinical activities (wound dressings and injections), personal care (bathing, dressing, eating or toileting); support activities (preparing meals, managing medication), and activities such as coordinating the myriad of services that care recipients may require. Additionally family caregivers maintain the house and household, which is more demanding when occupied than when the person is in hospital, for example.

Families with the means may retain SPOs to support their caregiving load. This care may be paid by privately-insured plans and/or direct private purchase. Home Care Ontario estimates that 150,000 Ontarians purchase an additional 20 million visits/hours of home care services annually in order to remain at home.<sup>7</sup>

*“The responsibility of caregiving is a social one, with deep connections and dependencies with community, government and business.” Jane Jensen, Canadian Policy Research Network, 2009*

Without the contributions of family caregivers, there would be an increased risk of institutionalization.<sup>8</sup> Premature placement in institutional care is both costly and socially unacceptable to Ontarians.

<sup>1</sup> Health Quality Ontario

<sup>2</sup> Canadian Institute for Health Information 2010, p1

<sup>3</sup> Ministry of Health and Long-Term Care 2009, p6

<sup>4</sup> Extrapolation from: Hollander, M., Liu, G., Chappelle, N. 2009, p48 Cost for Ontario assumes the province represents 38.9% of the country's population and there are no other material variables to consider.

<sup>5</sup> Caregivers Nova Scotia

<sup>6</sup> Ibid

<sup>7</sup> Ontario Home Care Association 2009

<sup>8</sup> Canadian Institute for Health Information 2010, p1

## Traditional Networks Disappearing

According to the 2012 General Social Survey on Caregiving and Care Receiving, 29% of Ontarians were actively engaged in providing care to a family member with a long-term health condition, disability or aging needs.<sup>9</sup>

Family caregiving is not new – most families expect to provide support when a loved one needs care. However, the context for caring has changed. Nuclear families are decreasing; families are smaller and more dispersed; there are more women in the formal workforce; childbearing occurs later in life; and, retirement is delayed. The result is a family life course that includes juggling child rearing, working, and caring for an elder family member. While caregiving is a positive experience for many, more than one in four (22%) showed signs of

*Caregiver distress is the overall impact of physical, psychological, social and financial demands of caregiver.<sup>11</sup>*

distress, including anger, depression, being overwhelmed and unable to continue providing care.<sup>10</sup>

In addition to the care recipient, caregiver distress has consequences for the health system and for the

individual caregiver.<sup>12 13</sup> Without caregiver support, patients may be more likely to require admission to a facility and caregivers experiencing distress may also require health care attention.

## Future Demand

With shifting demographics, family members will be called upon more frequently to support a loved one in a time of need. While most embrace the opportunity, the reality is that caregiving responsibilities can be challenging and the increased demand will compound the difficulties. By 2036 the numbers of seniors in Ontario will more than double from 1.9 million to 4.1.<sup>14</sup> The oldest age groups, and typically those that are most frail and in need of the most support from families, are increasing most rapidly with the 75plus group projected to grow by approximately 144 percent by 2036 and the 90plus group to triple in size.<sup>15</sup> The ballooning dependency ratio will challenge the ability of both the health system and families to respond.

As a founding member of the Ontario Caregiver Coalition, Home Care Ontario continues to call for enhanced policy initiatives to support family caregivers so they can better cope with the challenges of balancing caregiving responsibilities with paid employment in the regular workforce, raising children and maintaining wellbeing.

*“The responsibility of caregiving is a social one, with deep connections and dependencies with community, government and business.” Jane Jensen, Canadian Policy Research Network, 2009*

<sup>9</sup> Sinha, Marie 2013, 9

<sup>10</sup> Change Foundation 2011

<sup>11</sup> L. K. George et al. 1986

<sup>12</sup> N. Cousineau et al. 2003

<sup>13</sup> C. S. Mackenzie et al 2009

<sup>14</sup> Ontario's Seniors' Secretariat 2013, p5

<sup>15</sup> Ibid.

## **Recommendations**

Home Care Ontario recognizes the initiatives undertaken in the province to support family caregivers. However the frequency, duration and challenges arising from today's social and economic circumstances necessitate greater measures and approaches that support families. It is essential that policy measures be adopted to comprehensively address financial support, workplace protection, respite, increased home care and education for family caregivers. Home Care Ontario makes the following recommendations.

### *Education*

- Improve provider knowledge across the health system of all resources available to family caregivers.
- Provide clients and families with information about available public and private services in order to support their planning and ability to access the resources to support their care at home.

### *Service*

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### *Access*

Too often, good programs are under-utilized because of inadequate dissemination, confusing language, and/or restrictive criteria. It is therefore vital that families are provided with:

- Full disclosure as to the resources available to support them emotionally, mentally and physically
- Clarity of definitions, eligibility, restrictions and limitations of services
- Contact to an advocate/ombudsperson

## **Conclusion**

Family caregivers are integral to providing care in the home and acknowledging this vital role to society respects all Ontarians who will be called upon to fulfill caregiving responsibilities.

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