

# Community Engagement Survey Summary Caregiver Support Project

January 10, 2009

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 CELHIN, 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 249 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 CELHIN. Response has come from caregiver groups representing CELHIN priority areas of Mental Health and Addictions, Chronic Disease Prevention and Management and Seniors.

Haliburton	Kawartha Lakes	Peterborough	Northumberland	Durham East	Durham West	Durham North	Scarb
10	6	12	26	49	38	21	87

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.

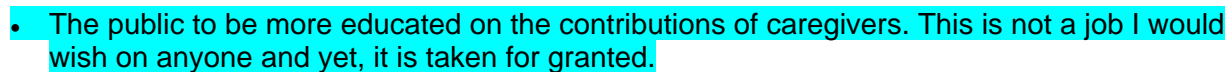
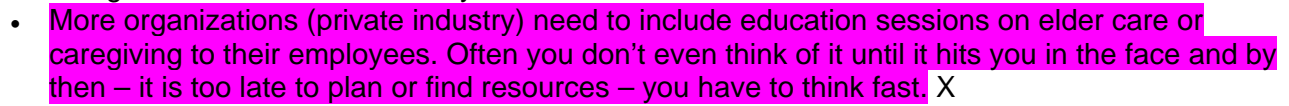
X – indicates this statement is cross referenced under more than one heading.

 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 its 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 am constantly having 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.
- 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. 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 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" or 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

- Somewhere to go where I can get information, education and support. I don't want to go all over town. Can this be all in one spot?
- 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, all improved communication between in home respite workers. It seems that I am constantly having 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 is client assessment not 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.
- Consistent 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 assesment?
- 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 healthcare.
- 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?