

Caregiver Support and Well-Being Executive Summary and Recommendations April 2009

Caregivers are family members or friends who provide both short term and ongoing care and assistance, without pay, to those in need of support due to physical, cognitive, mental health and/or addiction conditions, throughout the continuum of care. Caregivers may be spouses, parents, grandparents, siblings, children, grandchildren, extended family, friends and neighbours.

Caregivers provide the majority of the care needed by individuals and contribute approximately 8 billion dollars of unpaid labour annually to the healthcare system.ⁱ Caregivers are a part of the health provider “team” and need to be acknowledged and included as such. Caregivers provide the care which allows many individuals to stay at home longer and to avoid unnecessary hospitalization and/or institutionalization.

More than one third of caregivers report extra expenses due to their care giving responsibilities. Two-thirds of these caregivers spend more than \$100 per month on care giving. This is conservatively translated to an annual cost to Canadians of \$80 million.ⁱⁱ Without the care giving network of family and friends, the formal health care system would collapse because it is unlikely to have enough resources to meet all health care needs and demands of all citizensⁱⁱⁱ Caregivers have needs which are often very different from the needs of the care receiver, yet, in most cases, the programs, the services, the funding, the information and the education are all directly connected to the needs of the care recipient.

The Project Report, prepared by the Caregiver Support and Well Being Project Team provides an overview of the findings regarding caregiver needs and offers recommendations to support caregivers within the Central East LHIN. The report also details a planning and service framework for a Caregiver Support Centre model which provides a structure to deliver much needed supports to caregivers.

The Project Team of 7 caregivers and 11 health service professionals developed a work plan to address the following Project Team goals:

1. To coordinate and strengthen the system of care and support for caregivers.
2. To provide caregivers with access to the tools, resources and skills needed to improve control over their health and quality of life.
3. To improve availability and access to supports needed by caregivers through optimizing current investments and identifying the need for new investments.
4. To ensure health service providers in the Central East LHIN understand best practices in supporting caregivers.

The Project Team divided into task groups in order to complete the work of the work plan. The “Defining” group identified caregiver supports and developed a chart to illustrate the components which are necessary to make up caregiver support. The “Tools” group researched support models and developed the structure for the Caregiver Support Centre model. The “Access” group looked at the process of community engagement in order to identify needs and develop an understanding of the resources which exist within Central East. The “Education” group compared formal and informal caregiver education needs.

The Project Team investigated all component areas of support, reported the findings and identified recommendations to enhance caregiver support. In total, the Project Team identified 46 recommendations to improve support for caregivers. While all of these recommendations were considered necessary to improve the well-being of caregivers, the Project Team identified 4 areas for recommendation which would have the most immediate impact on the support and well being of caregivers within the Central East LHIN. Those areas of recommendation are:

1. Implementation of a Caregiver Support Service Model
2. Recognition of Caregivers
3. Respite Service Continuum
4. Compensation Support for Caregivers

As well as working through their Project Charter, throughout the year, the Caregiver Support and Well Being Project Team enthusiastically participated in and provided feedback to the Ministry of Health and Long Term Care’s project entitled “*Caring for Caregivers – Policy Implications of Long Range Planning.*”

Caregiver Support and Well-Being – Summary of Recommendations

In order to have an immediate impact on the health and wellbeing of caregivers within the Central East LHIN, the Caregiver Support and Well Being Project Team is recommending that the following areas be given priority.

General Recommendations Consistent Across All Areas of Support

- *Review the supply and demand for community support services to ensure equitable access across the Central East LHIN.*
- *Review the types of services in the basket of services provided to caregivers to continue to support care receivers in the home.*
- *Separate the eligibility for support for caregivers from the need for services for care receivers.*
- *Ensure that the needs of the culturally diverse population of Central East are considered in all implementations processes.*
- *Ensure that, within each implemented recommendation, there is a process for measuring outcomes in terms of quality of life improvements for caregivers.*

1) Caregiver Support Centre Framework and Service Delivery Model

In relation to the caregiver support model, the Project Team recommends:

- *The development of a Caregiver Telephone Support line and website.*
- *Collaboration with currently available navigational resources and expertise (i.e. 310 CCAC database, Information Centre's' databases.) to identify specific resources for caregivers.*
- *Centralized access to information and educational opportunities.*
- *The development of a database of culturally diverse resources, available by language.*

2) Recognition

In order to increase the recognition of the role of caregivers within the Central East LHIN, the following actions are recommended:

- *Educate health service providers on the importance of involving the caregiver in all aspects of care planning and decision making.*

Engaged Communities.
Healthy Communities.

- *Mandate regular education and training to service providers to assist them in communicating with caregivers and understanding their needs.*
- *Recommend that health service providers view and assess the needs of the caregiver separately from the needs of the care receiver.*

3) Respite

The following recommendations enhance the opportunities for respite for caregivers with the Central East LHIN:

- *Implement standard admission timelines and processes to simplify and shorten the admission to Adult Day Programs, or equivalent, across the Central East LHIN.*
- *Review the demand and supply for Adult Day Programs, or equivalent, ensuring equitable access across the Central East LHIN.*
- *Fund more subsidized in-home respite across the Central East LHIN, particularly throughout the underserved areas and sectors, ensuring equitable access.*
- *Implement a common assessment tool for the Community Support Services providing in-home respite – i.e. Inter RAI CHA (Community Home Assessment form)*
- *Simplify the admission process for short stay beds.*
- *Provide more short stay beds within Central East LHIN.*
- *Increase funding to community support agencies to provide more subsidized Instrumental Activities of Daily Living (IADL) services, to ensure equitable access across the Central East LHIN.*

4) Compensation Support

- *Explore self-directed funding options that would assist caregivers in paying for in-home respite, day programs or other support costs and allow them the flexibility to spend the funds on what they need most.*
- *Establish a subsidy program allowing caregivers to apply for financial assistance to purchase or lease caregiving supplies and equipment.*

ⁱ Health Canada, 2002, Final Report, National profile of Family Caregivers in Canada

ⁱⁱ Zukewich, Fall 2003, no 70 Unpaid, informal caregiving, (Internet), Canadian Social Trends,

ⁱⁱⁱ Health Canada (1995) *Health Human Resources in Community-Based Health Care (Executive Summary)*. p 3 Retrieved 8/18/2007 from http://www.hc-sc.gc.ca/hcs-sss/pubs/hhrhs/1995-build-plan-commun/build-plan-commun1/sum-som_e.html