

BACKGROUND

Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care

About “The Way Forward” Initiative:

In 2012, the federal government announced one-time funding of \$3 million over three years to support the development and implementation of a framework for community-integrated hospice palliative care models in Canada. “The Way Forward: An Integrated Palliative Approach to Care” ([The Way Forward](#) initiative), led by the Quality End-of-life Care Coalition of Canada and managed by the Canadian Hospice Palliative Care Association, aims to improve access to hospice palliative care in a broader range of settings. A number of discussion documents have been developed to encourage stakeholder dialogue, and inform the development of the framework. This Backgrounder on the discussion document *Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care* explores opportunities to further support informal caregivers, including the roles played by the health system, employers, governments and communities.

The Context for Action:

“Family caregivers” provide care and assistance for spouses, children, parents, extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability. The number of caregivers (including those caring for someone at end-of-life) in Canada today is estimated at five million (Canadian Caregiver Coalition, 2012). With the aging population, this number is expected to increase. More than three-quarters of family caregivers are employed and most work full time. In 2007, about 520,000 employed caregivers missed at least one day of work per month to provide care, and 313,000 reduced their work hours (Fast et al., 2011). Family caregivers typically have household incomes below the national average—only 35 percent of households with caregivers report income over \$45,000 (Fast, 2008). Women most often fulfill family caregiver responsibilities; however, the number of male family caregivers is increasing (Fast, 2008).

Historically, palliative care has been regarded as a service at the end of life when individuals did not receive any treatment. Today, palliative care integrated earlier in the disease/end-of-life trajectory is acknowledged as necessary and the desired standard of care. As an individual’s disease progresses, caregivers may develop misgivings about providing palliative care at home due to caregiver exhaustion, concern about access to medical care, risk of physical injury due to the limitations of the home environment, and increasing complexity of care required to manage pain and other symptoms (Stajduhar & Davies, 2005). Among the factors most influencing a caregiver’s coping ability is support from family, friends and the health-care system (Stajduhar, Martin, Barwich, & Fyles, 2008). Family caregivers list the following as their priority needs: protecting their health and wellbeing and increasing access to respite care; minimizing their financial burden; enhancing access to user-friendly information; creating flexible workplace environments; and investing in research on family caregiving (Canadian Caregiver Coalition, 2008).

Areas of Opportunity:

We can better prepare for and support patients and their families through the palliative phase of life by ensuring that:

- The preferred care setting (e.g., acute, long-term or home care) is determined in partnership with the patient and their family, with adequate resourcing to provide quality care; caregiver assessments are conducted; the professional team knows of and can refer to support services; there is effective advance care planning.
- Employers recognize the burden and stress placed on employees who assume the role of family caregivers and support them by offering flexibility at work, information and assistance, emotional and other forms of support.
- Governments (federal, provincial and local) establish the right balance of fiscal and social policy through levers such as tax measures, financial support programs, labour code modifications, employer incentives, and national strategies that integrate palliative care earlier in the care continuum.
- In communities, there are support groups, resource centres and other mechanisms to provide family caregivers with information and assistance.

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