

Caregiver Support and Well-Being Priority Project

For the complete report go to:

<http://centraleastlhin.on.ca/GetInvolved.aspx?id=1836>

The Central East LHIN has recently released its report on caregiver support. This project focuses on “individuals who provide on-going care and assistance to family members and friends in need of support due to physical, cognitive, mental health or addiction conditions¹” The term caregiver in this project refers to this network of family and friends.

Some information to consider:

Caregiver Profile

- One in five Canadians is an informal Caregiver.
- Seven out of ten caregivers are women.
- 27% of Ontarians have personally cared for a family member or close friend with a serious health problem in the last 12 months.
- There are 2.7 million caregivers who are aged 45 and over, an increase of 670,000 between 2002 and 2007.
- 25% of caregivers are at least 65.
- In CE LHIN, 19% of seniors reported that they are providing informal care to a family member or friend.
- 22% of those caring for individuals had to take time off work to provide care.
- 9% of those caring for an individual had to quit work.
- There are over 100,000 children, under the age of majority, who provide care and assistance to someone in their families who has a disability, a chronic illness, a mental health issue or a substance abuse problem.
- Most caregivers are looking after 1 individual, but close to 1 in 10 are also looking after a second family member.



Caregiver Contributions Profile

- It is estimated that caregivers provide 80% of the required care in the home, caring for individuals from all age groups, across all stages of life, and across the continuum of care
- Canadian research estimates 'caregiver care' and its "spin off" roles represent well over **\$80 billion** in economic value: an "industry" more than twice as large as the combined labour incomes for the financial, insurance and real estate industries.
- Canadians spend more than \$80 million per year on care giving expenses, most without receiving any credit, subsidy or allowance.
- One in six care receivers are children, many of whom have some form of mental disability.
- Family and friends often provide most of the care and support for people with mental illness. This results in significant benefits for both the individual and the health care system, including decreased rates of hospitalization and relapse and increased rates of recovery.

Caregiver Issues & Trends

- Families want to provide supports to a family member with an illness, chronic condition or disability but they require some economic contribution and support for this purpose. (e.g. access to homecare and respite, information and coordination assistance, economic compensation, workplace flexibility and job protection if they have to take time off).
- **All** employers can expect to have employees who will assume care giving responsibilities which will have an impact on the employment relationship and the human resource supply of our country.
- There are physical, psychological, social and financial risks assumed by families and friends providing care.
- Caregivers provide the invisible back-up that allows the health care system to keep functioning despite limited public resources. Caregivers make the shift away from institutionalized care possible.
- Despite these realities, the health system has been woefully inadequate in its recognition and support of family caregivers across Canada.
- A shift away from institutionalizing has left the bulk of care giving for seniors and individuals with mental health or addiction conditions and chronic diseases to family members and friends.
- In many cases, the presence and commitment of these caregivers makes an important difference in increasing the possibility that care receivers can stay in their homes.
- Caregivers' needs, networks, resources, strengths and limitations vary from caregiver to caregiver; caregivers of different ethnic groups may experience the caregiver role differently, due, in part, to different perceptions of family and family obligations as well as to differences in social supports and the personal coping capacities of the caregivers.

- Much of the current volunteering capacity is made up of today's seniors. We must consider what will happen when those seniors are in need of care themselves.
- Individuals providing four hours or more of care per week were more likely to reduce their work hours, change their work patterns or turn down a job offer or promotion. Among this group, 65% of women and 47% of men who were working over 40 hours per week were substantially affected.
- Most are providing care to someone with a physical disability with 1 in 5 having both physical and mental difficulties;
- The majority of people with disabilities who need support are supported entirely by their family members and friends.
- Approximately 50% of individuals with dementia in Canada live in the community and almost all of these individuals are cared for by family or friends until these caregivers are no longer able to maintain them at home.
- Individuals providing care to a family member are most likely to feel stressed in terms of their emotional health, with close to 80% of individuals providing care to a family member reporting some emotional difficulties for themselves? Many require the use of mental health services and medication for their own problems.
- Caregivers provide the majority of the care needed by individuals and contribute approximately 8 billion dollars of unpaid labour annually to the healthcare system. Caregivers are a part of the health provider "team" and not only need acknowledgement, but also need to be consulted at each stage of the healthcare process.
- More than one third of caregivers report extra expenses due to their caregiving 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. 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 citizens.
- This 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. This report also details a planning and service framework for a Caregiver Support Centre model providing a structure to deliver much needed supports to caregivers.

The project team of seven 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 CE LHIN understand best practices in supporting caregivers.

The report documents 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** (Implement the Caregiver Support Centre service delivery model included in this report and developed by the Caregiver Support and Well-Being Project team. This model provides a centralized point of access for all support needs in local communities. It consists of a Central East Caregiver Steering committee, a coordination centre and zone specific caregiver resource centres)
2. **Recognition** (The value of the contributions made by caregivers, to the health care system and to society in general, must be acknowledged and validated.)
3. **Respite** (Caregivers need time off from their care giving responsibilities in order to avoid burnout. Respite can take any number of forms, as long as it meets the caregiver's self-defined needs for relief, time off, a break from caregiver responsibilities and/or the experience of some rejuvenation and peace of mind.)
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.)

Local Data for Consideration

In the 2006 Census, Statistics Canada documented the number of people 15 years of age and older who reported they had worked without pay. In Peterborough County (including the City), 37,115 people reported that they had looked after children without pay. An additional 22,020 people stated that they had provided unpaid care or assistance to seniors.

2006	Family Structure and Living Arrangements for Seniors 65+ 2006							
	Ontario	%	City - County	%	City	%	County	%
Living with immediate family	1,022,345	67	15,410	67	8,190	63	7,220	75
Not living with family	513,050	33	7,240	32	4,790	37	2,450	25
Living with relative	94,330	6	775	3	365	3	410	4
Living with non-relative	23,545	2	440	2	260	2	180	2
Living alone	394,930	26	6,035	27	4,165	32	1,870	19
Total pop. 65+	1,535,620	100	22,660	100	12,980	100	9,680	100

*Immediate family refers to married or common-law spouse; may also include senior-led lone parent households. Source: Peterborough Social Planning Council, The Peterborough Profile, 2009.

"Statistics also show that between 1995 – 2002, the demand for home care services grew by 60 per cent. The aging population, consumer expectation for home and community care delivery, technology which allows more care to be delivered in the home and a shortage of beds and building, all contribute to the increasing demand for home and community care."*(Latest numbers paint a picture of Peterborough...and it's going grey, Don Peat, Peterborough Examiner, July 18, 2007)*

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