

# Caregiver Framework for Seniors Project

# 2011-2012

**Phase 1  
Year-end report  
March 31, 2012**

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# 1. Background

The Toronto Central LHIN's *2011-14 Strategic Plan* aims to ensure high-quality care oriented around people and communities, a goal which is closely aligned with the Ministry's *Excellent Care for All* legislation. TC LHIN stakeholder engagement has shown that most frail seniors prefer to age at home, cared for by family members able to call on community supports if and when needed. Caregiver resiliency is of critical importance in home care because the caregiving journey can be long and onerous, causing some caregivers to become stressed or ill, and unable to continue in their demanding caregiving role. From a system perspective, a major benefit of increasing caregiver resiliency is that the quality of life of the care recipient may be improved, inappropriate visits to ER may be reduced, ALC transitions back home may occur sooner, and placement in long-term care may be delayed by months or even years. Cost savings can be significant.

**The Caregiver Framework for Seniors Project** was created to find innovative, practicable and affordable ways to support at-risk family caregivers of elderly care recipients living at home. The project as designed advances the TC LHIN's *Value and Affordability* priority by identifying and addressing caregiver needs ***as defined by them***, valuing their voices and tangibly recognizing their contribution.

# 2. Project Goals

**Phase 1** of the Project began in June 2011. Distinct steps were to:

1. By September 2011, develop a theoretical framework and practical plan to increase the resiliency of at-risk caregivers by lightening their burden of care and reducing the emotional stress that causes them to feel isolated, overwhelmed or depressed.
2. Starting in October 2011, implement the plan by training Toronto Central CCAC Seniors Enhanced Care (SEC) coordinators in *Problem-Solving Therapy* to help them engage with caregivers in an innovative way.
3. Invite each trained care coordinator to carefully select five or more at-risk family caregivers from their normal caseload, and recruit those caregivers into the project, for a project target of 150 at-risk caregivers.
4. In a focused private conversation between the care coordinator and the caregiver, identify factors that contribute to each caregiver's distress, and develop an individualized care plan, at a suggested average cost of \$1,500 for implementing each plan.
5. Implement the approved individualized care plans, with operational support from the project coordinator if appropriate.
6. Provide an interim report to TC LHIN in January 2012.
7. Evaluate the success of the project and make final recommendations to TC LHIN by March 31, 2012.

In December 2011, TC LHIN advised that additional funds would be available to continue the project into **Phase 2**, with project timelines extended well into 2012-2013. The two phases converged in February 2012, with caregivers in Phase 1 offered the opportunity to continue into Phase 2, and additional organizations invited to partner in the project, for a new project goal of 300 caregivers.

### 3. Project Leadership

A **Core Group** was created to develop the framework, liaise with project partners, and oversee the implementation and evaluation of the project.

- Françoise Hébert, CEO, Alzheimer Society of Toronto, *Project Lead*
- Jamie Arthur, Client Services Manager of the Toronto Central Community Care Access Centre Seniors Enhanced Care Program, replaced in February 2012 by Kelly Clarke, *Care Coordinator Team Lead*
- Carol Kushner, health policy consultant, *Framework Lead*
- Frances Morton, health policy researcher and doctoral student in dementia care, *Orientation Lead*
- Marija Padjen, Chief Program Officer, Alzheimer Society of Toronto, *Associate Project Lead*
- Stephanie Smit, Consultant, Toronto Central LHIN, *Liaison with TC LHIN*
- Natalie Warrick, Alzheimer Society of Toronto, *Project Coordinator* (full –time)

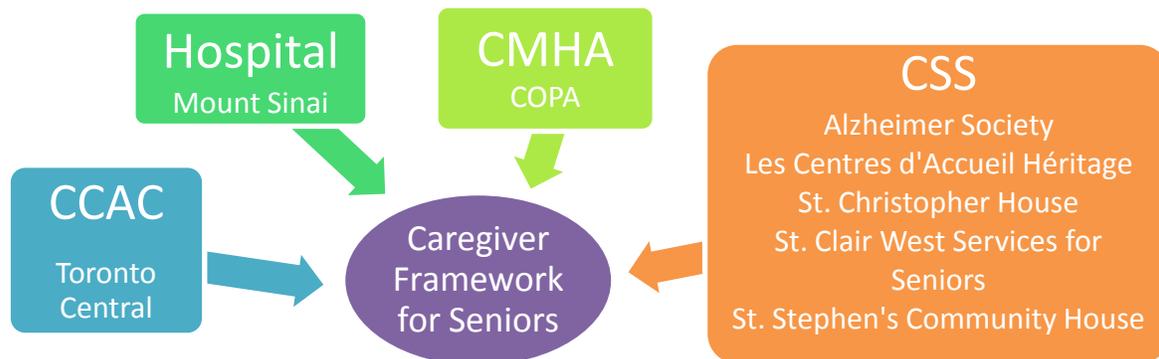
**Two teams of experts** are advising the Core Group:

- Dr. Joel Sadavoy and Dr. Virginia Wesson, assisted by Dr. Mary Chiu and by mental health clinicians Caitlin Agla, Valeria Grofman and K.C. Chan, from the Reitman Centre for Alzheimer Support and Training, Mount Sinai Hospital
- Dr. Paul Williams and his *Balance of Care* team Jillian Watkins, Allie Peckham and David Rudoler, from the Institute for Health Policy, Management and Evaluation, University of Toronto

Strategic oversight was provided by an **Advisory Committee** comprised of the following members:

- Barbara Cawley, Vice President Client Services – VHA Home HealthCare
- Gabriella Golea, Administrative Director Geriatric Mental Health Program – CAMH
- Wolf Klassen, Vice-President – Program Support Toronto East General Hospital
- Angelika Gollnow and Stephanie Smit, Toronto Central LHIN
- Dena Maule, Executive Director – Hospice Toronto
- Dipti Purbhoo, Senior Director, Client Services and Kelly Clarke, Client Services Manager – TC CCAC
- Diane Werner, Executive Director – P.o.i.n.t. (People and Organizations in North Toronto)
- Lisa Manuel, Director Family Services Toronto
- Cindy Bruce-Barrett, Director, Strategic Projects – Hospital for Sick Children
- Hélène Roussel, Director – Reflet Salvéo
- Seniors Groups: Lilian Wells - Toronto Council on Aging; Mary T. Hynes - Older Women’s Network; Gerda Kaegi - Canadian Pensioner’s Concerned; Lois Dent - Concerned Friends; Lorna MacGregor and Mary Ann Chang- CareWatch.

**Project Partners** include (to date):



## 4. Project Design and Implementation

### 4.1 Target Population: Family Caregivers At Risk

- **The target population** for this project is ‘family caregivers at risk or on the cusp of being at risk’ while caring for a senior who lives at home and requires ongoing assistance due to functional decline related to chronic health conditions. The frailty, medical complexity or medical instability of the care recipient puts them at risk for hospitalization or long-term care placement.
- **The care recipient** should be over 65 years of age (some exceptions allowed) and live in the TC LHIN catchment area.
- **The caregiver** must provide ten (10) or more hours per week of direct care to the care recipient. The caregiver may live outside the TC-LHIN catchment area.
- **Risk for the caregiver** includes physical, emotional, social or financial pressures that could lead to burn-out, and prevent the caregiver from continuing to provide care at home, increasing the care recipient’s risk of inappropriate use of ER, extended ALC or premature placement in long-term care.
- **Risk is measured** via the Resident Assessment Instrument –Home Care (RAI-HC) or Resident Assessment Instrument – Community Health Assessment (RAI-CHA) which flags a client as having a caregiver in distress when one or more of three triggers are present: 1) the caregiver is unable to continue in this role for any reason; 2) the caregiver is not satisfied with the support that others provide in caring for the client; and 3) the caregiver expresses distress, anger or conflict because of caring for the client. Other validated instruments to assess caregiver distress may be used if the RAI-HC/CHA is not available. The first wave of caregivers were recruited from Toronto Central Community Care Access Centre’s Seniors Enhanced Care team which uses the RAI-HC.
- **Caregiver demographics (to March 30, 2012)**

Caregivers –recruited to date				189
Caregivers – average age				66
Caregivers – range of age	Youngest	39	Oldest	95
Caregivers – sex	Female	74%	Male	26%
Caregivers – financial need (as observed by care coordinators)				97%

- **Caregivers representing the diversity of Toronto – (no formal targets set)**

Self-reported ethnic group		Language	
White	53%	English	69%
Asian / Southeast Asian	9%	Italian	11%
South Asian	6%	Portuguese	6%
Other/Declined to state	10%	Russian / Ukrainian	2%
Black	6%	Cantonese / Mandarin	2%
Italian	6%	Spanish	2%
Portuguese	5%	Greek	2%
Latin American	2%	Croatian	1%
Russian / Ukrainian	2%	Hindi	1%
Aboriginal	1%	Polish	1%
West Asian / Arab	1%	Tagalog	1%

**Simultaneous interpretation** is offered in the caregivers native language when requested. Translation of written materials can be provided in French only.

The majority of caregivers (177 or 94%) have been recruited by the TC CCAC, including

- 80 caregivers (42%) from Central area Seniors Enhanced Care (SEC) team
- 55 caregivers (29%) from West area (SEC) team
- 35 caregivers (19% from the East area (SEC) team
- 7 caregivers (4%) from the Integrated Client Care Program team

The Alzheimer Society of Toronto has recruited 7 caregivers.

Mount Sinai Hospital and St. Stephen's Community House have each recruited 1 caregiver.

Other project partners are preparing to recruit.

## 4.2 Liaison with the Target Population: The Care Coordinators

- From the outset, **TC CCAC** enthusiastically agreed to participate in this project, and their contribution has proved invaluable. In their database in July 2011, the TC CCAC *Seniors Enhanced Care* (SEC) program had 874 caregivers flagged as being at risk. This provided a well-defined target population of caregivers with consistent RAI and other assessment data, and with an existing relationship with their care coordinator, important considerations for a quick project start dictated by tight timelines, and for eventual evaluation purposes. Other agencies with care coordinators supporting at-risk caregivers were invited to partner with the project in February 2012.
- **The critical starting point** for this project is a conversation between the care coordinator and the caregiver: care coordinators select an eligible caregiver from their client roster and arrange to meet the caregiver to explain the project criteria and obtain the caregiver's informed consent to participate. Following the intake procedure, the care coordinator engages in a problem solving exercise with the caregiver to identify factors that contribute to the caregiver's stress, and to develop jointly *an individualized care plan* intended to reduce stress, mitigate risk and increase the caregiver's resiliency.
- Each care coordinator received a full-day of training in **problem solving therapy**, provided by geriatric psychiatrist Dr. Joel Sadavoy and his team at Mount Sinai Hospital. In this training, care coordinators learn to engage with caregivers in a highly focused way in order to address specific problems, agree on achievable goals and develop practicable interventions tailored to achieve those goals.
- Special training is essential because this project requires a paradigm-shifting conversation between the care coordinator and the caregiver that is substantively different from normal practice. The care coordinator in this project is entrusted with significant discretion to select caregivers from their normal caseload, recruit them to the project, explore the circumstances that are causing distress and suggest flexible, innovative interventions when negotiating the individualized care plan with the caregiver.
- *Problem solving therapy* training has to date been provided to care coordinators from:

Toronto Central Community Care Access Centre	54
Alzheimer Society of Toronto	7
Community Outreach Program in the Addictions	5
Les Centres d'Accueil Héritage	4
St. Christopher House	4
St. Clair West Services for Seniors	3
St. Stephen's Community House	3

### 4.3 Case Management Protocols and the Assessment Process

Six project-specific forms are used in this project. All forms are attached as appendices:

- **Consent form** signed by the caregiver following a scripted introduction by the care coordinator that:
  - the project is time limited
  - the caregiver can withdraw at any time without penalty to services currently provided
  - funding will cease if the care recipient no longer requires care at home
  - the project will maintain the highest level of privacy and confidentiality
  - the caregiver will be required to participate in developing a care plan
  - the caregiver will be asked to respond to surveys
- **Assessment** conducted by the care coordinator for baseline measurement and evaluation. The *Resident Assessment Instrument – Home Care (RAI-HC)* and *Resident Assessment Instrument – Community Health Assessment (RAI-CHA)*, performed as per usual case management practices. The *Caregiver Distress Scale* is used by partner agencies that do not use the RAI.
- **Care Plan** completed by the care coordinator to describe the stressors discussed with the caregiver, and the interventions agreed between them to mitigate the stresses.
- **Implementation Plan** completed by the care coordinator and the project coordinator to estimate the cost of the agreed interventions, and to assign responsibility for implementation and follow-up. Occupational therapists may advise on appropriateness of requested equipment and safety devices.
- **Funding Authorization** by the project lead.
- **Caregiver Questionnaire** mailed to each caregiver directly by the project coordinator when the care plan is approved. The questionnaire is returned to the project coordinator.
- Care coordinators record notes and upload files as per standard operating procedures. Notes are not shared with the project coordinator unless required to document unusual care plans.

### 4.4 The individualized care plan

- The project framework document listed **examples of interventions** that caregivers or care coordinators might be expected to request, such as respite care, transportation, home help, equipment, supplies, and direct funding of activities. The list was not intended to represent a specific basket of services that the project would fund, but rather provided a starting point for intervention ideas during the care planning stage of the conversation between care coordinator and the caregiver.
- Caregivers were invited to think creatively about how to address the problem situations that they found most stressful. They worked with their care coordinator to develop a plan uniquely tailored to their own circumstances. Normal rules and regulations about the type of services that could be funded by the CCAC were set aside, the focus placed instead on the needs of the caregivers **as defined by them**.

## Interventions requested in care plans

\* % column does not total 100 as many plans include multiple items %

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Informal respite care (relative, friend, neighbour, etc.) <i>Usually paid by the hour for an intensive short period (one or two weeks while the caregiver takes a vacation) or for several hours per day or per week over a longer time period of time for caregivers to enjoy personal time to attend church or family outings.</i>	35%
Health care supplies <i>Incontinence supplies, vitamins and supplements for caregivers and care recipients, medications not covered under Ontario Formulary and traditional Chinese medicine.</i>	25%
Social activity / self-care <i>Caregivers purchased tickets to attend events such as cinema, theatre, ballet, or gift cards for themselves, the care recipient and their family to attend events together.</i>	24%
Personal support worker <i>Preferably the same PSW provided by the CCAC, but otherwise a PSW provided by an agency serving their catchment area.</i>	23%
Equipment <i>Direct purchases made on behalf of caregivers for hospital bed, hooyer lift, stair glide, bathroom commode, mattress, wheelchair, walker, etc.</i>	20%
Bill payment <i>Payment of electric bill, groceries, courses at a University or trade college to improve job marketability or improve caregiving mastery (i.e. PSW course).</i>	17%
Physiotherapy <i>Payment for the caregiver or care recipient to receive physiotherapy not covered under OHIP.</i>	16%
Transportation <i>Taxi chits to attend medical appointments, church, adult day programs, grocery stores or other shopping destinations.</i>	16%
Home help (Meals on Wheels, cleaning services) <i>Professional de-cluttering services, bed bug pest removal, cleaning services, snow removal, home repair.</i>	12%
Adult day program <i>Fees for Initiation or addition of days for caregiver respite.</i>	8%
Short-stay respite in a residential facility <i>Caregivers recovering from recent surgery or who needed a short leave of absence to attend to overseas family matters opted to move their care recipient into a residential facility for a defined period of time (generally 3-4 weeks).</i>	7%

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## 4.5 Implementation of care plan interventions

- Most interventions requested in the care plans were congruent with framework expectations, within the suggested budgetary guidelines, and appeared in keeping with the goals of reducing caregiver stress. These were quickly approved and implementation proceeded apace, usually within a week or two.
- Intervention requests that were unusually costly or seemed questionable elicited a more thorough review. In these few cases, the project coordinator requested that the care coordinator discuss the case with their own manager, and provide fuller details to justify the request. There was a deliberate effort not to second-guess the interventions agreed between the care coordinator and the caregiver, but in rare instances care coordinators were asked to review the requested interventions with the caregiver to reduce costs or to select different interventions to achieve the same goal.
- Straightforward interventions such as additional personal support worker hours were generally arranged by the care coordinator, with invoices submitted to the project for payment. The project coordinator assumed the responsibility of implementation if requested by the care coordinator.
- Caregivers who preferred to arrange their own intervention were sent a cheque by mail by the project coordinator, and asked to provide receipts for large items (such as hospital beds or safety equipment), or invoice tracking sheets, in order to verify that funds had been used as intended.
- It was anticipated that a small number of caregivers receiving cheques by mail would be unable to implement the interventions due to changing circumstances in their own life or that of the care recipient. Follow-up calls or visits by the care coordinator or the project coordinator were instituted to assist in these cases.
- Care coordinators who carry a heavy caseload of clients appreciated that the project coordinator could implement the requested interventions, which in some instances required considerable time and effort. The project coordinator stepped in only when requested by the care coordinator, and did not communicate directly with the caregiver except with the explicit consent of the coordinator.
- Transitions can be stressful for caregivers and can add significantly to their burden. Care coordinators were encouraged to discuss changing circumstances with the caregiver and if appropriate to submit revised care plans, for example to reallocate adult day program fees to cover short-term transportation for hospital visits. But where circumstances changed permanently such that the caregiver would no longer be required to provide care at home, unexpended funds for services or equipment that were no longer required ceased to flow.
- Care coordinators were asked to follow up with caregivers approximately one month after initiation of the care plan intervention, to ensure that things were proceeding as expected, or to assist in addressing unexpected difficulties. Because of work load, some care coordinators asked the project coordinator to assume this follow-up task.

## 4.6 Cost of care plan interventions

The project framework envisioned average costs of \$1,500 per care plan. Caregivers recruited in the first phase of the project and continuing into the second phase could potentially receive \$3,000 or more. Total direct expenditures on implementation of the care plans would thus total \$450,000 for 300 caregivers.

Some care plans specified equipment interventions that significantly exceeded the expected average. A hospital bed, for example, could cost \$4,000. This type of intervention was usually approved, on the assumption that other care plans would cost less than the average, which seems to be the case to date. Costs are monitored closely to avoid an upward funding trend.

The table below categorizes intervention types, and contrasts the percentage of caregivers opting for those interventions with the percentage cost of all interventions.

<b>Interventions specified in care plans</b>			
<b>Intervention</b>	<b>Caregiver (n=189)</b>	<b>% Spent</b>	<b>\$ Spent</b>
Informal respite care (relative, friend, neighbour, etc.)	35%	25%	\$ 76,442
Personal support worker	23%	17%	\$ 50,779
Equipment	20%	10%	\$ 31,126
Bill payment	17%	10%	\$ 31,063
Health care supplies	25%	9%	\$ 28,003
Physiotherapy	16%	7%	\$ 20,760
Social activity / self-care	24%	6%	\$ 19,470
Adult day program	8%	4%	\$ 12,724
Short-stay respite	7%	4%	\$ 11,261
Transportation	16%	4%	\$ 11,252
Home help (MOWs, cleaning services)	12%	3%	\$ 10,363
<b>Total funds spent to date to implement care plans</b>			<b>\$ 303,242</b>
<b>Average spending per caregiver (n = 189)</b>			<b>\$ 1,604</b>

An interesting observation is that although 35 per cent of caregivers opted for informal respite care, the proportion of funds spent on this intervention was 25 per cent. This may be because the cost per hour of hiring a relative, friend or neighbour averages \$20, whereas the cost of a personal support worker supplied by an agency averages \$35 per hour. Savings from familial care can be significant, the number of hours almost doubled for the same expenditure.

Another interesting observation is that certain often requested interventions can be delivered in a more cost-effective way if the project coordinator aggregates the requests into a service contract with a supplier. For example, because the cost of incontinence products concerned many caregivers, the project coordinator contracted with dedicated suppliers to deliver products directly to the home of their care recipient, at a wholesale price. This had a two-fold benefit for caregivers in that they were relieved of the need to go the drugstore to pick up supplies, and of the financial burden which for some was upwards of \$180 per month.

## 4.7 Caregiver Attrition

It was recognized early on that a certain proportion of care recipients are likely to be admitted to hospital based on chronic health conditions and complex medical needs. Their caregivers will likely suffer from burnout as a result of the care recipient's serial hospital readmissions.

When the caregiver can be adequately supported, the risk of premature long-term care placement may be reduced. However, in spite of best efforts to support caregivers, other intervening circumstances may result in hospital readmission, long-term care placement and the death of a care recipient.



This project made it a policy that if the caregiver no longer provided home care because a care recipient moved permanently to a long-term care facility or died, the caregiver would no longer be eligible to participate in the caregiver project, and unexpended funds would cease to flow from the project.

To date, based on 189 caregivers in the project:

- 5 care recipients died,
- 3 care recipients went to long term care, and,
- 1 care recipient voluntarily withdrew from the project stating that she did not need the help.

## 5. Ongoing Evaluation Exercises

The theoretical framework for this project specified an iterative process in which feedback from caregivers, coordinators, and the project managers would be assessed by two expert groups, triggering course corrections to improve the effectiveness of the project as it progressed. Responses from caregivers to a mailed questionnaire would also inform the project and suggest course corrections.

### 5.1 Formative Evaluation

Led by Dr. Paul Williams, the University of Toronto's *Balance of Care Research Group* conducted an evaluation that included a targeted review of the literature, key informant interviews, a preliminary analysis of RAI-HC data from TC CCAC, and focus groups conducted with coordinators.

**The literature review** highlighted a growing emphasis on the crucial role that caregivers play in supporting the independence, quality of life and well-being of older persons, and in contributing to health system sustainability. From a policy perspective, a growing emphasis is placed on the importance of transitioning individuals from institutional settings to home, and keeping them healthy at home for as long as possible. However, while demonstrating the importance of recognizing and supporting this crucial role, published evidence nationally and internationally does not provide clearcut direction about what works best for which caregivers in which contexts. Indeed, the evidence strongly argues that "one size does not fit all," and that caregiver support initiatives need to consider a range of factors including the needs of caregivers and care recipients, as well as access to other needed community-based services and supports at the local level. For

example, caregivers to at-risk older persons in rural areas may have less access to needed community-based services than caregivers in urban areas, increasing their workloads and stress; likewise, even in urban areas, caregivers to-at risk older persons in emerging ethno-cultural communities may experience challenges accessing appropriate community-based services for their loved ones, also increasing workloads and stress.

**Key informants** provided insight into caregiver support projects across Canada, but revealed no consistent approaches: Nova Scotia's *Caregiver Benefit Program* provides a monthly payment for caregivers to use in any way they see fit, while Wesway's *Family Directed Respite* program and the VON *SMILE* program both develop an individualized care plan that can access a defined basket of services. Respite and self-managed care are among the most common intervention types, but there is great variability in program design, and no consistent method of determining program eligibility or assessing outcomes: some programs have very general eligibility criteria, whereas others base eligibility on rigid criteria and standardized assessments (e.g. MAPLe scores). Nor are there consistent processes related to funding per client or program administration.

**Preliminary RAI-HC data analysis** was conducted for individuals on the long-stay list, long-term care wait list, and in the Seniors Enhanced Care (SEC) Program focusing particularly on caregivers of care recipients receiving long-term care services, and on caregivers flagged as in distress.

- 62% of care recipients have live-in caregivers. The rest have caregivers that live outside the home, or no caregiver at all.
- 57% of care recipients have an adult child or child-in-law as their informal caregiver.
- 80% of caregivers help with instrumental activities of daily living including meal preparation, housekeeping, phone use and medication management. About 40% of caregivers provide "heavier care" such as assisting with eating, personal hygiene, locomotion and toilet use.
- Caregivers of care recipients in the SEC program spend about 22 hours per week on caregiving activities, compared to 10 hours for caregivers of long-stay clients, and 16 hours for caregivers of clients wait-listed for long-term care.
- 30% of caregivers in the SEC program experience feelings of distress, and 73% are unwilling to increase the amount of support they provide to the care recipient.
- 40% of care recipients with very high needs have a caregiver in distress.
- 40% of caregivers caring for an individual with moderate to severe cognitive impairment are distressed.

**Coordinators at focus groups** were asked four questions:

- 1) how they selected caregiver/care recipient dyads to participate in the project,
- 2) how they made decisions regarding the allocation of funds,
- 3) how they would know if the project was successful, and
- 4) what challenges and opportunities presented themselves.

**Key themes** that surfaced during the focus group sessions included:

- 1) **Selection criteria:** In addition to the previously-noted formal eligibility criteria for this project, coordinators considered other factors when selecting caregivers:
  - Limited family support
  - Cultural barriers, particularly language barriers
  - Low income
  - Struggling with mental health problems
  - Recently experiencing an acute episode
  - Caregivers with paid employment, in frail health, in their role for longer than six months, or at risk themselves of entering long-term care or hospital

- Coordinators also emphasized that the 55+ age criteria for caregivers was too rigid as younger caregivers also experience stress and would have been good candidates for the program  
[Note – age restriction for caregivers was removed in January 2012]

2) **Allocation Decisions:** Care coordinators valued the flexibility they were given to work with caregivers to determine how resources could be used to best support the caregiver/care recipient dyad. The project allowed care coordinators a great deal of flexibility in determining how to allocate services and this led to a wider variety of interventions.

When asked about providing cash allowance directly to caregivers (as in the Nova Scotia model), coordinators felt that cash alone might not be the most appropriate solution. They emphasized the importance of engaging in guided conversation with the caregiver. They suggested that the conversation itself had considerable value, since in addition to acknowledging and validating the crucial role of the caregiver, it provided an opportunity to problem-solve, to consider different approaches, and to find solutions that best met the needs of both caregivers and care recipients. Care coordinators also expressed concerns that funds could be abused or poorly spent by highly stressed caregivers, and that in some cases cash could make caregivers and care recipients ineligible for other financial supports such as Ontario Works.

3) **Measuring Outcomes:** When asked what would make this project successful, coordinators suggested:

- *Maintaining the caregiver's current capacity:* It was noted that care recipients in the caregiver project are already at high levels of assessed need and that they are likely to decline as time goes on, with increasing demands and stress experienced by caregivers. Thus success would be measured not by increasing the caregiver's capacity to support the older person, but by simply maintaining that capacity as needs increased.
- *Fewer crisis applications:* While the caregiver project would likely not reduce the number of admissions to residential long-term care (LTC) since cared-for older persons were already at high levels of assessed need, it could reduce the number of crisis admissions. A successful program would therefore delay LTC admissions and facilitate smoother transitions to appropriate LTC when needed.
- *Social, emotional and physical indicators:* To determine success, care coordinators suggested using social, emotional and physical indicators before, during and after the project: Feelings of depression, sadness and frustration are triggers for moving to long-term care, so avoiding such feelings would likely reduce placement. Care coordinators often do an 'off the books' assessment of coping, asking themselves, "how long will this caregiver be able to cope successfully?". They suggested a caregiver burden scale or something similar as an effective and appropriate tool for measuring caregiver distress. Again, care coordinators noted that because caregivers in this initiative were selected because they were already at high levels of stress, with corresponding social, emotional and physical consequences, a good outcome would see caregivers simply maintain their status without further decline.

4) **Challenges and Opportunities Moving Forward:**

- While this project requires significant administrative time, including training, communicating with case managers, gathering and delivering services, and collecting and inputting data, coordinators appreciate the implementation support and rapid turnaround in accessing funds and services.
- The project increases the amount of time each care coordinator spends with the caregiver. While in the long run the project may reduce the coordinator's workload (assuming client resiliency will increase), the project requires considerable work up-front.

- The project has the potential to lead to long-term system savings insofar as the program should prevent crisis applications to LTC and inappropriate utilization of healthcare services due to caregiver burnout.
- A consistent challenge is helping caregivers to focus on themselves and on the services that will help them cope. Most caregivers have difficulty with this as they are so used to thinking about the needs of the care recipient.

## 5.2 Evaluative Interviews with Caregivers

Dr. Mary Chiu of the Reitman Centre for Alzheimer Support and Training at Mount Sinai Hospital, conducted face-to-face interviews with 17 caregivers participating in the project. Her report, dated March 22, 2012, described the effects of the intervention on the caregivers, and identified project limitations, implementation lessons, and research implications.

### About the caregivers

Interviewing caregivers in their homes allowed Dr. Chiu to glimpse the very personal and practical issues that caregivers encounter in their daily lives. The living environment, living arrangement, the emotion displayed, the cultural values, and the unscripted dialogues between them and the person they care for created a powerful, authentic and representative image of what caregiving means.

Of the the 17 caregivers interviewed by Dr. Chiu:

- 16 lived with the person they were caring for
- 12 were spouses (7 women, 5 men) and 5 were daughters of the care recipient
- 9 of 17 caregivers were immigrants, all of whom had been in Toronto for more than 30 years
- 6 care recipients had a movement disorder ( Parkinson's, cerebral palsy, Guillain–Barré syndrome)
- 11 care recipients had Alzheimer's or other dementia
- 2 were bed-ridden

All caregivers commented positively on the professionalism of their respective care coordinators, who were described as great listeners, sensitive and responsive to caregiver needs. All caregivers had been given an opportunity to describe their personal situation and caregiving challenges before the care coordinators introduced the *Caregiver Project* to them.

All caregivers had previously been flagged by their care coordinator as being at 'high risk'. A common theme seems to be their determination to keep the care recipient at home. Most would not relinquish their caregiving role, and would accede to institutional care only as a last result:

*'It would break my heart...'*  
*'I'm responsible for her regardless...'*  
*'I have a promise to honour...'*

### Caregiver stresses

Caregivers are exposed to a wide range of stressors, including strains on the physical, psychological, emotional, social and financial aspects of their lives. All caregivers interviewed by Dr. Chiu experienced one or more of the stressors.

Physical strains related to transfers in or out of bed, bath, wheelchair or car.

*'it's a two-person job but most of the time it's me... and uh... I don't have the stamina I used to...'*

Especially when caring for someone with dementia, lack of sleep saps their energy and caregivers often drag themselves through the day, finding it even harder to cope with the caregiving burden. In addition, most of the caregivers are over 65 years of age, struggling with their own declining health.

Concerning psychological stress, caregivers described the overwhelming list of tasks to be completed, the daily decisions to be made, the round-the-clock care to provide, leaving little or no personal time. Emotional stress might not be relieved by having more personal time, such as a vacation, because caregivers when away are constantly preoccupied with their spouse or parent:

*'to tell the truth, I would prefer to have stayed here because I hate to see her so distressed. I called her every day... and if she tells me that she is ill or whatever, then it's even harder for me...'*

Caregivers lamented the lack of validation and acknowledgement for everything they do and the sacrifices that they make in their caregiving role. *Underappreciated* is a term that many used - underappreciated by other family members, by the spouse or parent they are caring for, by the general public.

For various reasons, many caregivers slowly detached from their social networks, finding less time and energy to connect with friends. One caregiver gave up the pottery classes she loved. Another had to give up choir singing, an activity he enjoyed for over 20 years, because his wife needed him at home.

Financial stresses are never insignificant, particularly in this project where 'financial need' had been observed by coordinators as being present in 97% of cases. But it may not be paramount as a stressor:

*'... the emotional burden is still there. Can it be done away with by the money? I don't know...'*

### **Caregiving styles useful to know in designing the care plan**

Dr. Chiu noted that it is important to know the root cause of the stressor and to set priorities when trying to solve a problem. And to help caregivers develop effective care plans, it is useful for care coordinators to understand the caregiving style of each caregiver, first identified by Corcoran in 2011:

- **Directing** – an overall focus on the physical health of the care recipient, including nutrition, medical routines and hygiene. This is the caregiving style of most caregivers interviewed by Dr. Chiu, especially prominent in spouse caregivers.
- **Facilitating** – focus on the emotional well-being of the care recipient, often achieved by engaging them in meaningful, cooperative activities involving working together, a strategy often employed by daughter caregivers.
- **Advocating** – vigilance about the well-being of the care recipient, and advocacy when problems are suspected. This style is characterized by careful monitoring of care recipient functioning, and little involvement with hands-on care. The high level of vigilance sometimes leads to emotional stress and anxiety for both the caregiver and the care recipient.
- **Balancing** – the least common caregiving style amongst caregivers that were interviewed focused on maintaining balance between the needs of the caregiver and the care recipient, thus preserving quality of life for everyone in the household.

The concept of caregiving styles provides a framework for individualized caregiving interventions, tailored to the unique circumstances, perspectives, and socio-cultural profile of each caregiver-care recipient dyad. Training could incorporate caregiving styles in future, so that coordinators might suggest interventions tailored specifically to support an individual's caregiving style.

### **Resiliency needs to be better defined and measured**

One of the project goals is to "implement individualized care plans to increase the resiliency of the caregiver". Indicators listed in the January 27, 2011 *Mid-term Report* include:

1. quality of care received by the care recipient
2. number of inappropriate visits to ER
3. time required for ALC stays to return home
4. placement in long-term care

Future study may aim to track these indicators, but Dr. Chiu pointed out that caregivers should be the focus when studying caregiver resiliency. Indicators such as the caregiver’s quality of life may be more appropriate in understanding how the project has affect caregivers.

Some effects of the project will only be seen months after it has ended. It might therefore be useful to track and survey caregiver throughout the implementation of the care plan and at the end of the project after the intervention funds have been spent.

**Overall comment based on interviews**

Financial assistance in the form of cash is a novel element of the *Caregiver Framework Project*. But cash on its own is not a complete solution to the complex problems of caregiving. Interventions must be accompanied by careful understanding of the caregiver situation, and thoughtful guidance and monitoring by an experienced coordinator. As the project looks to future development, several demonstration programs in the U.S.A. may be used as reference. One is the *Cash and Counselling* program which is very similar to this *Caregiver Framework* project in that consumers were offered the assistance of counsellors and a fiscal agent. A better infrastructure, clearer role expectation for personnel, and evaluation direction will help make this project even more beneficial for caregivers and the family members they are caring for.

**5.3 Caregiver Questionnaire Responses (See Appendix E.)**

A simple questionnaire is mailed by the project coordinator directly to the caregiver once the care plan is approved and the intervention initiated (i.e. through the purchase of equipment or supplies, the start of a new service or the transfer of funds to the careviger for agreed purposes).

A total of 106 responses (64%) out of 166 Caregiver Questionnaire mailed, have been returned to the project.

Caregiver satisfaction with the project is high, rated 8.9 out of 10 (n=97). Some caregivers reported that they did not respond to the satisfaction question because they had not yet received services or felt there was insufficient time to make an informed assessment. The caregivers who had not yet received services were on wait lists or in the trial stages for services such as adult day programs, housekeeping, short stay respite, etc.).

Respondents described their relationship with the care recipient:

Husband	44
Mother/ Mother-in-law	33
Wife	17
Father	8
Sibling/Neighbour/Friend	4

Respondents identified many common problems in the survey:

- Physical difficulty with transfers such as lifting the care recipient to and from bed
- Competing responsibilities & tasks (watching the care recipient while simultaneously cleaning house)
- Feeling overwhelmed/fatigued/depressed by the need to provide 24/7 care
- Inconsistent availability of personal support workers or poor quality of care provided
- Financial strain of caregiving role

- Inability to find work or compete in the labour market
- Desire to visit family/friends/church or go on outings
- Dealing with their own health problems

When asked what they needed to continue in their caregiving role, caregivers reported:

- More PSW hours from the CCAC
- Continued funding to make necessary purchases
- Additional assistance with:
  - incontinence changes and showering care recipient
  - household duties: laundry, cooking, yard work, grocery shopping, etc.
- “Help with the brief tasks that the support workers from agencies cannot do”
- A desire for counselling to help deal with issues of grief, loss, relationship changes
- Wanting a physician or nurse to make house calls or for lab tests to be performed at home

At this time it is not within the scope of the project to respond directly to the requests made by caregivers in the surveys. Care coordinators are advised of requests where possible, in order that they may follow-up with the caregiver.

## 5.4 Evaluations to Come

A more thorough thematic analysis of caregiver questionnaire responses will be completed by the evaluation team as the project progresses.

The appropriate level of risk for caregivers recruited in the project, and the relationship between project interventions and outcomes cannot be determined at this early stage. At risk caregivers are a group highly vulnerable to extraneous influence. As such, it is more challenging to isolate outcomes directly shaped by the program within the short time frame thus far (6 months). We anticipate that by collecting data at multiple points over a longer time frame, the evaluation team will be better equipped to isolate outcomes.

It is important to keep in mind that for some caregivers, changes to health or finances, or even the relocation of a family member may be a cause for crisis. Crisis situations precipitated by caregiver burnout were dealt with using a variety of interventions. For instance some caregivers placed their care recipient in short stay respite. Still for others, the wait time for a short stay respite was too long (sometimes upwards of 2 months), which meant that the caregiver would need to place the person they were caring for in a retirement home.

The difference in cost between short stay respite (\$ 252/week) and a stay at a retirement home (\$ 880/week) is nearly half the cost of supporting an additional client. However, when faced with no other sources of support or options other than for a caregiver to take the care recipient to hospital, the project decided that either intervention would be suitable. It is the likely result that many of these care recipients will move permanently to long-term care. Outcomes will likely be different between those caregivers who are supported during a period of crisis and also during the care recipient transitions and those who were unsupported. What we hope to find is that supported caregivers suffered less stress than comparable unsupported caregivers.

### Project Design Outcomes:

- **Comprehensive:** Our project pertains to two or more sectors (Hospital, Community Care Access Centre, Community Support Services, Community Mental Health and Addictions).
- **Alignment:** Reflects TC LHIN strategic priorities- *Value and Affordability, Excellent Care for All.*

- **Focus:** Transitions of care (assistance to caregivers during moments of crisis), timeliness of access-funding and services through care plans, effectiveness of the care plan.
- **Valid and Feasible:** Meets requirements as the project has demonstrated success in recruitment and retention of caregivers. Our project team will attempt to link caregivers with care recipient transitions to ALC and ED. One risk is the time lag between assessment, intervention and subsequent transition events (transition to hospital, etc.). In this case we are attempting to do a matched sample based on convenience sampling and therefore causality is compromised.

#### TC LHIN Priority Areas Being Met By This Project:

- ER/ALC- reduce ER demand
- Chronic disease management
- Senior's health
- Equity
- Appropriate management and resource allocation to caregivers providing care to patients with complex high care needs
- Intensive case management through targeted review of current problem profile, development of care plans and assistance with implementation where necessary
- Tracking of inpatient readmission to any hospital within 30 days of discharge for any reason (ED notification tool)
- Tracking of repeat unscheduled ED visits within 30 days for any reason (ED notification tool)
- Caregiver Satisfaction (Evaluations) analysis of themes – (i.e. If a request for house calls is present is this predictive of more ED visits? How does this compare to a group of caregivers without a request for house calls?)

## 6. Phase 2 Pilot Project Goals

Phase 2 of the Caregiver Framework for Seniors Pilot Project started in February 2012 to:

1. **Recruit 125 continuing and 175 new caregivers**, for a **total of 300** caregivers eventually taking part in both phases of the project.
2. **Continue to work with caregivers** to identify factors that contribute to their distress, and develop individualized care plans.
3. **Continue to implement the individualized care plans** (with operational support from the project if required) to relieve distress, mitigate risk and increase the resiliency of the caregiver.
4. **Schedule home visits** with Phase 1 caregivers to:



- a. Ensure that the care plan was implemented and goals were met. Coordinators advise the project coordinator if additional operational support is required for implementation of interventions.
  - b. Assess Phase 2 eligibility and revise current care plan or develop new care plans as necessary.
5. **Distribute questionnaire #2** to Phase 1 caregivers, to assess current level of stress and to determine ongoing level of satisfaction with the project.

## 7. Progress Towards Phase 1 and 2 Project Goals

1. Phase 1 goal of 150 caregivers recruited for the project was met on February 13, 2012.
2. Mount Sinai Reitman Centre, the Alzheimer Society of Toronto, Community Outreach Program in the Addictions (COPA), Les Centres D' Accueil Héritage, St. Stephen's Community House and St. Christopher House care coordinators received training March 12, 2012 and joined as project partners in order to recruit a total of 20 at risk caregivers each from their client roster. These agencies were chosen because of the catchment area they serve and because they are likely to encounter at risk caregivers in the course of their work.
3. Follow-up questionnaires were sent to all 150 caregivers from Phase 1 on March 21, 2012.
4. Feedback from coordinator debriefing sessions was incorporated into the training program to improve the coordinators' sense of ease with the open-ended nature and flexibility of the project, and to give them the confidence they need to respond creatively and to take risks within approved limits.
5. Phase 1 project expenses were carefully monitored and spending was on target. Consultant fees were less than expected. Funds were reallocated to purchase requested items above the \$1500 spending average.
6. Reitman Centre team completed 17 face-to-face interviews with caregivers who have taken part in this project. **The complete report is attached as Appendix B.**
7. Second round of coordinator debriefing sessions are scheduled to begin mid-April to early May 2012.
8. Monthly progress reports are meeting Project Charter milestones.

## 8. Strategic Alignment with Caregiver Framework for Children

### 8.1 Principles of Convergence

Complex medical needs of seniors are diverse; as are the complex medical needs of children. A result is that both caregivers caring for children and caregivers of seniors need care plans that are flexible and tailored to fit their unique situation.

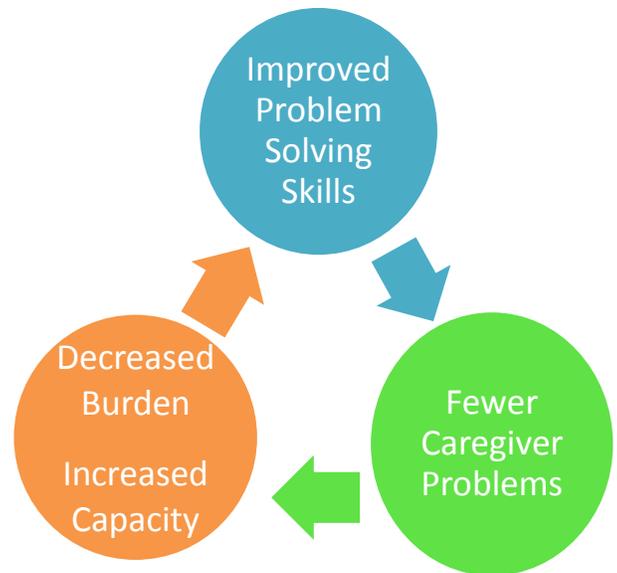
The Caregiver Project recognizes that valuable health care resources cannot be wasted. Right now, the focus is on how to keep people at home and out of hospital. This project poses a short term cost to the system to support caregivers over the course of their participation in the project. This modest investment has the potential to yield larger long term benefits. For instance, through minor home modifications, renovations and

equipment purchases, this project has produced more suitable living environments that support the caregivers in sustaining their care recipient at home.

Supporting the health and well-being of caregivers saves the system money. Caregivers in our project met with specially trained care coordinators to develop a list of problems. From this problem list care coordinators helped caregivers narrow the scope of their problems and identify key goals and clear action plans to meet those goals. Caregivers met with this kind of approach are better able to see and crystallize their problems. Caregivers improved problem-solving skills and increased ability to cope come from the early successes they experience after implementation of the plan.

Seeing the success of the care plan may relieve some immediate problems the caregivers may be facing. Consequently, the caregiver feels decreased burden and increased capacity.

In both the children and seniors' Frameworks, caregivers that are equipped with solutions at hand are better able to cope and continue to care for high needs individuals at home. By addressing the immediate needs of the caregiver by providing respite, relief, and support they are less vulnerable to deleterious health effects of caregiving. Supporting them now may mean that they have fewer health problems that would be very costly to the system later.



Adapted from Brodaty, H. (1996). Caregivers and behavioural disturbances: Effects and interventions. *International Psychogeriatrics*, 8(Suppl 3), S455-458.

## 8.2 Principles of Divergence

The caring role for parents of a child with ongoing complex medical needs can go on for many years well into adulthood and beyond the point where they continue to be eligible for school supports, other childrens' support programs, or benefits tied to parents' employment; also, LTC is usually not a viable or appropriate option for children. In the case of seniors, a shorter trajectory of declining capacity and increasing needs may be anticipated with LTC an option for those reaching the highest levels of need. While caregivers of children and older persons may similarly require support, there is little evidence to suggest that similar approaches will have similar outcomes given that the care needs of medically complex children and older persons may be very different. There are also key unanswered questions about what decision-makers expect from parents, and what they expect of older persons caring for other older persons.

Another difference are the kinds of assessment being performed with care recipients and caregivers of each project. In the seniors' project we use a standardized assessment tool (RAI-CHA/RAI-HC); there is no equivalent assessment tool for children with medically complex needs. Caregivers in the childrens' project are assessed by Key Workers using tools developed specifically for the childrens' project. Their assessment, like the seniors' assessment takes into account the intensity of resources and support required to care for the care recipient, however, the RAI-HC also collects other data which may prove useful for making linkages between the intervention and care recipient outcomes.

## 9. Caregiver Profiles



Jeanette has exhausted every other option. She and her siblings are taking turns to stay with their mother Louisa throughout the day and overnight with the exception of when Louisa attends St. Stephen's day program (4 days a week). Jeanette and her family are unable to afford overnight support out-of-pocket. Extended family have also been recruited to assist, however all members are exhausted by the need to provide continuous overnight care and assistance with transfers to toilet.

In the past few weeks Louisa has had multiple falls and is at very high risk for re-hospitalization. Louisa's coordinator put in a crisis application for long-term care. Meanwhile, the coordinator met with the family to discuss the Caregiver Project. Jeanette requested funding so that she can have a break during the night time hours when Louisa gets up to use the washroom and is at the greatest risk of falling. Until Louisa moves permanently to long-term care, the caregiver project will ensure that the family gets the overnight support they need, this way her caregivers are supported and her risk of falling and returning to the emergency department is reduced.

Sarah brought her mother-in-law, Grace, to live with her and her husband, after Grace was widowed 8 years ago. Grace needs assistance with toileting as a result of Parkinson's disease. Sarah's husband recently lost his job and now the cost of incontinence supplies has become unaffordable. Sarah said: "We cut back to bare necessities and started living on our savings." This has caused a tremendous amount of stress and has put a strain on her marriage. She and her husband worry about Grace getting lost and also report that Grace has had several falls over the last few years. The caregiver project purchased a shower chair and commode to assist Sarah and her husband in transferring Grace to the toilet, and have also covered the cost of incontinence supplies. Sarah says that "things have changed for better since we got help...I don't feel isolated caregiving."



Terumi's husband Jim needs constant supervision. In a typical day Terumi assists Jim with most activities of living. She provides him daily medications and vitamins, but because of a swallowing issue she needs to take the added step of mixing his juice with a thickening agent. Jim also suffers from high blood pressure and diabetes. Terumi specially prepares all his meals and provides him company to ensure that he finishes his food. The fact that Terumi has her own health issues, and that she does not have enough time for herself were the primary problems she presented to her care coordinator. Terumi and her care coordinator decided on taxi chits and additional funds to hire a private caregiver from her church who speaks Japanese to help prepare meals for Jim and to provide him company while she went to her own medical appointments.

## 10. Testimonials (unedited)

Caregivers completed a short questionnaire sent to them by mail which asked their opinion on whether the caregiver project is helping to meet their needs as caregivers. The great majority of responses have been positive.



**Caregiver satisfaction (n = 97)**

**Average: 8.9 out of 10**

Satisfaction Scale

“The Caregiver Project for Seniors is excellent assistance for us. It will help other families who are struggling with their loved ones who are very sick. Please continue this help for caregivers so that the caregivers will have some relief and are able to take care of their health to enable them to take care of their loved ones.” **10 out of 10**

“I know that if I have any questions or concerns I can contact them. Something that has bothered me is when I asked for help before, Mom got worse, like having a senior come and visit her just to talk to her as a friend over a cup, there wasn't anything there for her and that bothered me. There was either a cost or there was nothing in her area. I would like to thank the caregiver program for the help, it is much appreciated.” **10 out of 10**

“An extra day to clean up cellar and garage. We are afraid of falling doing these chores. We can't do them.” **10 out of 10**

“Financial help received toward paying for private care and supplies, has been beneficial but does not cover expenses associated with providing a quality of care at home for loved ones. I feel that keeping my mother with me is the best thing for her. “ **10 out of 10**

“It will help a lot because everything helps. Every bit helps, more hours would be helpful and for a longer period of time.” **10 out of 10**

“I think it is an excellent idea. Provides stimulation for my brother and gives me a break. I get very tired and stressed often. I do not want to burn out.” **10 out of 10**

“The taxi vouchers helped a lot. I had fallen last month (3 times).” **10 out of 10**

“The caregiver project for seniors is very well meeting my needs. Being a caregiver to seniors is not easy but knowing there are supports provided by organizations like yours, CCAC, it helps us a lot.”

**10 out of 10**

“CCAC caregiver support program sponsors my husband going to adult day program twice a week. This will provide good relief for me so that I can have a break. Then I will be able to manage taking care of my husband at night.”

**10 out of 10**



“This is the first time that I'm given the chance to join the Caregiver project for seniors, so far it has been helpful. I've taken three sundays off (8 hours a day) to spend with children and grandchildren. Three nights relief (she feels increasingly weak, sleepiness lately). I wish that the project keep helping because it works. Thank you for chosing me to participating in the project.”

**9 out of 10**

“My needs are met with the 3 days a week adult care and CCAC 14 hours/week- as I have been responsible 24/7 and last had dinner with my husband in August. This additional time for me has made a significant change in my attitude. I can breathe again.”

**9 out of 10**

“I did not know how badly I needed help until CCAC/CBI started sending PSWs to help. A little break.”

**8 out of 10**

“The project will help in many ways to relieve the stress... at the present time, my mind is confused and stressed out.”

**7 out of 10**

“Caregiver project is a unique, helpful and very encouraging for the primary caregiver to have a relief, rest and re-energize to help take care of the person who needed the help most. “

**7 out of 10**

“The help is a great benefit as I also have health issues.”

**6 out of 10**

“More hour is the only thing that I require.”

**6 out of 10**

“It will help to cover some of my expenses and medical equipment expenses, provide more financial.”

**6 out of 10**

“Could use a little more help.”

5 out of 10

“While this is an essential service which I appreciate my hours have decrease while my husband’s needs have increased. His illness is degenerative. The hours provided are taken up in caring for my husband. I have no time for myself. We are at the maximum allotment. 21 hours. 1 each day to get him up out of bed =7, 1 each day to put him back in bed=7. This leaves 7 to spend out intermittently throughout the week or everything else which might occur.”

4 out of 10



“More time to spend off.”

3 out of 10

**Appendix A: Caregiver Framework – Formative Evaluation – Preliminary 2012**

Please see attached PDF.

**Appendix B: Caregiver Support Initiative – Phase 2 Evaluation Proposal – March 27, 2012**

Please see attached PDF.

**Appendix C: Caregiver Framework – Interviews with Caregivers – Phase 1 Final 2012**

Please see attached PDF.

**Appendix D : From the E-Bulletin to be released – Mid-April 2012**

Please see attached PDF.

**Appendix E: Sample project forms**

Please see attached PDF.