

Central East **LHIN**

Caregiver Support and Well-Being Priority Project

April 2009

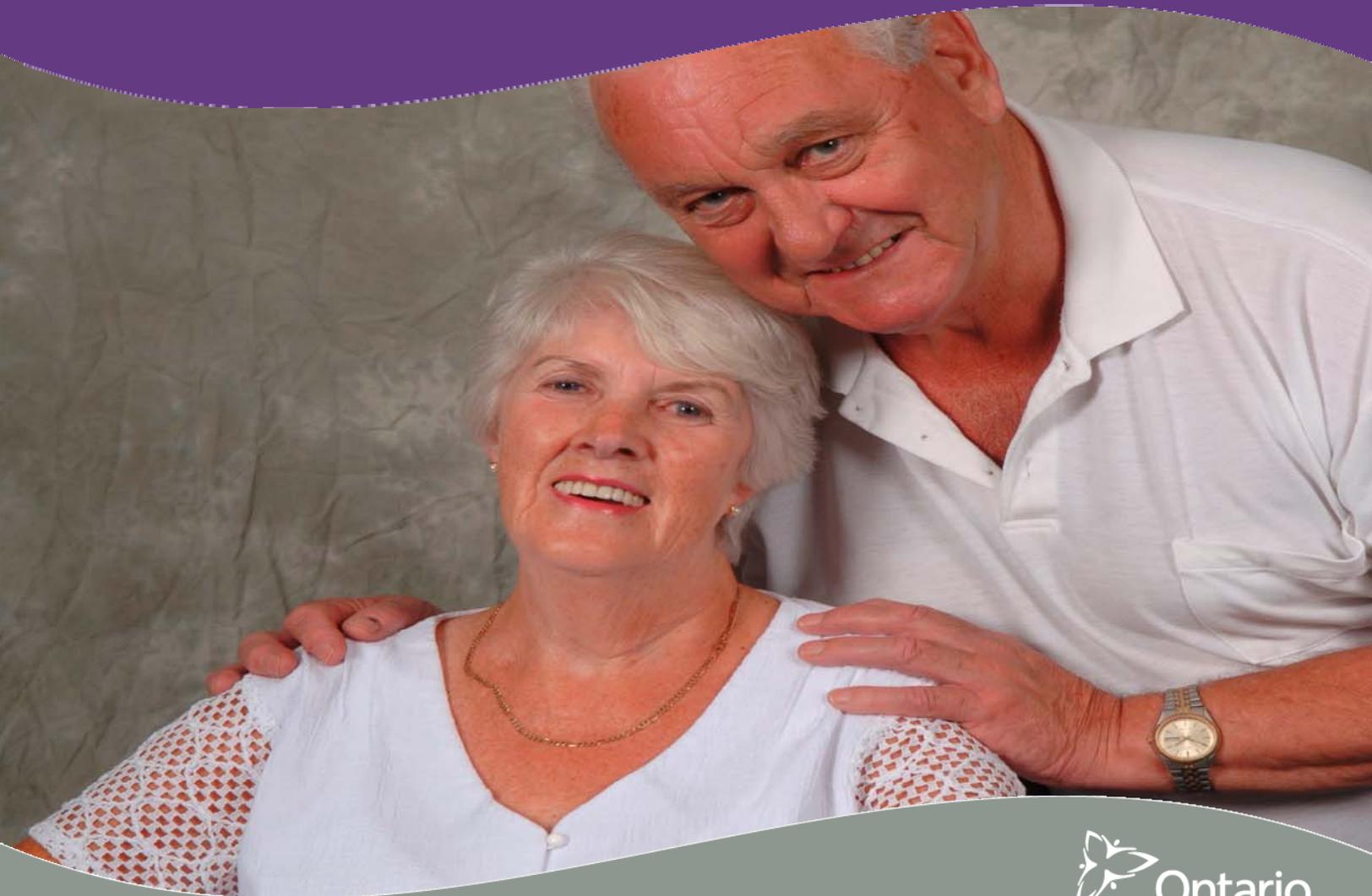


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ACKNOWLEDGEMENTS

Many thanks to the Central East LHIN for acknowledging that caregivers are essential to the health care system and for recognizing the value of their input in the planning process.

Thank you to the members of the Central East LHIN Caregiver Support Charter Writing Group and the Durham East Collaborative for your vision, insight and dedication to ensuring that caregivers have a voice and that it is heard.

Thank you to the Central East CCAC for your enthusiastic support of providing resources and leadership as the Host Service Agency.

Thank you to organizations and their boards who support the integration process by ensuring their staff be part of this project.

A special thank you goes to the **Caregiver Support Project Team and members of the task groups**. Your wisdom, dedication, knowledge and spirit in completing the work of this project will ensure that caregiver's needs are acknowledged and supported.

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This report is dedicated to the unsung heroes who tirelessly care for others who cannot care for themselves.

"There are only four types of people in the world: those who have been caregivers, those who are caregivers, those who will be caregivers and those who need care."

Former First Lady of the United States, Rosalyn Carter.

EXECUTIVE SUMMARY

Caregivers are family members or friends who provide both short term and on going care and assistance, without pay, to those in need of support due to physical, cognitive, mental health or addiction conditions throughout the continuum of care. Caregivers are 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 not only need acknowledgement, but also need to be consulted at each stage of the healthcare process.

Caregivers provide the care which allows many individuals to stay at home longer and to avoid unnecessary hospitalization or institutionalization.

Caregiving is not just about caring for someone, taking care of their needs; caregiving is caring about someone. And caregivers need help.

To be strong and avoid burnout, one must be supported. To make difficult decisions, one must be trusted. To make realistic judgments, one must have realistic options.

To care for themselves, caregivers must have reassurances that their loved ones are also receiving the best care possibleⁱⁱ

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.ⁱⁱⁱ 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^{iv} 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.

This project report, prepared by the Caregiver Support and Well-Being Project team (Appendix 1) 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 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 identified components of caregiver support are recognition, coping support, respite, information and education, financial/legal supports, daily living support and care planning support.

The “Tools” group researched support models and developed the structure for the Caregiver Support Centre model. The Caregiver Support model consists of a planning framework and a service delivery 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. In order to engage the community, the group developed surveys and delivered them to both caregivers and organizations that support them.

The “Education” group compared formal and informal caregiver education needs.

The task groups regularly presented their work to the main project team in order to receive further input and feedback.

Throughout this year, the Caregiver Support and Well-Being Project team participated in the Ministry of Health and Long-Term Care project entitled *Caring for Caregivers – Policy Implications of Long Range Planning* and were asked to provide feedback on the project report.

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. These recommendations are listed in the main body of the report and separated into local CE LHIN recommendations and provincial recommendations. 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
3. Respite
4. Compensation Support

An over view of the intent of these priority support recommendations is provided here. For a complete listing of support component recommendations, please see Caregiver Support Components Findings and Recommendations Page 14 of the Report.

Caregiver Support and Well-Being Project Priority Support Recommendations

In order to have an immediate impact on the health and wellbeing of caregivers within the CE LHIN, the Caregiver Support and Well-Being Project Team is recommending that the following areas be given priority. Implementing recommendations in these areas would begin to address the recommendations listed in the body of the report.

General Recommendations Consistent Across All Areas of Support

- Review the supply and demand for community support services to ensure equitable access across the CE LHIN.
- Review the types of services in the basket of services provided to caregivers to keep 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 within Central East are considered in all implementations of support.

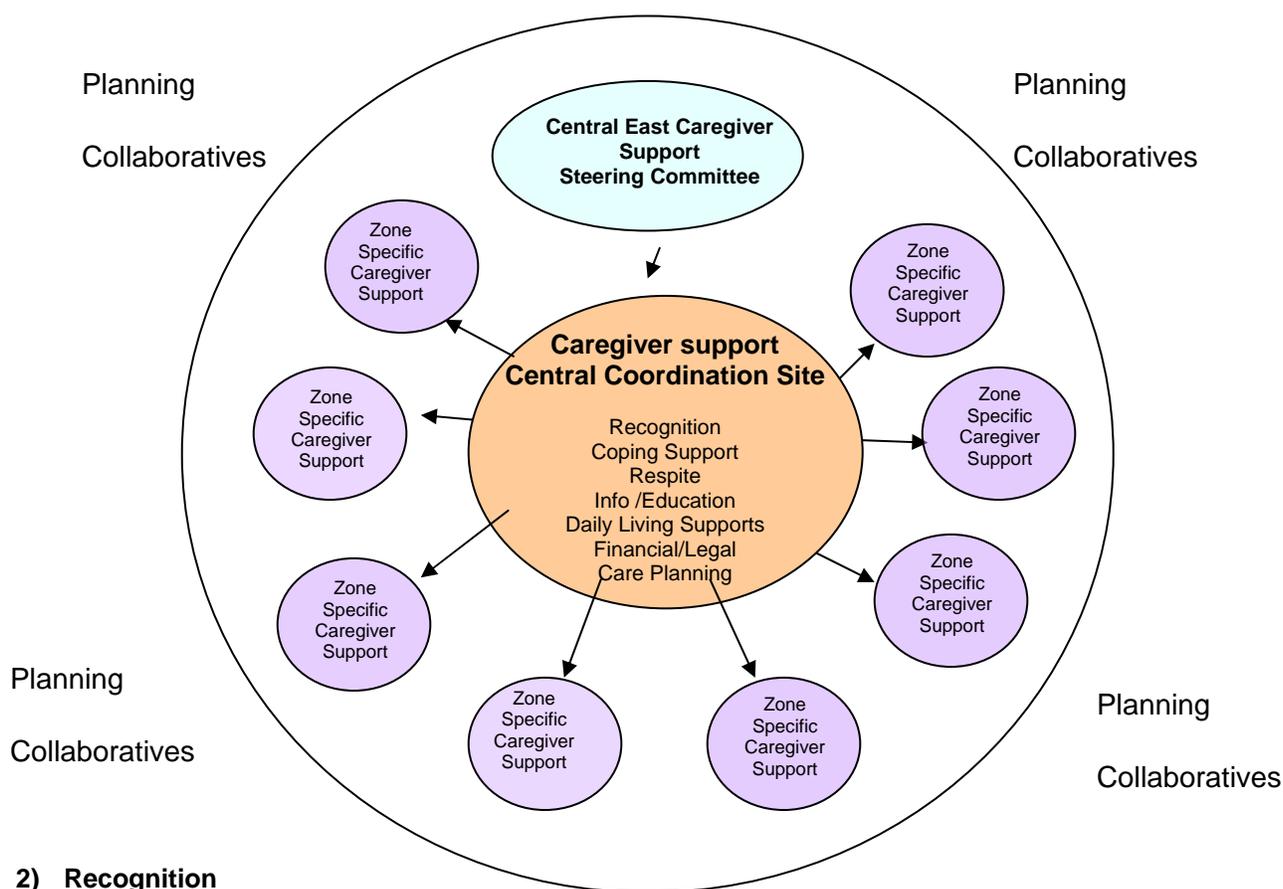
- Ensure that, within each implemented recommendation, there is a process for measuring outcomes in terms of quality of life improvements for caregivers.

1) Caregiver Support Centre Framework and Service Delivery Model

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 (see page 29 for details).

The support centre model facilitates CE LHIN-wide and local initiatives and increases availability and access by including:

- The development of a Caregiver Telephone Support line and website.
- Collaboration with currently available navigational resources and expertise (i.e. 310 CCAC database, Information Centres database.) 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

The value of the contributions made by caregivers, to the health care system and to society in general, must be acknowledged and validated. In order to increase the recognition of the role of caregivers within the CE 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.

- 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

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.^v The following recommendations enhance the opportunities for respite for caregivers with the CE LHIN:

- Implement standard admission timelines and processes to simplify and shorten the admission to Adult Day Programs, or equivalent, across the CE LHIN.
 - Review the demand and supply for Adult Day Programs, or equivalent, ensuring equitable access across the CE LHIN.
 - Fund more subsidized in-home respite across the CE 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. InterRAI CHA (Community Home Assessment form)
1. Simplify the admission process for short stay beds.
 2. Provide more short stay beds within Central East LHIN.
 3. Increase funding to community support agencies to provide more subsidized Instrumental Activities of Daily Living (IADL) services, to ensure equitable access across the CE 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.

The project team has worked tirelessly to ensure the message is clear, caregivers are an essential part of the healthcare system. Without caregivers, the system would certainly not be able to manage the care that is needed.

Nobody thinks they will become a family caregiver. One day you are a daughter or son, occasionally helping your parents. Seemingly overnight you become a case manager, disease specialist, chauffeur, researcher, care advocate – all in support of an aging parent. How did it happen? I am the third of five children, one son and four daughters. I'm responsible, caring, sensitive, an achiever, prime caregiver material. I took on the caregiver role unknowingly; never in a million years did I expect to become a parent to my parent and never have I had so much trouble understanding how to get help^{vi}.

PROJECT BACKGROUND

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.

Caregiver Profile

- One in five Canadians is an informal Caregiver.^{vii}
- Seven out of ten caregivers are women.^{viii}
- 27% of Ontarians have personally cared for a family member or close friend with a serious health problem in the last 12 months.^{ix}
- There are 2.7 million caregivers who are aged 45 and over, an increase of 670,000 between 2002 and 2007.^x
- 25% of caregivers are at least 65.^{xi}
- In CE LHIN, 19% of seniors reported that they are providing informal care to a family member or friend.^{xii}
- 22% of those caring for individuals had to take time off work to provide care.^{xiii}
- 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.^{xiv}
- Most caregivers are looking after 1 individual, but close to 1 in 10 are also looking after a second family member.^{xv}

Caregiver Contributions Profile

- “It is estimated that caregivers provide 80% of the required care in the home^{xxvi}, caring for individuals from all age groups, across all stages of life, and across the continuum of care.”^{xxvii}
- 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.^{xxviii}
- Canadians spend more than \$80 million per year on care giving expenses, most without receiving any credit, subsidy or allowance.^{xix}
- One in six care receivers are children, many of whom have some form of mental disability^{xx}; 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.^{xxi}

Caregiver Issues

- 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).^{xxii}
- **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.^{xxiii}
- There are physical, psychological, social and financial risks assumed by families and friends providing care.^{xxiv}

- 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.^{xxv}
- 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^{xxvi xxvii}; 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.^{xxviii}
- Caregivers' needs, networks, resources, strengths and limitations vary from caregiver to caregiver^{xxix}; 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.^{xxx}
- 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.^{xxxi}
- Most are providing care to someone with a physical disability with 1 in 5 having both physical and mental difficulties^{xxxii}; the majority of people with disabilities who need support are supported entirely by their family members and friends.^{xxxiii}
- 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.^{xxxiv}
- 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?^{xxxv} Many require the use of mental health services and medication for their own problems.^{xxxvi}

Project Charter

At the 2007 Central East LHIN symposium entitled, "From Planning to Action", planning partners prioritized a list of projects from the Integrated Health Service Plan. Participants identified that caregivers' health and well being was one of the priorities which needed to move forward; in fact, it was priority #1. In December 2007, the Central East LHIN Board of Directors approved the Caregiver Support and Well Being Priority Project along with a number of other projects which were aligned to the Central East LHIN's [strategic directions](#). The Caregiver Support and Well Being Priority Project was sponsored by the Durham East Collaborative and a project charter writing team was developed from that collaborative and from other interested community members.

The project charter (Appendix 2) outlines the scope, objectives and participants in the project and provided a valuable reference base for the development and completion of the project.

The Caregiver Support and Well Being Priority Project was funded from the Year One Aging at Home (AAH) strategy. The AAH Strategy is a three year strategy aimed at reviewing and revising the way services are delivered to seniors and providing more equitable access to health care for seniors.

With each year of the strategy, funding has been allocated for community support services to enhance services for caregivers (Appendix 3).

In March 2008, a project coordinator was hired and a project team was formed. The 18-member project team consisted of seven caregivers and 11 individuals representing organizations in the Central East LHIN that provide support for caregivers.

Purpose

In recognition that caregivers are an essential part of the health care continuum, the project's purpose is to ensure that caregivers are provided the right support, at the right time in the right place. The project's aim is to support caregivers more effectively and to build the capacity of individuals and families to be caregivers.

The project's purpose is further defined by its commitment to acknowledge and validate issues and needs specific to caregivers, to enhance and improve access to a variety of services, to improve the consistency and coordination of existing supports and to introduce new services as required.

Providing improved care and support to caregivers will ease demand on the health care system. It will enable caregivers to provide support in a manner which prevents "caregiver burnout" and chronic illness due to stress and fatigue.

The project identifies best practices and opportunities for integration of caregiver supports through examination of what exists and what is not currently in place. The project delineates the system of caregiver support required for Central East LHIN.

The project provides the LHIN with the framework and tools necessary to pursue consistent implementation and provide enhancements to the system of support by incorporating Caregiver Supports into Service Accountability Agreements with Health Service Provider Agencies.

Vision and Mission

Vision

Engaged Communities, Healthy Communities

The vision of this project is a system that is responsive to the needs of caregivers in our communities for today and tomorrow.

Mission

Caregiver Supports promote the health and well being of caregivers, enabling and assisting them in their caregiving roles.

Project 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 lobby for best practices in supporting caregivers to be known, valued and applied by all health service providers in the CE LHIN.

INFORMATION-GATHERING PROCESS

In order to ensure that the project team understood the issues facing caregivers within the Central East LHIN, a process was initiated to gather information. This process consisted of a review of the literature, including best practices within the CE LHIN, throughout other LHIN’s in Ontario, in other provinces of Canada and throughout the world. Information was also obtained from community consultation and data collection.

Literature Review

Several organizations such as the Seniors Health Research Transfer Network (SHRTN), the Murray Alzheimers Research and Education Program (MAREP), the National Institute in the Care of the Elderly (NICE), the Canadian Caregiver Coalition, the Canadian Mental Health Association and the Veterans Independent Program were instrumental in providing assistance in the information-gathering process. Literature was reviewed in order to determine common definitions of support for caregivers, varying service and support models, tools and resources available to caregivers, practices in the assessment of caregivers and approaches to meeting caregiver education needs.

Community Consultation

Caregiver Feedback

As per the CE LHIN framework for community engagement, community consultation was conducted with both caregivers and organizations who work with caregivers. During each consultation process, the project team developed a survey (Appendix 4) asking the participants to identify specific caregiver needs, asking what supports were missing and asking for feedback on how caregivers envisioned a caregiver support centre. The survey was distributed in caregiver forums, 1:1 interviews, support groups, and through the Caregiver page of the CE LHIN website. Community consultations resulted in 273 responses and those responses were influential in identifying the needs of caregivers within our CE LHIN.

The following table illustrates the breakdown of responses by CE LHIN planning zone:

Zone 1	Zone 2	Zone 3	Zone 4	Zone 5	Zone 6	Zone 7	Zone 8 & 9
Haliburton Highlands	Kawartha Lakes	Peterborough City & County	Northumberland Havelock	Durham East	Durham West	Durham North Central	Scarborough Agincourt/Rouge Scarborough Cliffs
14	9	20	28	49	43	21	89

“Sometimes I don’t know what I need, but if I could talk with someone who could steer me in the right direction or let me know that what I am doing is ok, then I would feel better.”

Summary of Predominant Feedback

(For the complete list of feedback see Appendix 5)

25% of all respondents stated that caregivers need:

- A help line to call.
- More in-home respite.
- To understand where to go for help (navigational support).
- One place to go to find information, support, and education – “no more running around.”
- Help with household maintenance tasks - snow shovelling, yard maintenance, house cleaning.

Community Support Organization Feedback

A process of community consultation was conducted with organizations who work with caregivers. For this process, the project team developed a survey (Appendix 6) asking organizations to identify the needs of caregivers they work with, what they need to support caregivers and what is missing. Surveys were sent to 53 CE LHIN Community Support Organizations and were available to any service provider through the caregiver page of the CE LHIN website. In total, and as depicted below, there were 47 surveys returned which identified some key issues.

Zone 1	Zone 2	Zone 3	Zone 4	Zone 5	Zone 6	Zone 7	Zone 8 & 9
Haliburton Highlands	Kawartha Lakes	Peterborough City & County	Northumberland Havelock	Durham East	Durham West	Durham North Central	Scarborough Agincourt/Rouge Scarborough Cliffs
2	2	4	10	8	7	5	9

Summary of Predominant Feedback from Organizations

(Complete list of all feedback found in Appendix 7)

Caregivers we work with need:

- To be taken seriously and to be included in the care planning process.
- Easy access to information – knowledge about how to navigate the system – an understanding of how to reach the right supports faster.
- Doctors who have more working knowledge of the supports in the community.
- Financial assistance, subsidies to offset care giving costs.
- A 24-hour help-line.

In order to support caregivers more effectively, organizations need:

- More formal acknowledgement that they are providing services for both the client and the caregiver and more funding specifically directed to support the caregivers' needs.
- Coordination of resources: Organizations have no easy access to the expertise and resources available in service areas other than their own. Coordination of these physical and human resources is needed to optimize their use and to improve service delivery in general.

Data Collection

Data was also collected from the following sources and for the respective reasons:

- Central East CCAC - number and location of short stay beds, wait lists of adult day programs.
- Central East LHIN – demographic data, Health Service provider information, in-home respite data.
- Trent University – Study of Needs of Caregivers of Palliative clients.

Work Plan

The Project Team was divided into Task Groups to address the work plans which were developed from each goal. In addition to Project Team members, Task Groups also included other interested caregivers and staff from organizations that had expertise in the areas of our work plan.

Group (Goal) 1: Definition

- Development of the definition of caregiver supports and the support components which caregivers need.

Group (Goal) 2: Tools and Resources

- Development of a service delivery model.

Group (Goal) 3: Access

- Development and implementation of a community engagement process to define caregiver needs and to understand the inventory of resources which exist.

Group (Goal) 4: Education

- Review of the learning needs of formal and informal caregivers.

Each month, at the Caregiver Support Priority Project meeting, each Task Group presented an update on its work and requested feedback. Work was approved and consolidated by the main caregiver support group and recommendations were developed in that forum, based on the issues presented by the task groups.

I have been the primary caregiver for my beloved wife who has Alzheimer Disease for the past 15 years. I have been with her every step of the way, caring and providing for her every need. On January 12, 2009 she had difficulty breathing. I have been visiting her each of the 77 days she has been dealing with breathing and swallowing difficulties. She is progressing well and will be discharged soon. Since her hospitalization her care needs have increased. I am willing and ready to take her home but need help and support in order to understand her complexity of care. There are so many questions I have, so many things which I am concerned about. I want to make sure I have the resources to provide her the care she needs. I don't know where to turn.^{xxxvii}

CAREGIVER SUPPORT: Findings and Recommendations

The initial work of the Project Team concentrated on defining the meaning of caregiver supports and identifying the types of supports which caregivers need. Through the processes of literature review and community consultation, the project team was able to identify components necessary to provide support to caregivers. The following chart is an illustration of the foundation of support which needs to be considered when planning delivery and evaluating programs for caregivers (See next page and Appendix 8). This chart and its components illustrate the project team's findings and recommendations. To provide clarity, each area of support and the listed components have been defined in detail (Appendix 9).

When considering the supports required by caregivers it is essential to take a comprehensive whole person/holistic approach and consider the various influences and environmental factors that determine consumer and family health; consideration must also be given to the need for support at both the diagnosed and undiagnosed stages of caregiving^{xxxviii}.

Recognition

Definition

Recognition is the philosophy that identifies and acknowledges the enormous contributions of caregivers in enhancing access, quality and sustainability of care and the importance of them making informed decisions about their level of involvement in care giving and care planning.

Components

- **Role in Decision Making:**
Caregivers are involved in the decision making, planning, implementation and evaluation of programs and services which affect them directly.
- **Inclusion in Care:**
The input of caregivers is included in the planning of care for the care recipient.
- **Validation of Caregiver Role:**
The importance of the contribution of caregivers is acknowledged and affirmed.
- **Community Awareness:**
Information and resources exist to assist and promote community awareness of the caregiver role.
- **Organizational Awareness:**
Individual organizations have an understanding of the contributions of caregivers.
- **Planning for the Caregiver:**
The needs of caregivers are separate from those of care recipients and are to be included in the planning and implementation of service delivery.

Findings

Sources include caregivers, organizations, and reviews of best practices:

1. Caregivers often feel they are not recognized as partners with health care providers and are not always included in the planning, delivery and evaluation of programs and services which have an effect on them and the care receiver.
2. Caregivers are not always given respect and recognition for the contributions they make to ensure that care is provided to individuals.
3. Organizations differ in the way they acknowledge and support employees who have care giving responsibilities. Ontario lacks a strong, high profile voice for caregivers in contrast to other areas such as the UK, Australia and Sweden. In these areas and others, independent representative associations are prominent in a national dialogue on caregiver issues.^{xxxix}

Recommendations

CE LHIN Recommendations:

1. Build a culture among health service providers within CE LHIN of involving caregivers in all aspects of care planning and decision making related to their own needs.
2. Advocate for the following provincial recommendations.

Provincial Recommendations:

1. Advocate formalizing the recognition of the role of the caregiver through a provincially funded Caregiver Strategy.
2. Advocate for public awareness initiatives which inform the public on the important role caregivers play (e.g. integrate the importance of care giving into school curriculums to prepare children and youth to take on the care giving role).^{xi}

Coping Support

Definition

Coping support provides opportunities to share thoughts and feelings with others in order to be able to manage caregiving. These opportunities could include individual support with a trained professional, facilitated group support, peer support and information on self help.

Components

- **Counselling:**
Counselling provides a process of helping caregivers resolve a wide range of issues.
- **Support Groups:**
Supports are in place to offer opportunities to share issues, thoughts and feelings in a group setting.
- **Advocacy:**
There is a process in place and resources available to work on behalf of the caregiver on a particular issue or idea.
- **Self Help:**
There are opportunities for individuals to receive care giving tools and strategies to assist them in their caregiving roles.
- **Mentorship:**
Programs exist to facilitate the interaction between caregivers and people with first hand, similar care giving experiences who may be able to guide other caregivers towards a better understanding of the care giving role and its many issues.

- Ethical Moral Issues:
Information and assistance is available to provide caregivers with strategies to deal with decisions that effect their personal values.
- Problem Resolution:
The interests of caregivers are represented in the investigation of and in the resolution to problematic situations.

Findings

1. Caregivers would like to have a single point of access to go to or call for support or to direct them to the appropriate place.
2. Caregivers would like to have a help line to call.
3. The transition points in the care process are quite stressful for caregivers. (i.e. care recipient is discharged home or moves to another level of care)
4. The supports which caregivers need are very separate from the needs of the care receiver.
5. In Central East LHIN there are currently 9 community support agencies that receive funding to provide 15 programs designated as caregiver supports.
6. There are 6 types of programs funded specifically for caregivers:
 - Counselling and support
 - Training information and education
 - Respite (paid)
 - Respite (volunteer)
 - Respite (brokerage)
 - Hospice visiting.
7. Many organizations who offer supports for caregivers use other funding sources such as fundraising and/or increasing existing job responsibilities.
8. There are not sufficient resources to accommodate the support needs of the culturally diverse.
9. It is often difficult to maintain enough volunteers to support caregivers.
10. Caregivers who are employed often have difficulty managing and balancing the responsibilities of work and care.
11. Currently the Ombudsman of Ontario does oversee and investigate complaints concerning the CE LHIN but does not address the organizations funded by the CE LHIN.

Recommendations

CE LHIN Recommendations:

1. Implement the Caregiver Support Centres model summarized in this document within the Central East LHIN to respond to the specific needs of caregivers in each local community.
2. Initiate a Central East Caregiver Support Telephone Line Service to respond to the identified need from both caregivers and organizations that support them.
3. Review the U of T "Timing it Right" Caregiver conceptual framework which looks at providing caregivers with specific support information and education at each stage of the continuum of care (from acute care to home care) and assess its applicability with the CE LHIN.
4. Enhance the capacity of the Community Support Agencies to recruit, train and manage volunteers.
5. Increase the capacity of CE LHIN organizations, with specific funding and other assistance measures, to provide supports for caregivers which are separate from those provided to the care receiver.
6. Establish an ombudsman within the CE LHIN who is responsible for investigating complaints related to services funded by the CE LHIN and whose mandate includes caregivers.

Respite

Definition

Respite is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home.

Components

- **Adult Day Programs:**
Support service provides supervised programs for care receivers outside of the home in a group setting which offers caregivers a break from their care responsibilities.
- **In Home Respite:**
Qualified workers come to the home, temporarily, to assume care responsibilities and to allow caregivers some personal time.
- **Short Stay Respite:**
Relief is offered to the caregivers by providing placement within long term care facilities for individuals who are expected to return home
- **Emergency Respite:**
Short term, home or institutional-based respite care is provided in the event of an emergency.
- **Alternate Respite:**
Innovative, alternate methods of providing short term, temporary relief from caregiving responsibilities are implemented.

Findings

Adult Day Programs:

1. Currently in CE LHIN, there are 14 organizations funded to provide 36 Adult Day Programs (ADP). There are integrated Adult Day Programs, and those which provide service to specialized populations.
2. Many physicians and health care providers do not know about Adult Day Programs or how to access them for their care receivers/care givers.
3. The method of referral and assessment is not standard throughout the Central East LHIN. The CECCAC is the central access point for referral and assessment in Durham, Peterborough, Haliburton and Northumberland, but not in the Scarborough area.
4. There are often long delays in processing applications to adult day programs.
5. Adult Day programs are not available in all parts of the Central East LHIN and are not often available to accommodate the caregiver's hours or the specific needs of the adult population it serves.
6. Each Adult Day Program establishes its own cost per day to attend. Costs per day can vary depending on site and whether transportation to the program is included.
7. Cost can be a barrier to accessing the Adult Day Program service.
8. Transportation to and from Adult Day Programs is a barrier for these Programs where transportation is not provided and is therefore the responsibility of the family.

In Home Respite:

- 1 Less than five organizations are funded to provide subsidized in-home respite throughout the CE LHIN.
- 2 Subsidized in-home respite is not available in all areas of the CE LHIN.
- 3 Organizations that provide subsidized respite care do not have a standard assessment process.
- 4 Clients/caregivers often can not afford even subsidized cost requirements.

- 5 CCAC provides funded caregiver relief/in-home respite based on *individual client* needs, identified through a case management assessment, and as part of the personal support services provided to the client.

Short Stay Bed:

- 1 There are 32 long term care facilities that provide 61 short stay beds in the Central East LHIN.
- 2 The wait time for short stay beds differs throughout the LHIN.
- 3 Between April 2008 and September 2008 there were 845 short stay respite admissions with an average length of stay of 14.5 days.
- 4 Long term care homes have to apply to the LHIN to have short stay respite beds.
- 5 The additional administrative work which accompanies short stay beds leaves little incentive for long term care homes to take a short stay bed.
- 6 Many caregivers are not aware of the option of short stay respite.

Recommendations

Adult Day Programs:

CE LHIN Recommendations:

1. Standardize and simplify the admission process to Adult Day Programs across the CE LHIN.
2. Establish and implement standard admission timelines to accelerate the admittance to Adult Day Programs.
3. Initiate targeted communication to Primary Care, Community Support Service agencies and to those working with caregivers, to ensure awareness of Adult Day Programs and Short Stay Respite.
4. Review the demand and supply for Adult Day Programs and ensure equitable access across the CE LHIN.
5. Review the various cost structures for Adult Day Programs across the LHIN (including transportation) to better understand the implications for access.

In home Respite:

CE LHIN Recommendations:

1. Fund more subsidized in-home respite throughout underserved areas of the CE LHIN.
2. Establish and implement a common assessment tool for the Community Support Services providing paid respite (i.e. InterRAI CHA (Community Home Assessment form)).
3. 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.

Short Stay Respite:

CE LHIN Recommendations:

1. Simplify the admission process for short stay beds.
2. Explore alternate areas for funded respite (i.e. retirement homes, supportive housing).
3. Advocate for the following provincial recommendation.

Provincial Recommendations:

1. Provide additional incentives to Long-Term Care Homes to have short stay respite beds.

General Respite Recommendations:

1. Separate the eligibility for respite for caregivers from the need for services for care receivers.^{xii}

Information and Education

Definition

Access to information and training programs and educational opportunities assists and enables caregivers in their caregiving role.

Components

- **Self Management:**
Education programs which provide strategies and insights into self-management encourage people with chronic illness and their caregivers to improve their own health.
- **Care giving Skills:**
Opportunities to provide information and education to help caregivers develop the skills they need to feel confident and safe in their caregiving roles.
- **Resources:**
Caregivers have opportunities to access strategies, tools, services and/or programs that support them.
- **Self Navigation Skills:**
Information and education is available to help caregivers identify access, utilize and coordinate appropriate resources.
- **Wellness and Health:**
Caregivers are provided with opportunities to take care of their own health.

Findings

1. The amount of information that caregivers need varies at each stage of the health care continuum.
2. Caregivers need information and educational opportunities to develop the skills needed to be a caregiver.
3. Caregivers need information and educational opportunities on how to care for themselves.
4. Caregivers are asking for a simple system of finding information and educational support opportunities.
5. Useable information and educational opportunities and resources on care giving are not always available to the culturally diverse population.
6. Useable information and educational opportunities and resources on care giving are not always available to those with hearing and sight impairments.
7. Employed caregivers need information and educational opportunities to prepare them and/or support them in their caregiving roles.

Recommendations

CE LHIN Recommendations:

1. Mandate regular education and training for service providers to assist them in communicating with caregivers and understand their needs.

2. Implement a “Timing it Right” Caregiver program which provides caregivers with specific support information and education at each stage of the continuum of care.^{xlii}
3. Promote the Self Management training program to caregivers.
4. Ensure that opportunities for education and information are practical, available and accessible for all the CE LHIN population.
5. Conduct an inventory and develop a database of top culturally diverse resources which are available by language. Where those culturally diverse resources are limited or do not exist, begin to develop the appropriate resources for culturally diverse populations.
6. Advocate for the following provincial recommendations.

Provincial Recommendations:

1. Develop a provincial educational system for the delivery of specific modules of caregiver education including but not limited to the basics of setting up care giving arrangements, how to assess and monitor quality of service delivery and support and specific learning on complex clinical/medical issues.^{xliii}
2. Provide specific educational opportunities for community programs to encourage a culture of care and to promote a change in the attitudes and assumptions regarding caring for the disabled and the elderly (i.e. Youth Education programs to prepare young people for future care giving responsibilities).
3. Provide education and information for Employers to create awareness of caregiver issues and their impact; encourage businesses and industry to offer information, educational opportunities and support as part of a wellness program for all employees.

Daily Living Support

Definition

Assistance with daily living tasks to reduce demands on caregivers.

Components

- **Transportation:**
Information and resources are available to provide caregivers with creative solutions to deal safely with transportation needs and challenges.
- **Personal Care:**
Support is given to caregivers to assist recipients with routine activities of daily living such as bathing, eating, dressing.
- **Home Maintenance:**
Programs provide the caregiver with assistance to do routine maintenance on homes or to make minor repairs.
- **Home Making:**
Support is given to caregivers to assist care recipients with activities associated with living (i.e. shopping, light housekeeping, meal preparation, paying bills, etc.)
- **Mobility and Safety Resources:**
Information is provided to ensure that caregivers have access to resources to allow the care recipient mobility in a safe environment.

Findings

1. In order to keep a loved one in the home, often a caregiver needs some help to maintain the home.
2. Instrumental Activities of Daily Living – IADL* are not fully subsidized in the basket of services to support the caregiver.
3. There are not enough subsidized resources (volunteer and paid) to assist caregivers with home maintenance/housekeeping.
4. Transportation services are not available in many areas of the CE LHIN, especially in rural areas.
5. The quantity and type of supports differ within each community and this is especially evident in the rural areas of the CE LHIN.
6. Most formal programs offering daily living supports are geared to supporting the needs of the care receiver.

Recommendations

CE LHIN Recommendations:

1. Review the types of services in the basket of services provided to caregivers to keep care receivers in the home.
2. Increase funding to community support agencies to provide more subsidized Instrumental Activities of Daily Living (IADL) services to ensure equitable access across the CE LHIN.
3. Review the supply and demand for community support services to ensure equitable access across the CE LHIN.
4. Investigate the feasibility of offering wrap around service funding that could help to support those caregivers who have IADL* needs.

During the worst years, I contemplated kicking my son out many times. It wasn't so much the constant damage to house and furnishings; it was what it was doing to my daughter's mental health. When caregivers in other sectors can't cope, they would never contemplate kicking the care recipients out. But that is a real and huge problem in the Mental Health and Addictions sector. The mental health sector talks a lot about the homelessness problem among people who have had contact with the mental health system. But the conflict and family breakdown that is the major contributing factor to the homelessness is hardly ever discussed. Caregivers of those with mental illness need a support system to help them understand how to cope. I was fortunate to receive information, education and support which were instrumental in reducing the conflict at home, and I believe also played a crucial role in my son's recovery.^{xiv}

* ADL – Instrumental Activities of Daily Living: the activities related to independent living performed by a person who is living independently in a community setting during the course of a normal day. IADL activities include, but are not limited to managing money, shopping, telephone use, and travel in community, housekeeping, minor home repairs, preparing meals, and taking medications correctly. Increasing inability to perform IADLs may result in the need for care facility placement⁴¹

* IADL – Instrumental Activities of Daily Living: the activities related to independent living performed by a person who is living independently in a community setting during the course of a normal day. IADL activities include, but are not limited to managing money, shopping, telephone use, traveling in the community, housekeeping, minor home repairs, preparing meals, and taking medications correctly. Increasing inability to perform IADLs may result in the need for care facility placement⁴¹

Financial/Legal

Definition

Support to provide access to financial and legal information, advice, advocacy and services.

Components

- Tax Incentives/Credits:
Federal and provincial income tax provisions ease the tax burden for caregivers.
- Equipment/Home Modification Subsidies:
Funding for equipment and renovations ease the workload and increase the safety of caregivers.
- Self Directed Funding Options:
Caregivers have the option of deciding on and implementing the types of supports which will be covered by funding with a set of criteria.
- Caregiver Employment Leave Options:
Employer policies enable employee leaves to perform caregiving roles, without penalty.
- Legal Issues:
Matters of law, which pertain to caregivers, are clearly represented.

Findings

1. Financial assistance programs are often focused on the person with the illness or disability, not the caregiver.
2. The cost of equipment and supplies needed to care for an individual is often significant.
3. The cost of reducing work hours in order to accommodate care giving needs can be significant.
4. Employment Insurance Compassionate Care benefits provide support, on a short term basis, for caregivers caring for the terminally ill.
5. Work hours often have to be decreased in order to take on the responsibilities of care giving.
6. There is currently no social assistance program which provides compensation to an individual who has had to leave or reduce work hours to meet care giving responsibilities.
7. Caregivers, eligible for a tax credit for the in-home care of a relative, must have sufficient income to apply against the credit. This does not translate into paying for care giving costs on an immediate basis.
8. All employers have employees who will assume care giving responsibilities and this will have an impact on the employment relationship
9. Employers vary in the way they support employees who are dealing with care giving issues.
10. Caregivers often do not know where to go for assistance and support regarding their legal or financial inquiries.
11. Other countries (e.g. Australia, Norway, Sweden, and UK) offer carer allowance or cash benefits to family caregivers of people requiring chronic at-home care.^{xlv}

Recommendations

CE LHIN Recommendations:

1. Ensure that caregivers are provided with access to information and educational opportunities on how to get support for their legal and financial questions or issues.
2. Establish a subsidy Program allowing caregivers to apply for financial assistance to purchase or lease caregiving supplies and equipment.
3. Explore the feasibility of self directed funding models for the CE LHIN.
4. Advocate for the following provincial recommendations.

Provincial Recommendations:

1. Advocate for the Provision of financial assistance programs/tax incentives to minimize the excessive financial burden on caregivers, separate from the support for the care receiver.
2. Advocate for the Provision of a social assistance model with an income allowance so that becoming a caregiver does not result in a poverty risk.^{xlvi}
3. Advocate for provincial incentives to encourage organizations to create flexible workplace environments that respect care giving obligations.^{xlvii}
4. Advocate for the implementation of a provincially supported program of financial assistance or equipment credits for caregivers.

Care Planning

Definition

The needs of caregivers are addressed when developing a plan of care.

Components

- Needs Assessments:
Individualized assessment of caregivers' support needs that will help to ensure the caregivers' health and well being.
- Support Planning:
Development of a service plan that meets caregivers' individual support needs and includes coordination of services and regular monitoring to reflect caregivers' changing needs.
- Navigation Support:
Assistance with linking to organizations that provide services which make a positive contribution to caregivers' health and wellbeing.

Findings

1. Caregivers have difficulty navigating the system. Although many are willing and able to find support and assistance, they often don't know where to begin.
2. Doctors/primary care needs to be more aware of the needs of the caregiver.
3. There are very few formal programs which acknowledge the caregiver as a separate care receiver with distinct needs.
4. Many organizations that provide support do not have a separate process to look at the needs of caregivers.
5. Three types of caregiver assessment tools were reviewed – Caregiver Burden Scale^{xlviii}, Caregiver Resiliency Scale^{xlix} and C.A.R.E. Tool.^l
6. There is not a standard assessment process which is utilized by organizations that support the client and caregiver.
7. Organizations often need support to find resources for their caregivers.

Recommendations

CE LHIN Recommendations:

1. Implement the useable, integrated **Caregiver Support Centre** service delivery model summarized in this document which provides a centralized point of access for all caregiver support needs.
2. Facilitate collaboration with the currently available navigational resources and expertise (i.e. 310 CCAC database, Information Centres database.) to locate specific resources presently available to meet the needs of caregivers.

3. Provide specific funding and other measures to increase the capacity of organizations to enable them to provide specific, separate and distinct support to caregivers in addition to the support given to care receivers and to the care giving situation.
4. Recommend that health service providers assess the needs of the caregiver separately from the needs of the care receiver.

Developing a Caregiver Support Model

In order to have success in supporting caregivers, it is important to provide a system of support which addresses the needs of caregivers. It is imperative that there is a support structure for caregivers, distinct from supports offered to care receivers. Overwhelmingly, caregivers are saying they need assistance to find the resources they need, to seek out someone to talk to, to participate in information and educational opportunities. Caregivers, in many cases, have no formal training. They learn on the job, have no organization that represents them, no pay or benefits, no support or regulations and are usually underappreciated.ⁱⁱ They require a support network to help them manage the care they provide. They need a standard set of resources which will ensure that their concerns are heard and that their needs are addressed.

Although many needs are consistent across the CE LHIN, there are a considerable number of issues which are reflective of individual communities in the CE LHIN, their available resources, their geographical location and their cultural diversity. It became very apparent, during the progress of this project, that it is imperative to develop a system which will address needs specific to local environments, cultures and community individuality. No single formal support program is effective in meeting all the needs of caregivers. Instead, caregivers need access to a range of services that address both the emotional and mental stresses of caregiving and the challenges associated with the physical day-to-day tasks associated with the caregiving role.ⁱⁱⁱ

To enhance support for caregivers in the Central East LHIN, the Caregiver Support and Well Being Priority Project has developed the **Central East Caregiver Support Model**

This model will include:

- **Planning Frame Work:**
Provides a reference framework, guidelines to ensure consistency during the implementation of systemic service delivery
- **Service Delivery Model:**
Provides an outline and summary of what this model will provide and of how it will provide those deliverables throughout the Central East LHIN

When individuals and families have access to the right information, support and resources, they develop the knowledge and skills they need to play a more active role in managing their health and coping with a chronic diseaseⁱⁱⁱⁱ

CAREGIVER SUPPORT MODEL

Planning Framework

This framework is intended to act as a *guideline for caregiver planning groups, providers and LHIN staff and Board* as they collectively plan and implement a system of care and supports for caregivers.

It is intended to provide the framework for:

- Communicating a vision and for moving forward to provide a system of care and support for caregivers in Central East;
- Monitoring the evolution of that system of care and support;
- Ensuring that solutions are developed systemically and not as a series of band-aids;
- Improving understanding of accountability across the continuum/sectors;
- Providing quality care for caregivers; and
- It is intended to act as a “lens” through which current and future programs can be viewed, monitored and evaluated.

A clear demonstration of a strong commitment to the principles of this planning framework is to be built into all planning, development, delivery and evaluation plans related to the system of care and support for caregivers.

Guiding Principles

These guiding principles are the **shared values** that guide health planning, decision-making and service delivery for a coordinated and quality seamless system of care and support for caregivers⁴ living in the Central East LHIN.

Integrity:

Caregivers are acknowledged, respected and valued:

- a) Caregivers are treated with dignity – treated with respect, regardless of the situation, and in a manner that encourages a sense of self-esteem.
- b) Caregivers are valued and respected for their contribution to society.
- c) Professional care providers respect the sanctity of the home when it is the site of care; they honour the family’s right to respect and dignity.
- d) Families differ in their capacity to provide care and caregivers have a right to modify their level of involvement at any time.
- e) The diversity of caregivers (e.g. on the basis of age, gender and cultural identity etc) and the diversity of their needs are recognized and addressed.
- f) The planning process incorporates the broad range of information and expertise available from caregivers.
- g) It is acknowledged that care is affected by the dynamics and interactions between paid care providers, care receivers and in-home caregivers. It is also acknowledged that care is affected by those who set policy and fund programs. (e.g. government and the CE LHIN).
- h) Planning, decision making and service delivery utilize a relationship based approach in which caregivers, service providers and LHIN staff work collaboratively together.
- i) Caregivers have a voice in all decisions which affect them.

Equity and Seamlessness:

The continuum of care and supports⁵ is comprised of comprehensive, equitable, timely, integrated, and easily accessed quality services that are responsive to the needs of caregivers across the CE LHIN.

Those involved in planning and service delivery for caregivers:

- a) Understand that the requirement for type and level of health and support services varies over time and that services must be able to respond appropriately to the changing needs of caregivers.
- b) Recognize the requirement for services to be delivered by individuals knowledgeable in, experienced with and sensitive to the health and support needs of the caregiver population.
- c) Appreciate that caregivers require unique support from health and social services which helps them to balance caregiving with their need for self care.
- d) Utilize a “whole person”⁶ approach to care and support which centers on the preferences of caregivers.
- e) Support caregivers managing their own health and wellness.
- f) Recognize the need for culturally and linguistically appropriate services.
- g) Embrace choice in the delivery of services at home or close to home⁷ and ensure a range of assistance available for caregivers which supports care giving in place by choice.
- h) Recognize the importance of the caregiver care system and the need for access to supports for caregivers.
- i) Expect success to be measured by the extent to which caregivers and service providers view the continuum of care and supports as being comprehensive, equitable, timely, integrated and easily accessed; the quality of services is measured according to how responsive those services are to the needs of caregivers across the CE LHIN.
- j) Caregivers require a range of high-quality services regardless of where they live within the CE LHIN and regardless of where the care recipient resides (if not at home).

Innovation:

The CE LHIN and its health and support service providers are open to new ideas and welcome new, innovative suggestions regarding improvement or expansion of existing quality health care services, methods or devices; additionally, they welcome innovative ideas regarding new approaches that would augment existing services.

Innovative solutions:

- a) Are built on best available evidence-based practices.
- b) Include service delivery models that foster innovative outreach to those in need
- c) Are designed to ensure effective and efficient use of resources and to be sustainable now and in the future.

Accountability:

There is shared accountability among people of the Central East LHIN for the delivery of an integrated continuum of care and support to caregivers.

This accountability includes:

- a) A collective accountability by the people within the geographic boundaries of the CE LHIN to the vision, mission and guiding principles expressed in this framework.
- b) Accountability by the CE LHIN to provide timely and equitable access to quality resources and support to caregivers and their paid care providers, and to maximize the use of taxpayer dollars.
- c) Accountability by health and support service providers and the broader community to use their skills and resources to the greatest effect for the benefit of caregivers.
- d) Joint accountability by health and support service providers for the outcomes of service delivery and for positive benchmarking against this planning framework.
- e) Accountability by caregivers to participate, to the extent possible, in collaborative planning activities with health service providers and the CE LHIN.

Here is my problem. My mom is 94 and lives in her own home. She is fiercely independent and wants to stay in her own home. Her health is generally good, but she is quite frail. She currently gets two hours per week of personal care. I live over an hour from her, but am coming in almost daily. The thing she really needs to stay at home is some help per week with household chores. When I called to discuss getting her more help, she was offered another hour of personal care. She does not need another bath; she needs some help with her home. When trying to keep the elderly in their homes, why can't we ask the simple question – What do you need to stay in your home and supply those services accordingly?^{liv}

Caregiver Support Component Chart

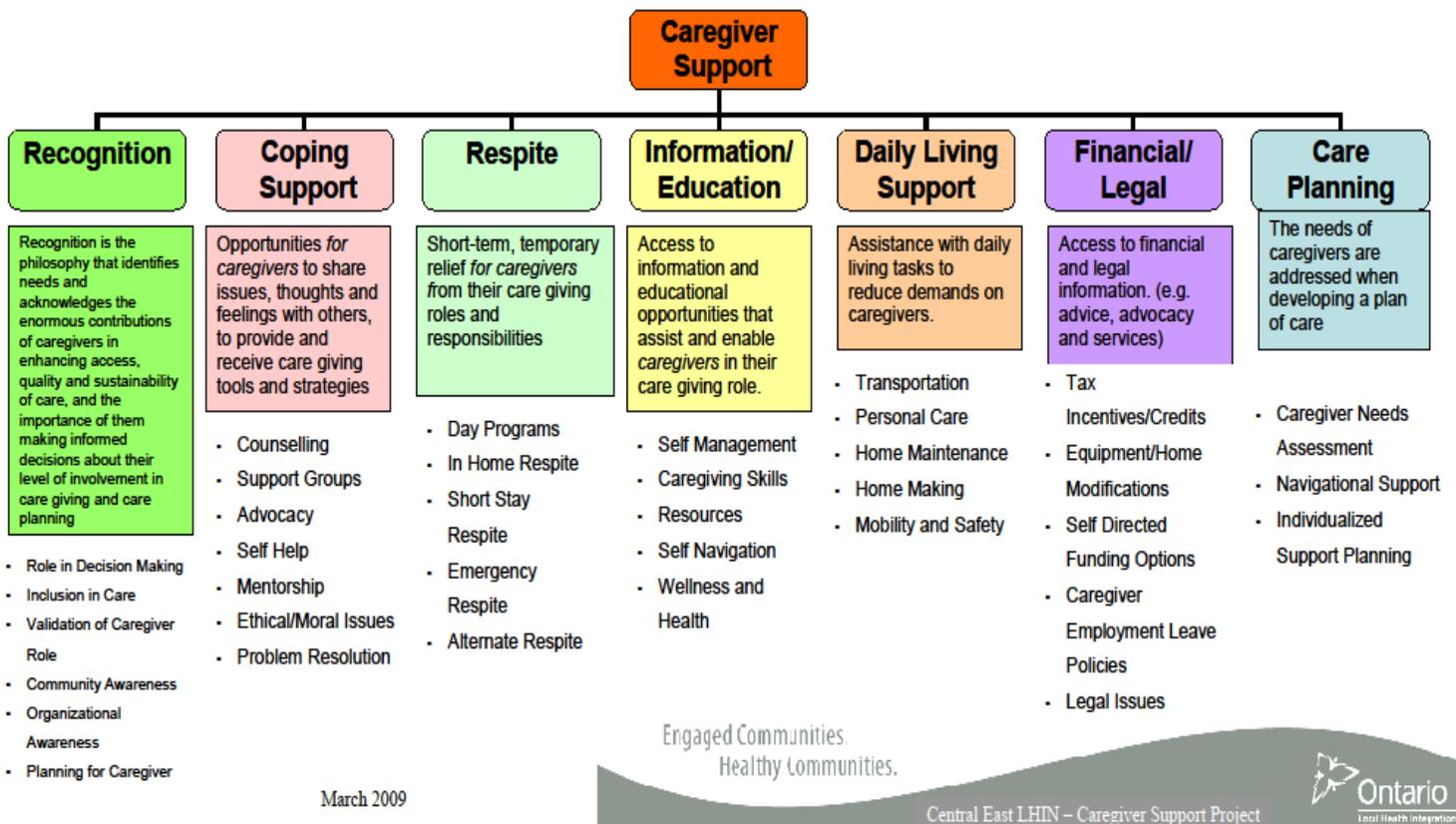
The follow chart details the components to be included in the basket of caregiver supports.

Caregiver Supports Component and Definition Chart
Central East LHIN Caregiver Supports and Wellbeing Project

Definition:

Caregiver* supports promote the health and well-being of caregivers, enabling and assisting in their care giving roles.

**The term caregiver in this project refers to this network of family and friends.*



March 2009

Service Delivery Model

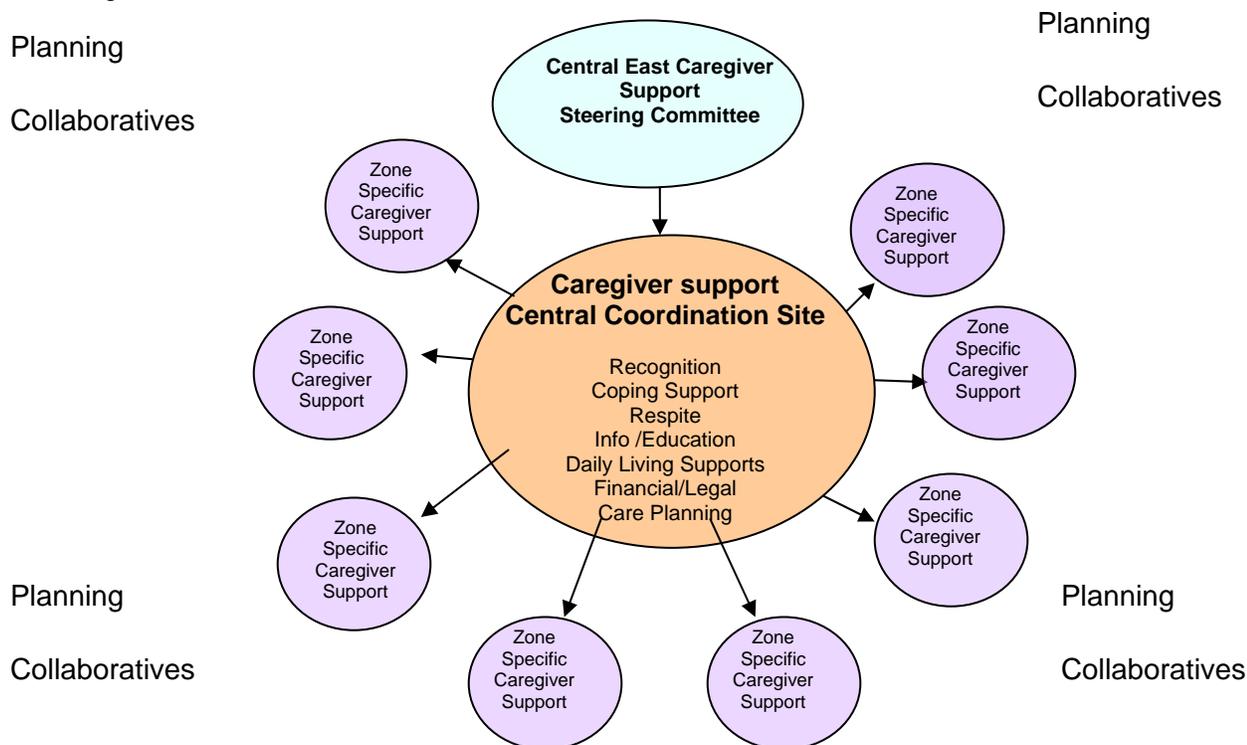
Many countries provide examples of managing the needs of caregivers through a network of independently managed **Caregiver Support Centres**. These centres have a “one stop shop” approach, offering assistance to address the support components outlined in this report - Recognition, Coping Support, Information and Education, Daily Living Support, Links to Financial and Legal Support and Care Planning. A Caregiver Support Centre network would lead to expanding communication networks and increased opportunities to connect to caregivers (i.e. telephone support lines, website, navigational support or face to face interaction). These support centres offer access to information, support, and education for any type of caregiving situation.

The following are examples of centralized networks of supports, found through the project's literature review of best practices.

- The CUSS Cavendish Caregiver Centre in Montreal Quebec offers direct and easy access to services and flexible and varied types of responses; this Centre encourages the active participation of caregivers in its operation, decision-making process and in a wide variety of activities.^{lv}
- The Saskatoon Caregiver Information Centre is a project of the Saskatoon Council on Aging Inc. Funded by “Population Health Fund” from Health Canada, the centre is a “one stop” information and support centre. This centre offers information, navigational support, referral to services, a telephone information line, and social and emotional support.^{lvi}
- Through the Year 1 Aging at Home funding with the Hamilton Niagara Haldiman Brant LHIN, Haldiman Abilities Centre is investigating the concept of a centralized “hub” of resources to support clients and caregivers within the community.^{lvii}
- The Calgary Family Caregiver Centre, an initiative of the Calgary Health Region in partnership with the Calgary Health Trust, opened in February 2000, in response to the need for a coordinated source of information, education and support to enable caregivers in their caregiving role.^{lviii}
- The Family Caregiver Network Centre of BC is a not-for-profit society established in 1989 whose mission is to inform, support and educate on issues of concern to family caregivers. FCNC is governed by a volunteer Board of Trustees, 60% of who are or have been family caregivers themselves.^{lix}
- Veterans Independence program in Canada is designed to assist veteran clients and their caregivers to remain healthy and independent in their own homes and communities. Support and assistance is provided through a website, a telephone support line and a variety of office support centre locations.^{lx}
- The state of California has a system of regionally based Caregiver Support Centres which receive operational funding from the California Department of Mental Health. These non-profit organizations are authorized under state law (reference) to provide a single point of entry for support services for caregivers. The services offered include navigational information and support, resource education and information, counselling and emotional support.^{lxi}
- In the United Kingdom, the Princess Royal Trust for Carers has developed a network of 144 independently managed Carer Centres. Along with interactive websites, this network provides support to over 350,000 annually.^{lxii}
- Carers Australia is a nationally funded organization which operates 8 Carer Resource Centres throughout the states of Australia. These centres are a single point of contact to enable carers to find support.^{lxiii}

Central East Caregiver Support Centre Service Model

The service model illustrates a structure of service delivery: what to deliver and how to deliver it. This model outlines the key components which are necessary in order to improve and enhance supports for caregivers within the Central East LHIN.



Central East Caregiver Support Steering Committee

The Steering Committee:

- Has a membership of 14, comprised of a CE LHIN representative, caregivers (at least 50%) and service providers from representation across the CE LHIN.
- It is the first point of contact for the CE LHIN, the three LHIN Health Interest Networks and other stakeholders with regards to caregiver support and wellbeing issues.
- Provides advice to the CE LHIN on the strategic priorities, goals, and objectives/strategies needed to improve the system of support for caregivers.
- Is supported by the **Caregiver Support Coordinator** (see outline of job in recommendations for staffing).
- With the Caregiver Support Coordinator, responds to the recommendations outlined within this report on supporting caregivers.
- Works with the LHIN to review and respond to provincial strategies/guidelines which impact caregivers.
- Acts as a resource to guide the work of the Caregiver Support Coordinator.
- Assesses and prioritizes the barriers to achieving effective and efficient caregiver support.
- Works with the CE LHIN to develop specific performance indicators which would be built into the Multi Sector Service Accountability Agreements (MSAA) of the organizations funded to deliver services in zone specific centres.
- It is a forum for communication/ collaboration/ knowledge exchange/innovation.

Caregiver Support Coordination Site

The coordination site:

- A health service provider organization would act as the transfer payment agency (host agency) and would develop performance indicators for the coordination site;
- Would be accountable for the caregiver support coordinator;
- Could be at the same location of a local zone specific centre; and
- Will be accountable to the Central East LHIN.

The role of the coordination site would be:

- To develop and initiate services or projects which have the capacity to increase access to all caregivers across the CE LHIN (i.e. caregiver help line, website, implementation of best practice models).
- In collaboration with the Central East Caregiver Steering Committee, to work on the implementation of recommendations within the Caregiver Support and Well Being Report.
- To identify LHIN wide needs/gaps that are barriers to achieving caregiver support.
- To develop and recommend standardized operational processes for the zone specific caregiver support centres (e.g. intake).
- To monitor and evaluate progress towards achieving CE LHIN and provincial strategies to improve caregiver support.
- To support evidence-based health planning by identifying and applying the best available information to describe the current situation and the desired outcomes for caregivers.
- To develop communications to and with the broader community regarding caregiver support and well being issues within the CE LHIN.

Zone Specific Caregiver Support Centres

Caregiver Support Centres are localized points of access and support, developed as

“One stop shops” to respond to the identified needs of caregivers in local settings. They represent a coordinated source of information, education and support for caregivers. Each zone-specific site is located in existing service provider agencies. The sites of the zone centres are determined by those who have existing infrastructures to support the program.

The role of the Zone Specific Caregiver Support Centre is:

- To connect caregivers to supports which exist within the local community and to work to provide supports which are not available.
- To ensure the provision of a range of supports using the Caregiver Support Component Chart developed by the Caregiver Support and Well Being project as their template for delivering service.
- To identify, assess and utilize caregiver support resources within the zone specific area.
- In response to identified gaps in service, to develop new caregiver supports as needed in collaboration with community organizations that have knowledge and expertise to assist.
- To provide a local point of access to help reduce the “running around the system” for caregivers.
- To collaborate with the Caregiver Support Coordinator to deliver standardized types of information and education and to assist in the identification of the types of support resources needed for the localized areas.

The intent of the Caregiver Support Centres is not to duplicate the work of other groups or providers, but to enhance, mobilize and coordinate existing services.

Zone Specific Advisory Groups

Zone-specific advisory groups have a system planning mandate to ensure that the localized needs of caregivers are being addressed. The CE LHIN Planning Collaboratives may be ideal to fill this role. This group would provide feedback to the Central East Caregiver Advisory Group on issues pertaining to caregivers within their planning area.

Service Delivery Model Recommendations

The following are considerations for the implementation of the Service Delivery Model:

1. Geographical Location Recommendations:

- Central Coordination Centre would be in one of the planning zone locations
- Caregiver Support Centres – within each planning zone of the CE LHIN
- Must be able to meet cultural and language diversity needs
- Must be able to adapt to the needs of rural communities
- Suggestion: could be mobile (office in a truck) for rural areas.
- Must be able to respond to cross sector needs
- Should be accessible to public transit

2. Physical location Recommendations:

- Centralized within each zone and accessible to the general public
- Close to a source of primary care and/or a multidisciplinary team setting
- Located within an existing facility or location which can offer sharing of physical resources i.e. meeting rooms and human resource sharing – social work, counselling services

3. Program Recommendations

Coordination Centre

- The main goal of the Coordination centre is to work on recommendations from this report which encompass the entire Central East LHIN and which enhance the delivery of services in all zone-specific centres (i.e. development of education resources, information resources, telephone line, and website). The coordination site could work on development, integration or promotion of support models, such as Timing it Right , Share the Care or Neighbours helping Neighbours (Appendix 9).

Zone Specific Centre

- The main goal of the zone-specific Caregiver Support centre is to assist in finding solutions to local care giving issues while utilizing the tools and resources developed at the coordination centre.
- The Caregiver Support component map would be utilized as a tool to understand the system solutions needed.
 - i. Recognition
 - ii. Coping
 - iii. Respite
 - iv. Information/Education
 - v. Activities of Daily Living
 - vi. Financial/Legal Matters
 - vii. Care Planning

- In the absence of actual service resources, the goal may be **to provide or contract out direct service** such as counselling support or education.
- Where there are sufficient community resources, the goal would be to **connect the caregiver to the appropriate service**.
- Programs are to be developed, implemented and evaluated according to the needs of the caregivers in the community.
- The goal should be the coordination and integration of available resources for their most equitable and effective use by caregivers across sectors and from diverse backgrounds
- Programs and Services at the Caregiver Support Centres will be provided by Centre staff and volunteers or by connections and collaboration with organizations that have the resources to provide specific supports.

4. Staffing Recommendations

Central Coordination Site

Caregiver Support Coordinator

- A staff member who provides resource support to the CE Caregiver Network (similar set up to the Central East Hospice Palliative Care Network model).
- Works with the CE LHIN and Central East Caregiver Support Network on the development and initiation of services or projects which have the capacity to increase access to all caregivers i.e. caregiver help line, website.
- Supports the work of the Caregiver Support Working Group/Advisory Group in the development of services/projects which have the capacity to increase access to all caregivers.
- Supports the development of effective communication to the broader community regarding caregiver support and well being issues.
- Works with the zone specific centres to assist them in accessing CE LHIN- wide support resources.
- Works with the zone specific centres to meet the needs of local communities and geographic areas.
- Is located at the Central Coordination Caregiver Support Centre.

Zone-Specific Sites

The staffing compliment would be directly dependent on the needs and the resources available within the community and the location site.

Caregiver Care Coordinator:

This coordinator provides system navigation, education delivery, volunteer leadership, intake and assessment, marketing, and administration.

Other suggested name: Support Consultants

Social Worker or Counsellor:

Staff to facilitate support groups, individual support counselling and the training of volunteers (e.g. telephone help line). This position could be contracted or shared with the existing support services of the organization.

Volunteers:

Supportive interaction – phone line, individual support

Administrative support:

Administrative support would assist with the organization of programs, the administrative functions of setting up a library of information, marketing and general office support. This position could be shared support within an existing staffing structure.

Recommendation for Zone Centre Staff:

Host organizations should look within their staffing compliment to understand if this role can or should be incorporated or added to roles and responsibilities of existing staff.

Moving ahead to Next Steps

Through the Ontario Aging at Home Strategy (AAH)* the Central East LHIN has directed a portion of its funding to go toward the enhancement of caregiver supports.

The following projects are being funded by the Aging at Home Strategy.

Implementation of Caregiver Support Centres

Enhanced Caregiver Project (Aging at Home Year 1 and 2)

Utilizing Aging at Home (AAH) funding from Year 1, the Enhanced Caregiver project began the process of implementing a caregiver support centre in the CE LHIN planning zone encompassing Northumberland County. The Enhanced Caregiver Support project team, through the work of a hired project coordinator, has developed an inventory of local resources available to support the caregiver and consulted with the public to identify their needs and the gaps in support. Currently, following the direction of the Caregiver Support and Well Being Project, this project team is developing the first centralized support centre. This project was recommended for funding from Year 2 AAH funding to continue the work of the Caregiver Support and Well Being Project. It will document the steps which are necessary to implement a caregiver support centre, identify the challenges and the benefits of the implementation process and monitor the outcomes of having a coordinated support centre for caregivers.

Scarborough Caregiver Project (Aging at Home Year 2)

Westhill Community Services, as the sponsor agency, working in collaboration with multiple community partners, has been recommended to receive Year 2 Aging at Home funding to open a Caregiver Support Centre in Scarborough. The purpose of the project is to provide an access point that responds to the growing and diverse needs of caregivers, to enable them to continue to assist their loved ones to remain in the community, and to minimize hospital visits and premature hospitalization.

This Caregiver Support Centre will continue to work towards a comprehensive understanding of the caregiver support service landscape in Scarborough including the needs and services for its diverse population.

* Aging at Home Strategy (AAH) is a 3 year strategy funded by the Ministry of Health and Long Term Care to invest in community services to enable seniors to age at home with dignity and independence.

Proposed programs and services:

- Education/ information sessions
- Elder abuse information and linkages
- Mind and wellness counselling/training
- System navigation assistance including linkages to the broader health care system
- Community outreach
- Telephone line
- Caregiver symposium.

Goal: to generate 1,200 face to face visits and 1,500 telephone interactions.

This initiative will also track the number and type of referrals from health and social service providers.

Summary:

A patient is discharged from the “formal” health care system, disappears from the accounting system and vanishes from the statistics of policies and practices horizon, but the cost has not gone away; it has simply been shifted to the family. You can measure the cost of tangible equipment and hospital beds but how do you measure the “cost” of countless hours spent with the care receiver, the inflexibility of having to be “always there”? What is the cost in terms of time not spent with other loved ones, emotional and family instability? What is the personal cost of isolation, lack of confidence, lack of respect or fear? What is the toll of financial insecurity?

The more families and friends in the Central East LHIN, and throughout Ontario, are required to do to support the health and well being of their loved ones, the more supports and assistance the Central East LHIN and the Province of Ontario must provide for these caregivers so that they have the capacity to meet the challenges, the emotional strength to “weather the storms” and the financial security to maintain quality of life.

“On one side you have highly trained, highly paid, highly specialized, highly regulated, and highly respected. On the other you have caregivers with no formal training, who learn on the job, have no organization that represents them, no pay, no benefits, no support, and no regulations and are usually under-appreciated. If all informal caregivers booked off sick, the entire long-term care, if not the entire health system would collapse.”^{ixiv}

Caregivers remain silent and invisible because they are generally too busy giving care to protest. If the emphasis is placed on keeping people out of institutions and caring for them at home, caregivers must become a more recognized entity, provided with useable supports within the health care system. If proper supports are not placed with those caring for individuals in the home now, the result may be even greater demands on the system from burned out, ailing caregivers in the future.

Caregivers have needs independent from 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. While some organizations fully acknowledge the caregiver as a full partner with the care receiver in the provision of services, there may not be the resources available to support the caregiver.

Caregivers need a useable system to access information and educational opportunities. They need a single point of access to find support and information. They need abundant opportunities for adequate respite and they need financial compensation to remain viable in their care giving roles.

Caregivers' contributions need to be recognized and their input needs to be valued. Their contributions are enormous in their output of physical work, in their emotional support of those in their care and in their role in sustaining the economic health of the system, the province and the tax payer.

In a health care system which places emphasis on providing care at home, there must be a commitment to the people who provide that care at home and provisions in place to ensure that they are adequately acknowledged and supported.

Ensuring that there are enough caregivers to attend to an aging population with compassion, confidence and quality care will be one of the biggest challenges ever faced by our society and our health care system. How successfully we meet that challenge depends on the care giving support decisions we make today and on the care giving actions we begin today in preparation for tomorrow.

Appendices

1. Caregiver Support Project Team and Task Team Membership
2. Caregiver Support and Wellbeing Project Charter
3. Aging at Home Year 1 Funding Summary
4. Community Consultation – Caregiver Survey
5. Community Consultation – Summary of Caregiver Feedback
6. Community Consultation – Organization Survey
7. Community Consultation – Summary of Organization Feedback
8. Caregiver Support Component and Definition Chart
9. Caregiver Support Definition Map

Appendix 1

Project Team Name Caregiver Supports		Representation	CE LHIN Involvement	AREA
First Name	Last Name			
Diane	Bennett	CECCAC		Scarborough, Port Hope
Joan	Skelton(to Sept 08)	Alzheimer Society of Durham	Durham East Collaborative	Durham
Brenda	Davie (Sept 08 present)			
Tina	Demmers	Lakeridge Health Port Perry	North Durham Collaborative	Port Perry
Sheilagh	Fertile	Caregiver	Kawartha Lakes Collaborative	Kawartha Lakes
Susan	Haines	Community Care Durham	Durham East Collaborative	Durham Region
Janet	Irvine	Caregiver & private caregiver organization	Northumberland Collaborative	Northumberland
Jennifer	Josephson	Brock Community Health Centre		Brock Township
Marie	Kwok	Caregiver	Mental Health and Addictions Network	Scarborough
Laura	MacDermaid	Region of Durham		Durham Region
Cheryl	McCarthy	Caregiver	Durham East Collaborative	Oshawa Courtice
Milton	Moonah	Caregiver		Scarborough
Barb	North	Caregiver		Oshawa
Scott	Pepin	Northumberland Hills Hospital		Durham
Anne Marie	Yaraskavitch	Caregiver	Seamless Care for Seniors	Whitby
Kelly	Weeks (from Jan 09)	Canadian Mental Health Association		Durham
Natisha	Debutte	Enhanced Caregiver Project Coordinator		Northumberland
Colleen	Zavrel (Chair)	Oshawa Senior Citizens Centres	Durham East Collaborative	Oshawa
Susan	Locke	Project Coordinator		
Maria	Grant	CE LHIN		
Kate	Reed	CE LHIN Project Sponsor		

Additional membership on the Task/Consultation Groups

Selena	Skinner	Alzheimer Society of Durham	Durham
Dana	Turnham	Caregiver	Peterborough
Loretta	Tanner	Alzheimer Society of Durham	Durham
Frank	Murphy	Durham Head Injury Association	Durham

Appendix 2

Central East Priority Project Summary

Project Name: Supporting Caregiver Health and Well-being in the CE LHIN

Purpose of Board Review	<input type="checkbox"/> For Information Only <input type="checkbox"/> For Approval <input checked="" type="checkbox"/> For Endorsement to Proceed with Further Planning/Refinement/Review		
Project Charter Writing Sponsor(s)	Durham East Collaborative		
Project Sponsor	CE LHIN – Portfolio Lead		
Health Service Provider	Central East CCAC		
Project Type	<input checked="" type="checkbox"/> Service Enhancement <input type="checkbox"/> New Service / Program <input type="checkbox"/> Integration Activity <input checked="" type="checkbox"/> Demonstration Project <input type="checkbox"/> Single Phase Project <input checked="" type="checkbox"/> Multi-Phase Project		
Funding Required	\$394,600 [2008-09: \$ 140,062] 2009/2010 \$262,000		
Funding Source	Aging at Home	Funding Year (s) 2008-09, 2009-2010 beyond based on Strategic Plan	Funding Type 2 Yr. Demonstration
Anticipated Project Owner (Accountability)	<input type="checkbox"/> CE LHIN <input type="checkbox"/> CE LHIN Health Service Provider <input checked="" type="checkbox"/> Assigned CE LHIN Project Team		
Project Deliverables / Goals	<ul style="list-style-type: none"> Strategic Plan to guide investments to strengthen the caregiver support system in CE LHIN including a Best Practices review (agencies/literature) and design of an Evaluation process. Design and implement a pilot Caregiver Support Resolution Program to respond to and resolve complex and problematic caregiving situations. 		
Project Timelines	Start: November 2007	Completion: Phased enhancements to caregiver support system	
Project Reviewed By:	Networks: CDPM and Seamless Care for Seniors Steering Committee received update on project goals; Members participate on project sponsor group		

Collaboratives: Durham East Collaborative lead Charter Development

Task Groups: No

CE LHIN Staff: Involved in Charter Development

Strategic Directions

- The LHIN Board will lead the transformation of the health care system into a culture of interdependence.
- Healthcare will be person-centred in safe environments of quality care.
- Create an integrated system of care that is easily accessed, sustainable and achieves good outcomes.
Resource investments in the Central East LHIN will be fiscally responsible and prudent.

Priorities for Change

- Seamless Care for Seniors
- Mental Health and Addictions
- CDPM
- Wait Times and Critical Care

Enablers

- Primary Care
- E-health
- Health Services Planning
- Health Human Resources
- Diversity
- Back Office Transformation
- Moving People Through The System

System Outcomes

- | | | |
|--|--|---|
| <input checked="" type="checkbox"/> Accessible | <input type="checkbox"/> Safe | <input checked="" type="checkbox"/> Appropriately Resourced |
| <input type="checkbox"/> Effective | <input checked="" type="checkbox"/> People Centred | <input checked="" type="checkbox"/> Equitable |
| <input type="checkbox"/> Efficient | <input type="checkbox"/> Integrated | <input type="checkbox"/> Focused on Population Health |

Project Name:

Supporting Caregiver Health and Well-being in the CE LHIN

Project Acronym or No.

Caregiver Support

Workstream Lead/Project Sponsor(s)

- Seamless Care for Seniors Steering Committee
- Mental Health & Addictions Steering Committee
- Chronic Disease Prevention and Management Steering Committee

Workstream Project Coordinator

- Jeanne Thomas

Target Project Completion Date

- 3 Year phased implementation to strengthen caregiver support system

Project Lead/Project Manager

Project Charter Development: Durham East Collaborative & Other Planning Partner Representatives

Version No.

0.8

Version Date

2008/09/30

Project Background

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 conditions⁸” The term caregiver in this project refers to this network of family and friends.

The role of caregivers in the health care continuum

Health Canada’s 1995 report titled *Health Human Resources in Community-Based Health Care* report, noted that the traditional view of health human resources, which had tended to focus almost exclusively on formal caregivers (service providers), needed to be replaced by one that saw health human resources as a continuum, with those who care for relatives and friends forming part of the health care continuum. The report went on to note that without this caregiving 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” (p.3).

The important role that caregivers play within the health care continuum is well documented:

- “In North America today, the aging population, coupled with fundamental changes in the provision of health care services, is translating into an increased requirement for individuals to provide in-home care for family members in the home who have chronic health problems or disabilities” (Decima Research, 2002, p.1).
- “Caregivers care for individuals from all age groups, across all stages of life, and across the continuum of care” (VON Canada, 2005, p. 5).
- “There are approximately 4.2 million people with disabilities in this country” (Canadian Association for Community Living, 2002, p. 1) “The majority of people who need disability supports – children, youth, and adults – are supported entirely by their family members and friends” (Canadian Coalition for Family Supportive Policy, 2004,p2).
- “A shift away from institutionalizing has left the bulk of caregiving (for seniors) to family members and friends (Cranswick, 2003, p. 8). “Among all seniors in Ontario who received help because of a long-term problem, about three quarters received this help, in part or in total, from informal sources (a spouse, relative or friend)” (Turcotte M. & Schellenberg, 2007, 2007, p. 166). “In many cases, the presence and commitment of a close family member, a spouse or a neighbour can make an important difference in their quality of life, increasing the possibility that they can stay in their home”. (Turcotte M. & Schellenberg, 2007, p 161).
- Dupuis, Epp & Smale (2004) note that approximately half of the individuals with dementia in Canada live in the community and that almost all of these individuals (94%) are cared for by family or friends up until these caregivers are no longer able to maintain them at home.
- Family and friends often provide most of the care and support to people with mental illness. “Numerous studies have shown that involvement (of family and friends) in this role results in significant benefits for both the individual and the health care system.... (including) decreased rates of hospitalization and relapse, enhanced adherences to treatment choices, increased rates of recovery, decreased involvement with the criminal justice system, (and) savings to the mental health and addictions system”. (Family Mental Health Alliance, 2006, p 6).
- “It is estimated that caregivers provide 80% of the required care in the home” (Canadian Caregiver Coalition, 2003).

Caregiver profile

- In many instances caregivers are a network of family and friends who provide assistance and care on a 24hour per day/ 7 day per week basis.

⁸ Wording based on Canadian Caregiver Coalition’s definition of caregiver (Canadian Caregiver Coalition, 2007)

- Whether or not particular family members regard themselves as part of the core “team” providing care to an individual, they intentionally or unintentionally, influence and are impacted by the environment of care.
- Family caregivers are predominantly female and typically older than the population-at-large. Seven in ten are 45 years of age or older. Consistent with these characteristics, family caregivers are most likely to be either retired or homemakers. Just over one in five are employed full time, while a similar proportion work either part time or are self-employed. (Decima Research, 2002).
- The composition of family caregivers largely mirrors the Canadian population in terms of language and ethnic background (Decima Research, 2002, p. 3).
- Most caregivers are looking after only one individual, but close to one in ten are looking after a second family member (in most cases the other parent). Most are receiving care because of physical disability; close to one in five have both physical and mental difficulties. One in six care receivers are children, many of whom have some form of mental disability. (Decima Research, 2002).
- “We often think of seniors as the receiver of care, but older Canadians are also actively involved in caregiving”. (Cranswick, 2003, p.11). One quarter of family caregivers are at least 65 (Decima Research, 2002, p.3).
- “A new trend in caregiving is young caregivers, often teenagers or young adults caring for parents with chronic illnesses, such as MS or mental health problems” (Keating et al., 1999).
- Care can be categorized by personal care, household work, coordination of care, support and nursing care; caregiver who, live with the care receiver often provide more care and a wider variety of care tasks than other caregivers who do not live with the care receiver (VON, 2005).
- In many cases, formal or professional home care services are an essential or valuable support to caregivers looking after family members.... Survey results suggest that the use of formal care is more closely associated with care recipients requiring a lot of care, than as a means of caregivers minimizing their involvement (Decima, 2002, p. 23).
- ‘Homecare is an increasingly important component of the health care system in Canada. As family caregivers play a growing role in providing care, their need for respite, or time off, is also growing’ (Dunbrack, 2003. p. 1).

Challenges faced by caregivers in their role as caregiver.

- “While caregiving includes immeasurable personal rewards, there are physical, psychological, social and financial risks assumed by family and friends providing care (Canadian Caregiver Coalition,2003, p 1).
- 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; 50% also report difficulties in terms of physical health (Decima Research, 2002. p 6).“
- There are variations across the systems of care with regards to the types and level of support provided to caregivers, including variations in provider interpretation of what is needed and/or their obligation to provide information and services.
- In it’s report titled *OUT OF THE SHADOWS AT LAST – Transforming Mental Health, Mental Illness and Addiction Services in Canada* (2006) The Standing Senate Committee on Social Affairs, Science and Technology (2006) noted that “...many caregivers have feel excluded, ignored by the mental health, mental illness and addictions system in Canada” (p. 18).
- The J.W. McConnell Family Foundation (2007) notes that in spite of being the invisible back-up that allows the health care system to keep functioning despite limited public resources and a shift away from institutionalized care, the health system has been woefully inadequate in it’s support of family caregivers across Canada.

Supporting caregiver health and well-being

- Caregivers' "needs networks, resources, strengths and limitations vary from caregiver to caregiver". (VON, 2005, p. 3). "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" (Dupuis, Epp & Smale, p. 33).
- When considering the supports required by caregivers it is essential to take a comprehensive whole person/holistic approach and consider the various influences and environmental factors that determine consumer and family health; consideration must also be given to the need for support at both the diagnosed and undiagnosed stages of caregiving.
- Enhanced knowledge, coping skills and resilience of caregivers promotes better health, improves quality of life and provides a supportive environment for the entire family.
- "When individuals and families have access to the right information, support and resources, they develop the knowledge and skills they need to play a more active role in managing their health and coping with a chronic disease (Ministry of Health and Long-Term Care, 2005, p. 18).
- "No single formal support program is effective in meeting all the needs of caregivers... Instead, caregivers need a range of integrated services that address both the emotional and mental stresses of caregiving and the challenges associated with the physical day-to-day tasks associated with the caregiving role" (Dupuis, Epp & Smale, 2004, p. 70).

Project Purpose

In recognition that Caregivers are an essential part of the health care continuum, the project's purpose is to ensure that caregivers are provided the right support, at the right time in the right place. The project aim is to support caregivers more effectively and to build the capacity of individuals and families to be caregivers.

The project will acknowledge and validate issues and needs specific to caregivers, enhance and improve access to a variety of services, improve the consistency and coordination of existing supports and introduce new services as required.

Providing improved care and support to caregivers will ease demand on the health care system by enabling caregivers to provide support in a manner which prevents "caregiver burnout" and chronic illness due to stress and fatigue.

The project will identify best practices and opportunities for integration of caregiver supports through examination of what exists and what is not currently in place. The project will delineate the system of Caregiver support required for Central East LHIN. The LHIN will pursue consistent implementation and enhancements to the system of support by incorporating Caregiver Supports into Service Accountability Agreements with Health Service Provider Agencies.

In keeping with the Guiding Principles of the Chronic Disease Prevention and Management and the Seamless Care for Seniors Networks, the following Principles will guide the Caregiver Support project:

Integrity

Health planning and delivery of services will empower and enable caregivers.

Innovation

The CE LHIN, health and support service providers, consumers and caregivers are prepared to test new waters, are open to new ideas, methods or devices.

Responsiveness and Respect

Planning, decision-making and service delivery will utilize a "relationship based approach" in which

consumers, caregivers and service providers work collaboratively.

Equity and Seamlessness

The continuum of care and supports should be comprehensive and equitable for caregivers across the CE LHIN.

Accountability

There is shared accountability among caregivers and service providers in the Central East LHIN for the delivery and on-going evaluation of the system of caregiver supports.

Strategic Alignment

This project impacts every aspect of the health care system. It has linkages with several health initiatives for the province; it has ties with several different ministries. It impacts all other LHIN initiatives and will directly impact local people and communities.

The Caregiver Support Project will:

- Identify resources currently invested by the province in caregiving services within the CE LHIN (e.g. MoHLTC funded Community Support Services that currently provide caregiver support).
- Provide information during the development of new health initiatives effecting caregivers (e.g. Community Health Centres, Family Health Teams, private health/physician clinics).
- Be relevant to multiple provincial ministries including the MoHLTC and the Ministry of Health Promotion (e.g. support and prevent decline of caregivers' physical or mental health and promote their well-being).
- Support the growing and essential role of individuals in taking responsibility for their own health and for the well-being of family/friends. Growth in the responsibilities of caregivers is resulting from the complexity of care options, stretched public resources, the growing number of elderly and the recognition of the important goal of aging at home/in community.
- As a component of the Aging at Home Strategy for CE LHIN this project will inform and be informed by activities in neighbouring LHINs and across the province.
- Be relevant to caregivers who provide care and support to people with various healthcare needs (seniors, people with mental health/addictions needs and chronic conditions) by recognizing the variety of supports needed. For example, many consumer and family organizations in mental health and addictions (i.e. Family Mental Health Alliance) have identified meaningful daytime activities for consumers as not only important for consumers, but also a source of respite for caregivers.

Project Benefits

Enhancing caregiver supports in CE LHIN will have qualitative and quantitative benefits for the caregiver, the consumer, individual health service providers and the healthcare system. In many instances, benefits attributed to individual caregivers and the individual(s) they are supporting will also directly benefit health service providers and the healthcare system.

Benefits to the Caregiver:

- Individualized care and support acknowledging gender and cultural differences;
- Supports to assist caregivers to regain/maintain control of their lives;
- Provide real life tools and support-solutions (e.g. planning guide, respite opportunities);
- A clear avenue for problem-solving is in place to support caregivers in resolving difficult/challenging

Project Benefits

situations;

- Provide right information to caregivers in a timely manner;
- Improved Quality of Life for caregiver by providing strategies for maintaining caregiver health, supporting well-being and preventing illness;
- Public recognition of caregivers / public visibility of caregiver supports / ease of access
- Celebrating the role of caregivers through sharing of successes, sacrifices, accomplishments (i.e. the un-sung heroes supporting the healthcare system).

Benefits to Individual the Caregiver is Supporting:

- Improved health outcomes, both physical and mental;
- Improved health maintenance;
- Increased rates of recovery;
- Increased likelihood to adhere to treatment choices;
- Reduced hospitalizations;
- Reduced or delayed admission to LTC Homes;

Benefits to Health Service Providers and the Healthcare System:

- Providing caregiver supports and “reaching caregivers before they are desperate/burnt-out” provides sustainable on-going health and non-medical supports to consumers and minimizes crisis;
- Communities will be better positioned to support the growing number and needs of caregivers (e.g. projected growth in dementia rates will increase the number and demands caregivers of this client group);
- Will inform and influence the model of care delivery to clients and caregivers in various healthcare settings;
- Will support the realignment and reallocation of costs and responsibilities within the healthcare system by recognizing that the care provided by caregivers has an economic impact on the ability of programs to deliver effective and efficient services;
- Strengthen the ability of caregivers to prevent crisis and the ability of the healthcare provider community to respond to client or caregiver crisis;
- Best use of existing and new caregiver resources – What is provided by healthcare system improves quality of life for caregiver and addresses what is most needed by leveraging local (Planning Zone) and LHIN-wide supports;
- Provides HSPs with consistent and coordinated information and tools to improve their ability to support caregivers.

Goals, Objectives & Performance Measures

Goals	Objectives/Deliverables	Performance Measures
<p>1. To coordinate and strengthen the system of care and support for caregivers.</p>	<p>The caregiver support system in CE LHIN includes:</p> <p>A. Structures and associated processes to plan, coordinate, strengthen and monitor the caregiver support system in CE LHIN. (e.g. a LHIN Caregiver Council, Zone-level Lead Agencies, etc.)</p> <p>B. Existing or newly developed mechanisms to support caregivers during times of transition between services and settings.</p> <p>C. Integration, partnership and coordination between generic and condition specific caregiver supports.</p>	<p>a) The preferred structure is designed, implemented and evaluated.</p> <p>b) HSPs implement mechanisms to support caregivers prior to, during and after transition.</p> <p>c) Mechanisms to link generic and condition specific caregiver supports are in place.</p>
<p>2. To provide caregivers with the tools, resources and skills needed to improve control over their health and quality of life.</p>	<p>The caregiver support system in CE LHIN includes:</p> <p>A. Innovative models and practices to ensure caregivers have easy access to specific “caregiver support locations” where caregivers are assisted in accessing the tools, resources and skills they need (e.g. information, peer supports)</p> <p>B. Individualized planning that recognizes the specific strengths and needs of the caregiver including cultural differences.</p> <p>C. Access to Self Management Training programs for caregivers. Caregivers become trained Peer Leaders in the Self-Management</p>	<p>a) Models that improve ease of access to caregiver supports in all Planning Zones are implemented and evaluated.</p> <p>b) Individualized caregiver support needs are identified and a plan to implement strategies is developed.</p> <p>c) Caregivers are enrolled in Self Management Training education sessions.</p>

⁹ It is recognized that caregivers will not be identified as primary recipients of services by all HSPs. However, HSPs will be requested to consider how their Charter of Rights can appropriately reflect the role of caregivers.

Goals, Objectives & Performance Measures

Goals	Objectives/Deliverables	Performance Measures
	<p>program.</p> <p>D. Development and dissemination of planning guideline(s) to assist caregivers in identifying the resources they need. Planning guideline(s) will build on resource material currently available.</p> <p>E. Inclusion of caregiver needs in the Charter of Client⁹ Rights and Responsibilities of HSP.</p> <p>F. Design and implement (pilot) a Caregiver Support Resolution program to respond to and resolve complex and problematic care giving situations (i.e. enacting a community/ multi-agency response when current options are exhausted)</p> <p>G. Advice/Recommendations to the LHIN Board in determining their role in providing advice to provincial and federal bodies responsible for income tax relief for caregivers and employment supports (e.g. time off, compensation)</p>	<p>Planning Guides are accessed by caregivers.</p> <p>d) HSPs measure and report on their performance against their Charter of Client and Caregiver rights</p> <p>e) Caregiver Support Resolution program is piloted and evaluated.</p> <p>f) Feedback is received from LHIN on next steps.</p>
<p>3. To improve availability and access to supports needed by caregivers through optimizing current investments and identifying the need for new investments.</p>	<p>The caregiver support system in CE LHIN includes:</p> <p>A. Identification of the range of supports required by caregivers and the availability and accessibility of these supports in the CE LHIN.</p> <p>Note:</p> <ul style="list-style-type: none"> This important baseline of information on CE LHIN caregiver services must include identification of caregiver support resources that currently exist; what is working well and where there are gaps/ weaknesses [are]. Those caregiver programs/services which are delivered by HSPs but only partially 	<p>a) A database of currently available caregiver support resources is compiled.</p> <p>i. Project Team provides input to design of survey and/or identifies questions to guide literature review.</p> <p>ii. The database is regularly</p>

Goals, Objectives & Performance Measures

Goals	Objectives/Deliverables	Performance Measures
	<p>funded by provincial MoHLTC resources should be included. Further bereavement support needs for caregivers after consumer has passed-away will also be identified. (i.e. a survey to agencies and caregivers and/or literature review).</p> <ul style="list-style-type: none"> • Information compiled should be incorporated into an existing web accessible database and/or the CCAC Information and Referral system. <p>B. An improved understanding of the benefits to the health system of investing in caregiver supports based upon existing research</p> <p>C. Building on the assessment of what exists and what the gaps are, identification of the priorities for new investments in caregiver supports across the CE LHIN. Which builds upon the assessment of what exists and where the gaps in are.</p> <p>Investments should improve equity of access to:</p> <ul style="list-style-type: none"> a. A range of support service options including but not limited to: caregiver supports as outlined in Goal #2; professional counseling supports; peer support programs; day to day coping/life skills, and access to assistive devices. b. In-home and out of home caregiver relief (respite) which 	<p>maintained.</p> <ul style="list-style-type: none"> iii. The database is incorporated into an existing database and/or CCAC Information and Referral system. <p>b) A Strategic Plan to guide investments to strengthen the caregiver support system in CE LHIN is completed.</p> <ul style="list-style-type: none"> i. Investments increase equity of access to C. a) – d) ii. Administrative processes are streamlined to improve access to relief (respite) options <p>c) Evaluative processes designed and evaluation complete</p>

Goals, Objectives & Performance Measures

Goals	Objectives/Deliverables	Performance Measures
	<p>may include consumer accompaniment, meaningful daytime activities day/evening/overnight, camps, day programs, work options or drop-in programs.</p> <p>c. Short-stay/transitional residential options (e.g. LTC Home short-stay beds; partnerships with retirement homes or assisted living services)</p> <p>d. Supportive housing with 24/7 on-call access to personal care, nursing and other supports.</p> <p>D. Streamlined administrative processes to improve access to respite options (i.e. reduce testing/paperwork for completion by LTC Homes for re-admission to short-stay beds).</p> <p>E. A qualitative and quantitative evaluative process is needed for continuous quality improvement and program sustainability.</p>	
<p>4. Best practices in supporting caregivers are known and applied by all health service providers in CE LHIN.</p> <p>Best practices support the following philosophy:</p> <p>The distinct needs of caregivers, and the knowledge base that they possess regarding the needs and abilities of their family member/friend, are understood, legitimized and supported, with caregivers recognized as core members of the health care and support team.</p>	<p>The caregiver support system in CE LHIN includes:</p> <p>A. The identification and recommendations for the delivery of best/promising practices in maintaining and enhancing the health of caregivers.</p> <p>B. Innovative caregiver support models. Learn from and provide education to front-line healthcare staff</p> <p>C. An education strategy on how to. Learn from and provide education to front-line healthcare staff based upon best practices (e.g. Caregiver Expert Advisory Coaching Teams to visit agencies, gathering and dissemination of real life experiences/case studies).</p> <p>D. Processes to ensure that Health Service Providers assess the needs of the caregiver independently</p>	<p>a) Best/promising practices are known and applied.</p> <p>b) Innovative models are in place.</p> <p>c) Best practices and learnings from the front-line healthcare staff are applied and knowledge transferred in an educational setting</p> <p>d) Caregiver support needs are assessed.</p>

Goals, Objectives & Performance Measures

Goals	Objectives/Deliverables	Performance Measures
	<p>/distinct from medical needs of consumer.</p> <p>E. A process to ensure that care planning includes identification and inclusion of the caregiver on the team providing care and support to client.</p>	<p>e) Planning for the needs of Caregivers is included in the care planning process.</p>

Project "IN" & "OUT" of Scope Items

"IN" Scope	"OUT" of Scope
<ul style="list-style-type: none"> Caregivers providing care and support to individuals who have or do not have a formal medical diagnosis. Caregiver support needs in a variety of care settings (i.e. home, community, institutional settings, from a distance) Strategies to restore relationships or create alternatives to traditional caregivers for those individuals who do not have a family/friend caregiver but who would benefit/accept support (i.e. 39% of people with mental health/addictions have no family/friend caregivers). 	<ul style="list-style-type: none"> Although individuals who provide care as part of a health service provider organization (volunteer or paid) are not the primary target population for this project; it is recommended that the Project Team remain aware of the supportive role of agency volunteers and paid front-line providers (e.g. respite workers) and define opportunities to engage these individuals as the caregiver support project is implemented.

Project Timelines

High-Level Milestones	Target Completion Dates
Secure Project Developer (proposed application of Aging at Home planning resources).	♦ November 2007
Create Project Team to advise on development of Caregiver Strategic Plan (temporary).	♦ November/Dec 2007
STRATEGIC PLAN to guide enhancements/investments to strengthen [to] the Caregiver Support System in CE LHIN is developed.	♦ May 2009
Caregiver Supports and the components which make up a caregiver support system are Identified.	♦ Nov 15, 2008
The on-going structure and processes to plan, coordinate, strengthen and monitor the caregiver support system are identified.	♦ March 2009
Models that improve ease of access to caregiver supports in all Planning Zones are identified.	♦ Feb 2009
Identify the range of supports required by caregivers in the CE LHIN.	♦ Nov 15, 2008
Identify the availability and accessibility of current supports within the CE LHIN.	♦ April 2009
Identify the gaps in caregiver supports.	♦ May 2009

High-Level Milestones	Target Completion Dates
HSP ACTIVITIES: ¹⁰ Related to Strengthening the System of Caregiver Supports.	2009/2010
Guidelines for HSPs to implement processes to identify individualized caregiver support needs and develop strategies to address needs.	♦ May 2009
HSPs have identified current and proposed mechanisms to support caregivers prior to, during and after transition.	♦ July 2009
HSPs have identified current and proposed mechanisms to link generic and condition specific caregiver supports.	♦ July 2009
Recommendations and Development of a process for Inclusion of caregiver needs in the Charter of Client Rights and Responsibilities of every HSP	♦ Concurrent with Strategic Plan development
Development and dissemination of planning guideline(s) to assist caregivers in identifying the resources they need.	♦ Oct 2009
Identification and/or development of a caregiver needs assessment tool.	♦ Dec 2009
HSPs identify or develop strategies to ensure care plans are developed in a collaborative manner.	
Other Activities:	
Caregivers begin to enroll in Self Management Training education sessions Caregivers are trained as Peer Leaders through the Self Management Program.	♦ August 2008 (part of Self Management workplan)
Processes are in place for Caregivers to be aware and access Self Management training programs.	♦ March 2009
Design and implement (pilot) a Caregiver Support Resolution program to respond to and resolve complex and problematic care giving situations work with external consultant organization to design model and develop costing).	♦ March 2010
LHIN Board has reviewed and determined their role in providing advice to provincial and federal bodies responsible for income tax relief, employment supports and advocacy for caregivers.	♦ April 2009
Review of Literature and agency practices regarding staff training regarding needs of caregivers (local, provincial, national, and international).	♦ March 2009
Best/promising practices and learnings from the front-line healthcare staff are known and applied.	♦ April 2009
Hold Education events and/or establish Best Practice Coaching teams	♦ Beginning January 2009 ongoing
Development of a project communication strategy	♦ November 2008 and ongoing

¹⁰ These actions could be communicated/requested of HSPs concurrent with Strategic Plan development

Project Costs

			Fiscal Yr: 08-09	Fiscal Yr: 07-09-10	TOTAL
Salaries and Wages	Project Management Shared with Supportive Housing and CSS Review (Includes: Salaries/Wages, benefits, ODOE)		\$33,020		\$33,020
	Admin. Assistant – (Includes: Salaries/Wages, benefits, ODOE)			\$40,000 Proposing for this year to have some support to implement some of the tangible items to the project charter.	\$40,000
	Project Coordinator/Manager: On-going System Coordination (Includes: Salaries/Wages, benefits 18%, ODOE 5%)		\$82,600	\$87,600	\$182,600
Materials and Equipment/ Sponsor Costs			\$20,000	\$25,000	\$45,000
Community Engagement	Consultation, day sessions, focus group		\$5,000	\$12,000	\$17,000
Consulting Resources	For activities related to Strategic Plan Development or other System Enhancements				
	Project Developer: Initiation and Strategic Plan Development (07-08)				
Best Practice Identification and Dissemination	Best Practices review & report and identification literature and review of agency practices (local, provincial, national, international) – all three pop(n) Delivering caregiver education			\$5,000	\$5,000

Pilot Program	Design and Pilot a Caregiver Support Resolution Program			\$85,000	\$85,000
Investments to Caregiver Support System	<i>Specific resource requirements will be confirmed through Strategic Plan development</i>				
Tools, resources and skill-building	A range of supports as outlined in Goal #2 and including but not limited to, professional counseling supports; peer support programs; day to day coping/life skills, and access to assistive devices.	+\$	+\$	+\$	<i>Identify a target amt/ envelope from within Aging in place</i>
In-home and out of home caregiver relief (respite)	Examples: Consumer accompaniment (day, evening or overnight), meaningful daytime activities, day/week programs, work options or drop-in programs.		+\$	+\$	<i>Identify a target amt/ envelope from within Aging in place</i>
Short-stay/transitional residential options	LTC Home short-stay beds; partnerships with retirement homes or assisted living providers.		+\$	+\$	<i>Identify a target amt/ envelope from within Aging in place</i>
Education Events	e.g. Education events, Coaching Team development, etc.		+\$	+\$	<i>Identify a target amt/ envelope from within Aging in place</i>
Supportive Housing	Supportive housing with 24/7 on-call access to personal care, nursing and other supports.				
TOTALS			\$140,062	\$254,600	\$394,662

Funding Source

Aging at Home Strategy (Provincial MoHLTC Resources)

CE LHIN Priority Funding

CE LHIN Health Service Agencies

Health Canada

Partnerships with Insurance Companies

Project Team

Team Member, Organization	Role on the Project	Required Involvement	
		Estimated Duration	Level of Effort
<p>Project Team to advise on development of Caregiver Strategic Plan (Target 9-12)</p> <ul style="list-style-type: none"> Caregivers with different perspectives Physician/Primary Care Working Group representative Front-line providers of in-home health care (paid and volunteer) Durham East Collaborative rep(s) CECCAC LTC Home Current agencies delivering significant caregiver support (e.g. Community support Services; Seniors Centres) SCFS Steering Committee Rep CDPM Steering Committee Rep MHA Steering Committee Rep 	<ul style="list-style-type: none"> Advisory to Strategic Plan Development Advisory to Program Developer on other Caregiver Support System project deliverables Note: Goal #1 identifies the need to design and implement the most appropriate on-going structure to plan, coordinate, strengthen and monitor the caregiver support system in CE LHIN. (e.g. a LHIN Caregiver Council, Zone-level Lead Agencies, etc.) 	<ul style="list-style-type: none"> Concurrently in the 2008/2009 year and 2009/2010 year 	<ul style="list-style-type: none"> 2-3 meetings (6 hours per month additional activity related tasks (3hours) 2-3 meetings per month (6 hours) Prep work, activity tasks 3 hours Chair of working group will have an additional 1 hour per month. CECCAC – 2 additional hours per month

Project Partners

Provincial:

Ministry of Health – branches TBD

Ministry of Health Promotion

Public Health Units

Seniors Secretariat – Ministry of Citizenship

Ministry of Community and Social Services – Special Services at Home (respite program)

Health Service Providers:

All

Family (GP/FP)

Specialist Physicians

LHIN Planning Partnerships:

Collaboratives (9)

CDPM Network

Seamless Care for Seniors Network

Mental Health and Addictions Network

Primary Care Working Group

Other:

Retirement Home Providers

Private and Not-for-profit visiting nursing and personal care agencies

SHRTN

MAREP

Project Stakeholders

Other Related Projects & Initiatives

Stakeholders	Interests & Needs	Management Strategies
<ul style="list-style-type: none">CaregiversHealth Service Provider AgenciesIndividuals who receive care and support from caregivers	<ul style="list-style-type: none">Target populationProvide Services to Target PopulationReceive care and support from target population	<ul style="list-style-type: none">Include in planning and deliberations; provide updates/communications.

Project/Initiative	Interdependency & Impact
<ul style="list-style-type: none"> • Aging at Home Strategy • LHIN Priority Projects: Supportive Housing, Self-Management Training, Community Support Service Review. • Agency/community initiatives focused on caregiver support enhancements (to be identified) 	<ul style="list-style-type: none"> • Enhancements will need to be coordinated with objectives of the Aging at Home Strategy • Will be influenced by outcomes of other LHIN projects • Community projects/initiatives will have to be identified and linkages made to leverage/coordinate investments.

People & Organization Change Impacts

Description of Impact	Impact Management Strategies
<p>All Health Service Providers – positive impact</p> <ul style="list-style-type: none"> • LTC Homes • CCAC • Community Support Agencies • Hospitals • Physician/Primary Care • Mental Health and Addictions • Providing caregiver supports and “reaching caregivers before they are desperate/burnt-out” provides sustainable on-going health and non-medical supports to consumers and minimizes crisis; • Will inform and influence the model of care delivery to clients and caregivers in various healthcare settings; • Will support the realignment and reallocation of costs and responsibilities within the healthcare system by recognizing that the care provided by caregivers has an economic impact on the ability of programs to deliver effective and efficient services; • Strengthen the ability of caregivers to prevent crisis and the ability of the healthcare provider community to respond to client or caregiver crisis; • Best use of existing and new caregiver resources – What is provided by healthcare system improves quality of life for caregiver and addresses what is most needed by leveraging local (Planning Zone) and LHIN-wide supports; • Provides HSPs with consistent and coordinated information and tools to improve their ability to support caregivers <p>Caregivers</p> <ul style="list-style-type: none"> • Individualized care and support acknowledging gender and cultural differences; • Supports to assist caregivers to regain/maintain control of their lives; • Provide real life tools and support-solutions (e.g. 	<ul style="list-style-type: none"> • Engagement in Strategic Plan development • Development of a communications strategy • Integration strategies

Description of Impact	Impact Management Strategies
<p>planning guide, respite opportunities);</p> <ul style="list-style-type: none"> • A clear avenue for problem-solving is in place to support caregivers in resolving difficult/challenging situations; • Provide right information to caregivers in a timely manner; • Improved Quality of Life for caregiver by providing strategies for maintaining caregiver health, supporting well-being and preventing illness; • Public recognition of caregivers / public visibility of caregiver support / ease of access celebrating the role of caregivers through sharing of successes, sacrifices, accomplishments (i.e. the un-sung heroes supporting the healthcare system). <p>Extended Family</p> <ul style="list-style-type: none"> • Improved health outcomes, both physical and mental; • Improved health maintenance; • Increased rates of recovery; • Increased likelihood to adhere to treatment choices; • Reduced hospitalizations; • Reduced or delayed admission to LTC Homes; • Reduced contact with criminal justice system 	

Project Communications

Audience	Information Needs	Format & Timing	Responsible
<ul style="list-style-type: none"> • Caregivers • Health Service Providers • General population • Individuals receiving care and support from caregivers 	<ul style="list-style-type: none"> • A project communication strategy will be developed 	<ul style="list-style-type: none"> • As a component of Strategic Plan development 	<ul style="list-style-type: none"> • Developed in consultation with LHIN Communications team

Project Risks

Risk	Likelihood	Impact	Risk Response
<p><u>Opportunity and Threat:</u></p> <p>Caregiver support is recognized as an area for enhancement by various priority populations/sectors (e.g. Seniors, People with Chronic Conditions, those with Mental Health and Addictions needs)</p>	<ul style="list-style-type: none"> • High 	<ul style="list-style-type: none"> • High 	<ul style="list-style-type: none"> • Awareness of activities and communication with other interested partners/stakeholders

Project Risks

Risk	Likelihood	Impact	Risk Response
<p><u>Threat:</u></p> <p>Resource requirements/demand for programming will increase given large number of caregivers who presently receive no/very limited support</p>	<ul style="list-style-type: none"> High 	<ul style="list-style-type: none"> Moderate 	<ul style="list-style-type: none"> Although number of caregivers will increase the enhancements to system proposed will reduce demands on system and will provide needed supports.

Critical Success Factors

- Caregiver participation and input
- Core resources
- Build on existing research
- Identify and address general and unique needs of caregivers to individuals with certain conditions (e.g. dementia, mental health and addictions)
- Project produces real improvements/tools – that can be immediately applied and benefit caregivers and HSPs
- Public recognition of caregivers / public visibility of caregiver supports / ease of access

Assumptions & Constraints

Assumptions	Constraints
<ul style="list-style-type: none"> Aging at Home strategy will provide on-going resources for caregiver enhancements LHIN organization will support enhancements to caregivers services Health service providers will buy-in to need for caregiver system enhancements 	

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Appendix 3

Year One Aging at Home Funding Allocation

Caregiver Support and Wellbeing

Organization	Project Name	Base Funding	One-Time Funding	Innovation Funding
CECCAC	Caregiver Support and Wellbeing Project Charter		\$100,000	
Oshawa Senior Citizens Centre	Conant Branch ADP	\$150,000	\$14,000	
Community Care – Kawartha Lakes	In Home Respite – paid Expansion of ADP	\$35,000	\$12,000	
St. Elizabeth Health Care – Northumberland	Enhanced Caregiver Support			\$145,000
Community Care Durham	In home Respite – (paid), expansion of ADP in Uxbridge and Pickering	\$179,375	\$23,000	
Scarborough Support Services for the Elderly	In Home Respite (paid), ADP expansion	\$16,400		
Yee Hong Centre For Geriatric Care	Care Ambassador Program			\$100,000 \$80,000 base \$20,000 one time
TOTAL		\$731,975	\$352,500	

Appendix 4

Caregiver Support and Wellbeing Priority Project

Identification of Caregiver Needs

Kindly take a few moments to fill in this questionnaire. If you need more space, use the back of page.

I live in _____ (please indicate, city,town or area in which you live)

I am a caregiver for my

_____ spouse

_____ child

_____ parent

_____ extended family

_____ friend

_____ other

I have been caregiving for:

_____ less than 6 months

_____ 6 months – 5 years

_____ 5-10 years

_____ more than 10 years

What are the top 3 things which you need to help you in your caregiving role?

Please review the chart outlining the definition of caregiver support and the corresponding components which make up caregiver support.

The coloured boxes represent a definition of the types of supports which caregivers may need

The points under the colour boxes are the types of supports which could exist.

Is there any area of support missing? If yes, please add your comment.

Any other comments:

Thank you very much for your feedback. Your input will help our group to understand the needs in order to make recommendations to enhance supports for caregivers throughout the Central East LHIN. Please send your comments to Susan Locke at susan.locke@ce.ccac-ont.ca or by FAX to 905-430-7019 or if you wish to remain anonymous - mail to CECCAC, 209 Dundas Street, Whitby ON, L1N 7H8.

Appendix 5

Community Engagement Survey Summary January 22, 2009

Caregiver Support Project

In an effort to understand the needs of caregivers within the Central East LHIN, a process of community engagement was implemented from November 1 to December 20, 2008. Caregivers were asked to identify, their location within the CE LHIN, the length of time they have been a caregiver and their top three needs. They were asked to comment on the caregiver definition and support component chart which has been developed. The responses from this process will ensure that adequate input has been received from caregivers.

To date response has been received from 273 caregivers throughout the Central East LHIN. Feedback was received from focus groups, 1:1 interviews, email, website viewing and written letters. It was indicated on the survey that audience response has come from cultural groups representing French, Cantonese, Mandarin, Tamil, Sri Lanka, Italian, Greek, Japanese and Chinese.

The following chart represents a summary of the response from the planning zones of the CE LHIN. Response has come from caregiver groups representing CE LHIN priority areas of Mental Health and Addictions, Chronic Disease Prevention and Management and Seniors.

Zone 1	Zone 2	Zone 3	Zone 4	Zone 5	Zone 6	Zone 7	Zone 8 & 9
Haliburton Highlands	Kawartha Lakes	Peterborough City & County	Northumberland Havelock	Durham East	Durham West	Durham North Central	Scarborough Agincourt/Rouge Scarborough Cliffs
14	9	20	28	49	43	21	89

The following is a summary of comments received regarding the top three needs of caregivers. The comments have been broken down into the developed support components.

X – Indicates this statement is cross referenced under more than one heading.

 Indicates this type of statement was repeated **15 times or more**

 Indicates this type of statement was repeated **10 times or more.**

 Indicates this type of statement was repeated **5 times or more**

Recognition

- The public to be more educated on the contributions of caregivers. This is not a job I would wish on anyone and yet, it is taken for granted.
- Formalizing of the caregiver relationship so that the medical community acknowledges our existence and provides information and support to us before the power of attorney stage.
- My employer is not aware of employment leaves. Thinks I am trying to get out of work when all I am doing is caring for a sick relative. How can the issue of employee leaves be more recognized within the community.
- More organizations (private industry) need to include education sessions on elder care or caregiving to their employees. Often you don't even think of it until it hits you in the face and by then – it is too late to plan or find resources – you have to think fast. **X**
- Sometime I just need to know that what I am doing is understood and value added to the community.
- I do all the care; I should have a role in the decision making. Agencies need to realize this.

Coping Support

- Someone to talk to, to listen to my needs, to ensure I am doing the right thing.
- When I drop my mom off at the day program, I would like some support myself. Why can't the Day programs offer a service for caregivers even one day a week?
- Very difficult being in the sandwich generation having parents with needs and teenagers with needs, I need support to cope.
- I need some understanding from my extended family. I am the sibling who is taking on all the care and it is just assumed that I will continue to do this indefinitely.
- A help line to call. Sometimes I don't know what I need, but if I could talk with someone who could steer me in the right direction or let me know that what I am doing is ok, then I would feel better. Is there a support line? **X**
- I need some mentoring from someone who has "been there, done that" to let me know it's ok to feel the way I do and that I am doing the right thing.
- Peer support that has the cultural and language capacities.
- Option of having 1:1 support in my home or on the phone.

Respite

Respite services which are extended or at short notice:

- More in home respite care.
- Emergency Respite.
- Alternate respite – like camps or resorts for caregivers. Like a spa for those who care for others.
- Respite options on how to care for my parents while I am at work.
- Respite in retirement homes which is subsidized.
- The agency to stop switching the PSW who comes. Dad gets to know them and likes them and when there is a switch, I have to come to ensure that the care is correct. This happens all the time.
- Why are there such a small amount of short stay respite care beds and they are not local.
- A subsidy available to all providers of day programs and in home respite to be able to provide service based on a means test. **X**
- Improved communication between in home respite workers. It seems that I constantly have to re-explain care to them. This is tiring for me. **X**

Information and Education

- Subsidized programs which allow me to get out and exercise – to maintain my health.
- To understand where to go for support. Where do you get this information? I am sure the resources are out there, but I have difficulty understanding how to get to them. My family helps me, but there has to be an easier way. It just needs to be simpler.
- Subsidized programs which allow me to get out and exercise – to maintain my health.
- Information on the specific condition which my mom suffers from.

- Somewhere to go where I can get information, education and support. Can this be all in one spot?
- More organizations to include education sessions on elder care or caregiving to their employees. Often you don't even think of it until it hits you in the face and by then – it is too late to plan or find resources – you have to think fast. **X**
- More knowledge of caregiving skills. How do I learn to be a better caregiver?
- The cost of private or subsidized support programs. I can afford to pay but don't know where to get the information.
- Bring all service providers together and compile a list of resources, make it simple, all information under one cover, good indexing, help me to know where to go and how to get help.
- Online local resource listings for caregivers.

Daily Living Support

- Transportation – I need help to get my mom to appointments. There needs to be a better way to book accessible transportation.
- Help with household maintenance tasks – I am at my mom's every day helping with her care, doing her errands and I have my own life. Doing this additional work is so hard for me.
- Increase support for housekeeping support.
- I need help managing my wife's medication. The pharmacy helps by putting it in those packages, but sometimes my wife wants to control all of it and she forgets to take the medication. How do I help her (skills)?
- Equipment and Home modifications – who does this?
- Prescriptions which can't be renewed on the phone. Makes the caregiver have to do extra running around.
- Why can't there be case management in order to provide subsidized services which deal with the maintenance and upkeep of my mom's house. This is often what makes the caregiver burnout and pushes them over the edge. **X**
- Concept of assisted living that would be mandated by the Provincial Government.

Financial Legal

- More consistent government policies on caregiver leave. Government policies are not well known and are not comprehensive enough. The loss of income when caring for someone is tremendous.
- I need legal and financial advice. Even though I have power of attorney for my Dad I want to ensure I am managing his funds properly and ensuring he has the best possible care. I think he can afford to pay for some things but I am always worried he will run out of savings and that his care will impact on our finances. If I had some support in this area, it may be possible to pay for some extended service if it is available.
- Financial compensation/tax benefits – The cost of caregiving needs to be measured and those providing consistent care should be compensated for their efforts.
- My employer is not aware of employment leaves. Think I am trying to get out of work when all I am doing is caring for a sick relative. How can the issue of employee leaves be more recognized within the community **X**
- Instead of paying the caregiver, provide free respite. **X**
- Equipment and supplies for care are very costly. It would be very helpful to have an incentive/cost saving program for those who are caring for someone at home. The cost of caring for someone at home is cheaper than the cost of caring for that same person in an institution so why can't caregivers get equipment at "cost" nor have a sum of money given to them to purchase supplies or have it covered.
- A subsidy available to all providers of day programs and in home respite to be able to provide service based on a means test. **X**

Care Planning

- More supports in the community which look at the needs of caregivers.
- Case management and care planning for the caregiver -Why is this not available?
- Having our doctor realize that I have caregiving issues. It is a package deal. The patient and their caregiver. Decisions on care need to be addressed to both and also the the caregiver has needs.
- I want organizations to also think of the caregiver when planning their programs and supports.
- Individualized support planning.

Other

- More supports in the rural areas.
- Doctor who is willing to make housecalls. Very hard for me to get my wife to the doctors, it is an all day event, very stressful, she is in pain, complains and hard on me physically.
- Bring all service providers together and compile a list of resources, make it simple.
- Improved communication between in home respite workers. It seems that I constantly have to re-explain care to them. This is tiring for me.
- Agencies to be consistent on how they assess and admit to programs. In this age of information and electronics, why client assessment isn't used in all support agencies (with client permission of course). This would eliminate the hours of duplication when trying to get someone into a program. Caregivers waste so much time telling agencies the same information.
- Visiting nurse practitioner who can come in to check on my mom. It is very difficult to get her to the doctors office, it is not very accessible and a strain on me.
- Consistant medical care for mother and me. I am a senior looking after a senior.
- Other health related professionals who are willing to come into the home ie dentist, footcare, physio, etc.
- In home respite agencies giving PSW more information on the care needs of the client. They come in and do their best, but have gotten no information ahead of time.

Questions:

- My mother is currently in complex continuing care in Bowmanville. We would love assistance in planning for my mother to return to us, however we are being told that assistance to plan to come home and also apply to nursing home is considered "double dipping". How is one supposed to know if its possible to resume care at home without some assesement?
- Why does my mom need to go through a comprehensive assessment to attend the day program and why can't I decide where she goes? Can this process be speeded up?
- Why can't each support agency share assessments. Since I have been trying to get help for my Dad, he has been assessed by each different agency using, what I can see, different assessments. In this age of technology, with our permission, why can't these agencies share the assessment information so we don't have to go through this again and again?
- My husband has dementia and we have been involved with the Alzheimer Society for the last year. I am so impressed with the system they have where they call you after your diagnosis. Why isn't this type of system in place in more areas of health care? People would then get the help they need earlier in the disease process?
- Why is everything so hard to find? I am an intelligent person; trying to find support for my 85 year old father and I have not had to do this much research since I studied for my Masters degree. There needs to be a better way to inform people what services exist.
- We go to our doctor for health problems. They only look at what is in front of them. Why can't there be a system with a health navigator. The doctor diagnosis the problem and then refers the patient to the health navigator to help find resources in the community. Right at the doctors office or clinics or health centres. I am walking in circles trying to find help and I don't need to be told again that my mom is frail. I know she is WHAT can I do?
- How do I get more PSW support?
- Here is my problem. My mom is 94 and lives in her own home. She is fiercely independent and wants to stay at home. Her health is generally good, but she is quite frail. She currently gets 2 hours per

week for personal care. I live over an hour from her, but am coming in almost daily. The thing she really needs to stay at home is some help per week with household chores, maintenance etc. When I called her case manager to discuss this, she was offered another hour of personal care. She does not need another bath; she needs to have help with her home. When trying to keep the elderly in their homes why can't we ask the simple question – What do you need to stay in your home and then services are supplied accordingly?

- How is it determined how much you are eligible for? I understand there must be some sort of scale based on the needs, but my wife's condition has worsened considerably in the last 4 months, yet we still get the same amount of in home care.
- I am 85, relatively healthy and caring for my frail wife. We have support coming in to do personal care but I would like the option of having a grocery store deliver in case I can't get out. Is there such a thing in this area?
- Equipment and Home modifications –who does this?
- Case management and care planning for the caregiver -Why is this not available?

Appendix 6

Caregiver Support and Wellbeing Priority Project

Kindly take a few moments to fill in this questionnaire. If you need more space, use the back of page

Organization:

CE LHIN area served:

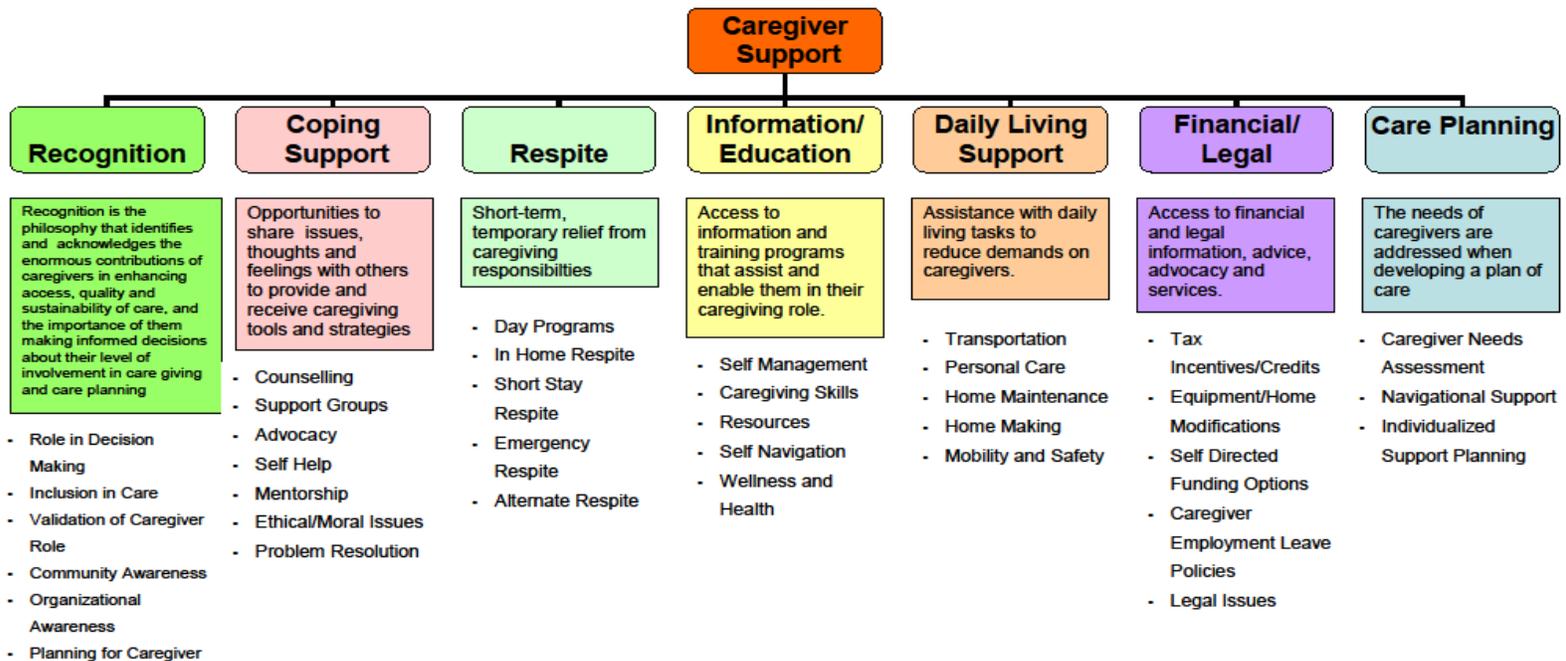
Contact Information: (name, phone, email)

Please review below chart outlining the definition of caregiver support and the corresponding components which make up caregiver support.

The coloured boxes represent a definition of the types of supports caregivers may need

The points under the coloured boxes are the types of supports which could exist.

Definition:
Caregiver* supports promote the health and well-being of caregivers, enabling and assisting in their care giving roles.



1. Indicate using point form the supports which are provided to caregivers by your organization using the caregiver support model.

2. Are there any areas of support which could be added to this chart? If yes, please add your comment.

3. What do the caregivers you work with need to stay healthy and independent?

4. Please identify any unmet needs or issues which arise when supporting caregivers.

Question 5-7 is for those organizations which provide RESPITE services

(We are specifically looking at admission and referral processes)

Please indicated the type(s) of Respite Care provided

Short Stay

In-Home

Adult Day Program

Emergency or Alternate

5. Please identify the referral process for each type of respite offered (use back of page if necessary)

6. Please indicate the type of assessment used (include/attach a copy if possible)

7. Identify some opportunities for change with the admission and referral process (es).

8. After reviewing the 'Caregiver Supports Definition and Component Chart', what would you envision a 'Caregiver Support Centre' in Northumberland being? Please do so from perspective of your organization and also for the caregivers that you service

Thank you very much for your feedback! Your input will help our group to understand the needs in order to make recommendations to enhance supports for caregivers throughout the Central East LHIN. Please send your comments to Susan Locke at susan.locke@ce.ccac-ont.ca or by FAX to 905-430-7019 or if you wish to - mail to CECCAC, 209 Dundas Street, Whitby ON, L1N 7H8.

Appendix 7

Caregiver Support and Wellbeing Priority Project

Organization Community Consultation

53 Survey's have been distributed

47 returned

Zone 1	Zone 2	Zone 3	Zone 4	Zone 5	Zone 6	Zone 7	Zone 8 & 9
Haliburton Highlands	Kawartha Lakes	Peterborough City & County	Northumberland Havelock	Durham East	Durham West	Durham North Central	Scarborough Agincourt/Rouge Scarborough Cliffs
2	2	4	10	8	7	5	9

1. Indicate using point form the supports which are provided to caregivers by your organization using the caregiver support model.

2. Are there any areas of support which could be added to this chart? If yes, please add your comment.

- Please add **accessibility** under Care Planning. It is important to recognize that sometimes alternate methods of communication and information sharing are needed for caregivers to get the information and support they need.
- **Transition** from home to LTC facility.
- **In home counseling** – having an actual person to call anytime during a stressful time.
- **Support through technology** – online inquiries, video conferencing, peer support groups with online discussions, caregiver resource and linkae website.

3. What do the caregivers you work with need to stay healthy and independent?

- To be taken seriously, the inquiries are not just seen as complaining.
- Easy access to information to increase knowledge and confidence of caregivers.
- No waiting lists – when they reach out for help, most need it immediately and can't wait.
- Back up plans if respite is cancelled – so often we hear of a scheduled PSW was to come and at the last minute the plan was cancelled or changed.
- A shoulder to lean on.
- More consistent training on how to provide illness specific care i.e. post stroke recovery.
- More opportunities for respite.
- 24 help line like the Kids help phone.
- Doctors to be more knowledgeable to the supports within the Community.
- Financial assistance, subsidy, etc.
- Financial assistance for the expenses of caring for their loved one ie transportation, medical equipment.
- Support for legal/financial advice.
- Understand how to cope during transition phases – discharge from hospital, etc.
- Support to help educate their family on what is going on.
- Education about how to care for themselves.
- Respite – time to sleep, do chores, read, and stay at home when in home respite comes in.
- A caregiver office or location which has information, opportunities for education, help to deal with anger.
- Culturally sensitive information and support – which helps caregivers understand the system of support which is available. Also to understand the social supports available to the client.
- More services in the community. – if there isn't anywhere for people to go for support this is a problem.
- Better communication and coordination between organizations – i.e. organization which supports those with hearing loss and other support agencies most don't think to access each others expertise and resources.
- Programs and services which are for caregivers separately and not just because they accompany a client.
- Acknowledgement.

4. Please identify any unmet needs or issues which arise when supporting caregivers.

- 24 hour sign language interpreting services.
- More respite of any type is needed, short stay, in home and ADP.
- An Adult Day program in Whitby.
- Equitable access to short stay respite beds.
- Seeing a caregiver under stress and not being able to take more time to address their situation. We need more resources specific to the caregiver in addition to the client.
- Somewhere to call to get support for caregivers who we deal with. Sometimes they need the type of information or education which we do not have.
- More types of support groups.
- In home respite is generally not available for MHA.

- Huge gap of culturally and linguistically relevant caregivers education and support programs for immigrant population. These caregivers encounter challenges such as language barriers and diverse cultural values.
- Lack of informal support mechanisms for immigrant families.
- Lack of knowledge of what is available.
- Caregivers not being able to afford in home services.
- Other than ConnexOntario, there is currently no coordinated access to MHA services other than supportive housing and case management.

Question 5-7 is for those organizations which provide RESPITE services

(We are specifically looking at admission and referral processes

Please indicated the type(s) of Respite Care provided

- Short Stay In-Home
 Adult Day Program Emergency or Alternate

5. Please identify the referral process for each type of respite offered (use back of page if necessary)

Adult Day Program –

Durham Region

All referrals come through CECCAC. Anyone can contact day program directly for information, tour, but specific referral must come through CCAC. Intake and assessment done by CECCAC case manager using the RAI assessment form.

Fees: different depending upon agency

Scarborough

Self referral, physician, other health care professionals. Individual or caregiver calls specific organization and makes appointment to come in for an assessment. Intake and assessment policies differ – some have Client services coordinator who determine eligibility for admission

Peterborough

CCAC assessment and referral, fee varied, multi sited

6. Please indicate the type of assessment used (include/attach a copy if possible)

Adult Day Program –

Durham/ Peterborough – RAI assessment tool – then agency intake assessment form

All other areas of LHIN – individual organization assessment tool

7. Identify some opportunities for change with the admission and referral process(es)

ADP which utilize CCAC for intake and Assessment:

- More community awareness of CECCAC. Many people have never heard of it and are constantly confused with community Care Durham. Doctors need to be aware of the community resources.
- Referrals from CCAC to Adult Day program are not a priority to Case managers/system. It takes a minimum of 2-6 weeks to receive actual paperwork from CCAC. We get many phone calls during the waiting period. This adds to the already stressed out caregiver.
- Too much paperwork. 30 page plus referral that is faxed and sometimes faxed numerous times on same referral. Most of the information on intake assessment is irrelevant to what we require.
- Would eliminate stress for caregiver not having to go thru CCAC for referral and then again interview process at day program – double process for caregivers and potential day program client.
- Most times, not able to contact Case manager or CCAC designate – mostly voice mail and therefore a lot of phone tag and internal waiting when already squeezed for time.
- Case managers could keep the wait lists and allow individual day programs to do the intake and assessment using a standard assessment form which has been developed in collaboration with Day programs and CCAC, understanding what information Day programs need. This information could be transferred to the RAI assessment form if needed.
- Leave the intake and assessment with the CCAC because they are the central point of access, but make the assessment form more streamlined to capture the information needed by Day programs and also have more staff at CCAC doing these intakes.
- We have found that not all case managers are aware of the Day programs. Why is this?
- Allow us as a Day Program to move forward with our intake process while the CCAC is assigning case managers and sending referral. This would allow us to serve a client we feel is appropriate for the program while they are waiting for their home visit.
- Day programs receive up to 35 pages of an assessment from CCAC, most information is not needed. An additional assessment is needed from the family for our agency. Our assessment is more personal to cover the ADL's that the member will need while in our Day program.
- CCAC and Day program coordinators meet regularly to ensure that waitlist are managed. Clients can either come directly to Day program to be assessed and then the assessment is sent back to CCAC.
- This would speed things up.

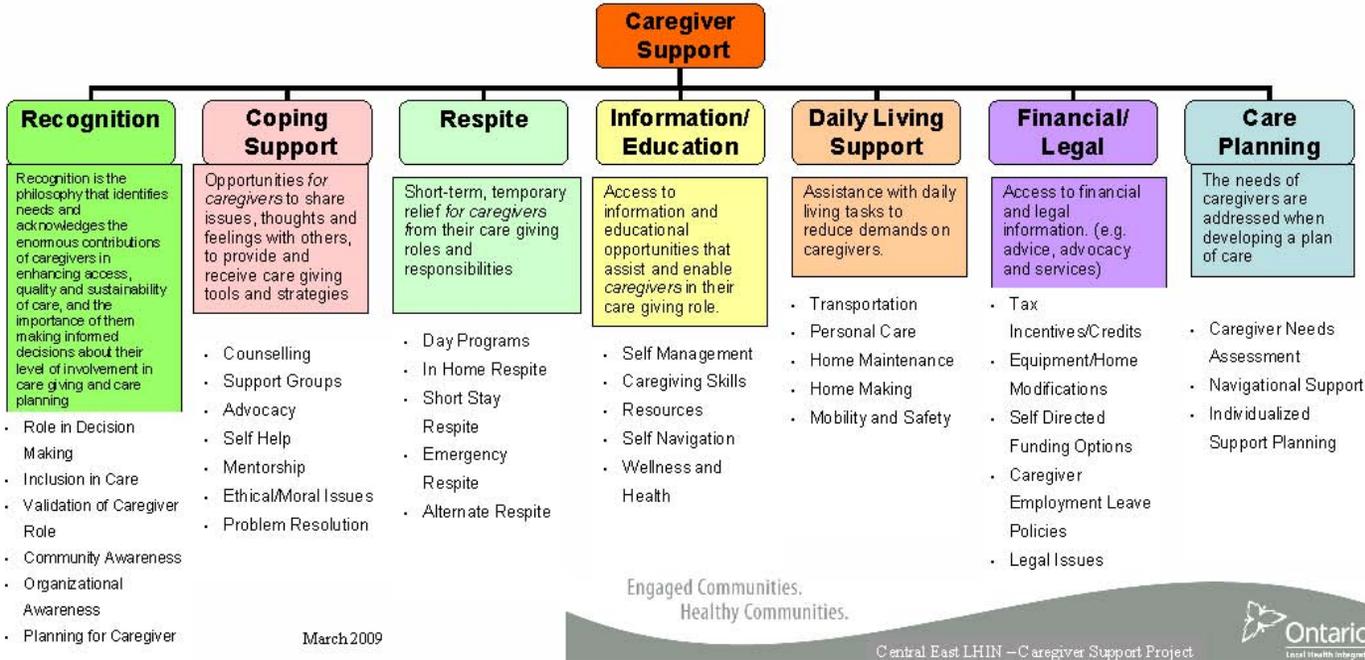
ADP which do not utilize CCAC for intake and assessment

- Make inter-agency referral process less cumbersome – CCAC referral to CSS agencies or vice versa.
 - When clients are familiar with an organization allow them to by pass an intake process with CCAC.
 - Standardize the package of caregiver information across the LHIN. Make all fees, admission policies uniform across the CE LHIN. Very difficult to advise families who are trying to access service outside our immediate geographical area.
 - Common intake and assessment process across the CE LHIN.
 - We need some consistency to prevent one day program from accessing clients with “lighter” care needs.
 - Program content can be standardized based upon Best Practice.
 - Clients don't know about CCAC, may effect utilization of program. Will our program remain full?
8. After reviewing the 'Caregiver Supports Definition and Component Chart', what would you envision a 'Caregiver Support Centre' being? Please do so from perspective of your organization and also for the caregivers that you service
- One stop shop, person on the phone.
 - Support to not only the caregiver but information source for agencies supporting caregivers.
 - Drop in centre – offering workshops with community agency experts.

Thank you very much for your feedback! Your input will help our group to understand the needs in order to make recommendations to enhance supports for caregivers throughout the Central East LHIN. Please send your comments to Susan Locke at susan.locke@ce.ccac-ont.ca or by FAX to 905-430-7019 or if you wish to - mail to CECCAC, 209 Dundas Street, Whitby ON, L1N 7H8.

Caregiver Supports Component and Definition Chart
 Central East LHIN Caregiver Supports and Wellbeing Project

Definition:
Caregiver* supports promote the health and well-being of caregivers, enabling and assisting in their care giving roles.
 *The term caregiver in this project refers to a network of family and friends.



March 2009

Engaged Communities.
 Healthy Communities.

Central East LHIN – Caregiver Support Project



Appendix 8

Recognition	Coping Support	Respite	Information/Education	Daily Living Support	Financial/Legal	Care Planning
<p>Recognition is the philosophy that identifies and acknowledges the enormous contributions of caregivers in enhancing access, quality and sustainability of care, and the importance of them making informed decisions about their level of involvement in care giving and care planning</p>	<p>Opportunities to share issues, thoughts and feelings with others to provide and receive caregiving tools and strategies.</p>	<p>Short-term, temporary relief from caregiving responsibilities.</p>	<p>Access to information and training programs that assist and enable them in their caregiving role.</p>	<p>Assistance with daily living tasks to reduce demands on caregivers.</p>	<p>Access to financial and legal information, advice, advocacy and services.</p>	<p>The needs of caregivers are addressed when developing a plan of care</p>

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