

# 2010

## “Conversations about Care”- The Lived Experience



The Ontario Behavioural  
Support System Project

August 2010

Conversations about Care: The Lived Experience  
Ontario Behavioural Support System Project

The Ontario Behavioural Support System project (BSS) is led by the North Simcoe Muskoka Local Health Integration Network (NSM LHIN) in partnership with the Alzheimer Society of Ontario (ASO) and the Alzheimer Knowledge Exchange (AKE) as well as divisions of the Ministry of Health and Long-Term Care (MOHLTC).

More information can be obtained by visiting: [www.bssproject.ca](http://www.bssproject.ca)

The Conversations about Care initiative was created to understand more about the lived experience of caregivers of individuals with responsive behaviours. In spring 2010 over 100 caregivers took part in providing their advice on how the system in Ontario should work best to support individuals with responsive behaviours and their caregivers.



**From One Caregiver.....**

**Conversations about Care: Personal Reflection Handout- Page 2**

IN THE MID STAGES E... WOULD EXPERIENCE  
EXTREME MOOD SWINGS GOING FROM  
CALM QUIET LOVING TO EXTREME VIOLENCE  
ATTACKING ME WITHOUT WARNING.

THE ONLY WAY TO GET THROUGH THIS  
WAS TO TRY AND HOLD HER HAND  
TALK QUIETLY TELLING HER HOW  
MUCH I LOVED HER.

MY ADVISE IS THAT WHEN THE DR  
IS TOLD ABOUT THIS CONDITION BESIDES  
A PILL A REFERENCE TO SOMEONE  
~~WHO~~ WHO COULD OFFER ADVISE WOULD  
HAVE HELPED

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## Introduction

Over the past several years, Ontario's health care leaders have identified the need to understand more about the needs of Ontarians with behaviours associated with complex and challenging mental health dementia or other neurological conditions. These behaviours are often referred to as "challenging" or "responsive" to reflect both their impact and the potential to mitigate their effect with early and appropriate intervention and management.

In January 2010, the Ontario Ministry of Health and Long-Term Care provided funding for the first phase of an Ontario Behavioural Support System Project (BSS). The project team's first task was to propose a behavioural support system based on the best and most current knowledge in Ontario and other jurisdictions. The project's long-range vision is an integrated cross-sectoral system of supports and treatments designed to meet the needs of patients as well as caregivers and based on high quality and evidence-based care and practice. Central to the success of the system is ensuring that people are treated with dignity and respect in an environment that supports safety for all.

To obtain the advice of caregivers with experience with these behaviours, the BSS project team embarked on a process called "Conversations about Care." Caregivers were asked to share their perspectives on the health care system and to contribute their ideas of what the system should do differently to address the needs of both people with behavioural challenges and those who care for them. The messages from the participants in the conversations fall into eight themes:

- ✓ Teach health care workers about responsive behaviours associated with dementia
  - ✓ Improve respite services
  - ✓ Streamline referrals
  - ✓ Fix staffing issues
  - ✓ Address caregiver finances
  - ✓ Provide 24/7 hotline for issues
  - ✓ Educate the public
  - ✓ Share what works!

We will use these conversations to help us to develop a proposal for a new system model. In this report, we are sharing these conversations with you so that we can all work toward a collective vision of a truly inspired health care system.

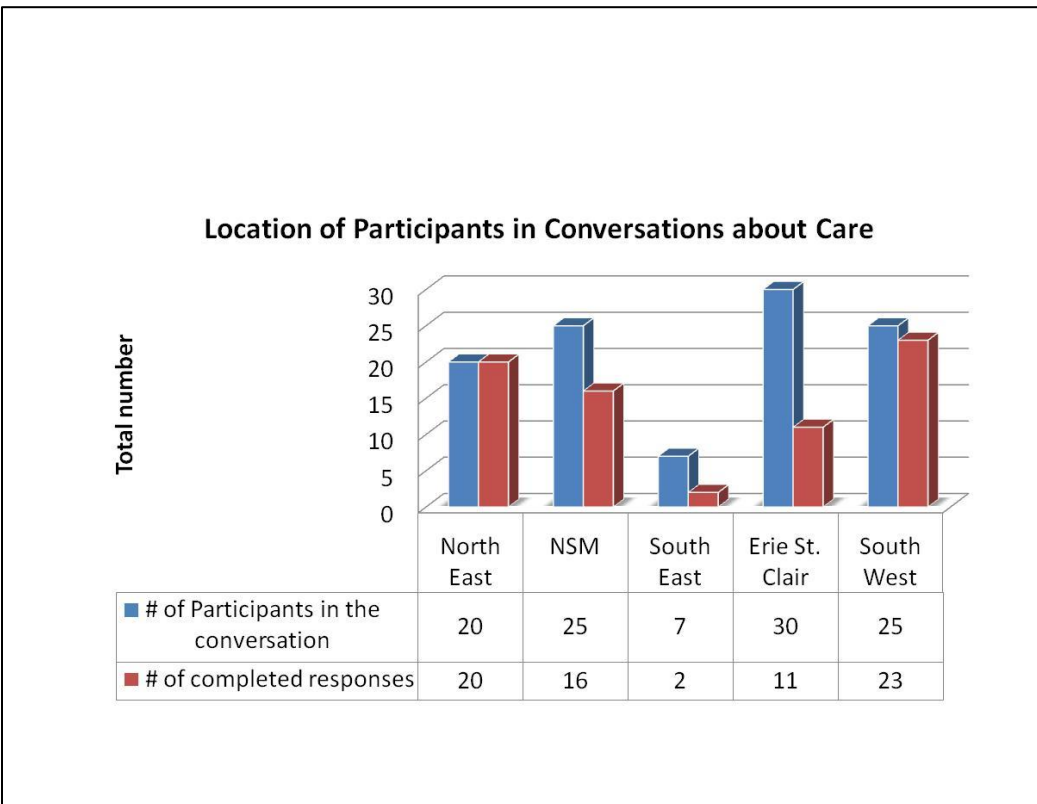
**Results**

**Total responses**

A total of **107** individuals participated in the conversations. **72** written responses were received, some identified as from individuals and some identified as a “group response” summarizing the ideas of the entire caregiver support group.

**Location of participants – by LHIN**

Responses were received from five LHINs and 10 caregiver support groups. Nine groups were from Alzheimer Societies in Ontario and one was from an Ontario Dementia Network.

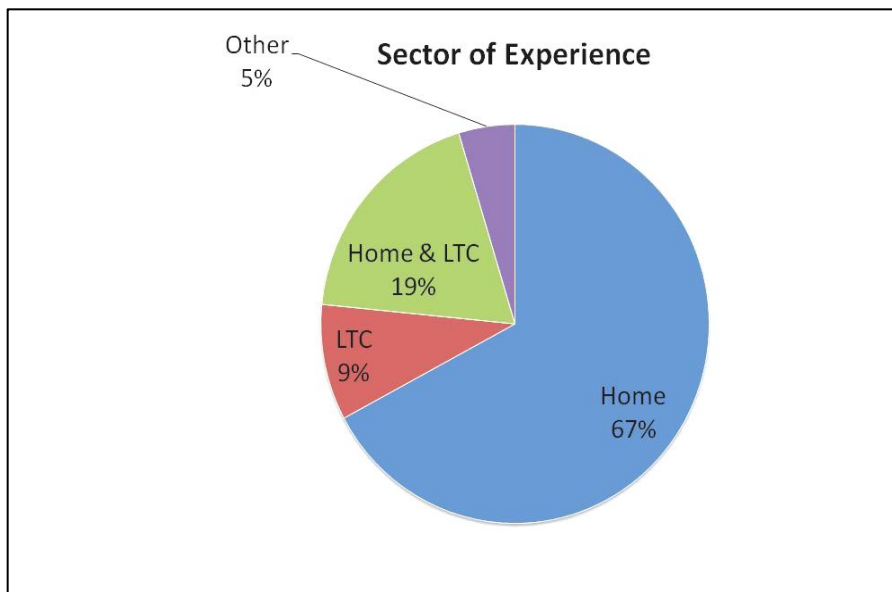


**Type of respondent**

The majority (89%) of respondents described themselves as unpaid caregivers. The remainder defined themselves as paid caregivers and educators.

***Sector of experience with the target population***

Participants were asked where their experience with individuals with responsive behaviours occurred. The majority (67%) stated their experience was in the community (home); 28% had experience with the long-term care sector.



## Key Themes

### ***Theme #1 Teach health care workers about responsive behaviours associated with dementia***

Participants commented that health care workers lacked knowledge in several areas related to behavioural supports.

Family physicians, nurses and other types of clinicians and health care workers were seen to have limited understanding about the signs and symptoms of Alzheimer's disease and related dementias (ARD) and the effect of these on the daily lives of both caregivers and patients.

The impact of this lack of knowledge can be profound. Respondents gave examples from incidents experienced before diagnosis and throughout the progression of the disease.

Long delays in providing a diagnosis were painful for families and patients alike. The universal request was for the clinicians to truly "listen" to what caregivers and patients were saying and experiencing.

As the disease progressed, the respondents identified a need for information about the triggers to behaviours and how to prevent them. Many respondents understood that the behaviours could be managed or prevented but commented that the healthcare workers often were not aware of this critical piece of information.

Other workers with direct contact with patients and caregivers such as police and office staff in long term care residences were also identified as needing more information and education.

*"When at appointments (i.e. ultra sounds, x-rays etc) nurses should be more understanding of dementia. We were turned away because we were 4 minutes too late. My father was very difficult to get there in the first place. Very upsetting."*

*"Doctors need to know more about this disease and its symptoms so that they can catch it earlier and treat it properly from the onset (husband's diagnosis took more than 3 years)."*

*"GP did not listen – said it was normal aging."*

*"Family physicians or family health care teams need to be educated about initial signs of dementia; to listen to seniors when they say that there has been a change in their health."*

*"Caregiver and support workers need information on how to recognize early signs of aggressive behaviors with the person with the illness before the aggressiveness becomes out of hand."*

*"I had my husband at emergency one day and a nurse tried to get his wandering bracelet off. Told her it can't come off. I understand this had happened to other Alzheimer patients – nurses should know this."*

*“Need more flexibility in respite hours. I wanted to attend church but CCAC would only offer respite hours after church.”*

*“More short term respite beds. Why do our loved ones have to be on the CCAC crisis list in long term care before the care givers can get more than 12 hours a month of support? I am worn out!!”*

*“Assistance during the night is essential, the current respite is insufficient.”*

*“I have a problem getting time away because my husband won't let anyone else stay with him.”*

*“Doctors should refer caregivers to support groups.”*

*“It wasn't until the second specialist that the Alzheimer Society was recommended; our own doctor should have done this.”*

*“No one tells you what services are available until you are so tired and frustrated that you cannot cope yourself.”*

*“As soon as a diagnosis is made a referral should be made to groups that can help caregivers.”*

## **Theme #2: Improve respite services**

Participants commented that respite services did not adequately meet their needs. In some instances, it was available, but not flexible enough to meet their schedules and support their day to day living.

One respondent noted that respite was not even possible since the patient was not willing to accept it, even though it was needed by the caregiver.

Comments demonstrated the need to consider the caregivers' expectations when developing policy about respite services and ensuring that rules around availability of respite supported the concept of keeping the patient at home as long as possible.

## **Theme #3: Streamline referrals**

Participants commented they did not receive timely referrals to support groups and other services. In some instances, they felt it was a lack of knowledge that the service was available. They also identified that health care workers did not seem to understand that they all shared a role in suggesting, communicating and referring people to available services.

### **Theme #4: Staffing concerns**

Respondents made many references to staffing issues both in the community and in long-term care settings.

There was frequent referral to the need for more staff or more specifically more time available for staff to spend with people with behavioural challenges, for both prevention and management of behavioural issues.

They also identified the need for consistent staffing as much as possible to reduce the number of new faces and approaches for the patient.

*“More staff on hospital floors so that the professionals have a chance to be more personal with the patient.”*

*“PSW’s don’t have time to learn the specific likes/dislikes of the resident.”*

*“To have an assigned experienced caregiver that can be stable –change of faces is hard.”*

*“Continuity and routine work well – we need the same person providing care.”*

*“More thought to match client with workers. Husband’s PSW could not lift him and were not comfortable being alone with him”*

### **Theme #5: Caregiver finances**

Respondents felt that more financial resources should be available for caregivers to offset the cost of losing time at work and the increased costs of medications.

Several respondents commented on the additional financial burden created when the patient is under 65 years of age and medications and other services may not be covered by OHIP.

*“I would quit my job today if there was funding to keep my mother with me.”*

*“Caregivers need to know what they are signing up for – you give up your income. Friends leave after 2-3 years.”*

*“Downside is the number of years my pension will be affected.”*

**Theme #6: 24/7 hotline:**

Several respondents suggested the need for immediate help when behaviour escalates - 24 hours a day, seven days a week.

*"We need a dementia hotline to help at the moment of the behavior."*

*"24/7 Hotline"*

**Theme #7: More public education:**

*"My wife has Alzheimer's and her greatest complaint is that she feels a lot of her friends have disengaged from her. I feel that system should continue to try and inform the public that this is not a contagious disease."*

*"Information regarding available services should be easier to access and made available for consideration. Workers tend to only offer what they feel is needed and in some instances it is not the best options. We don't know what to request."*

**Theme #8: Find ways to share what works!**

*"My husband has started to talk without thinking – things that are racist or scary. Salesperson "I'd like all your money" I could see panic in the salespersons eye for a fleeting second until I hit my husband in the arm and told him not to say thing like that in public as the salesperson does not know you! My husband thought he was being humorous. I used the humor technique to smooth things over with the salesperson and apologized."*

## Appendix Background and methodology detail

The Conversations about Care initiative was created to understand more about the lived experience of caregivers of individuals with responsive behaviours. To move efficiently and effectively, the team approached existing caregiver support groups for help. Led by the BSS team members from the Alzheimer Society of Ontario (ASO), invitations were sent directly to caregiver support group leads in Ontario Alzheimer Societies as well as to the Ontario Dementia Networks. At the same time, a note in the monthly BSS Project Communiqué invited interested groups to participate. The invitations included a detailed facilitator's guide and an opportunity for facilitators to participate in a teleconference call with members of the BSS Project team to answer any questions and provide clarification.

The project team considered various approaches to gathering the advice from people with lived experience. The chosen approach involved asking one question and then providing time for personal reflection and responses and group discussion. The participants were given a second opportunity to reflect and potentially enhance their responses. The design of the discussion session was simple and flexible to help facilitators fit into pre-existing meeting agendas and was predicted to last between 30 and 40 minutes.

The facilitator's package included details on how to run the session with the following key sections:

The **Welcome and Context** section 'set the stage' for participants to begin thinking a) about the kind of system required to support those with behaviours associated with mental health, dementia or neurological challenges and b) understand the BSS project and how their reflections would be used to inform the project. A one page overview of the project was provided.

The **Opening Reflection** gave participants an opportunity to provide a brief yet comprehensive look at their best advice for the 'best possible care system.' Participants were informed that their participation was totally voluntary and the information provided to the team would be anonymous and summarized without attribution in project publications. Once they agreed to participate, each participant was asked to consider their response to the following question and document their initial thinking on their "Personal Reflection Handout." The handout also gave participants a chance to provide basic information about their experience with responsive behaviours and their own status as a caregiver.

*"Please take a moment to think about your experience with the health care system in relation to your relative/client with behavioural issues. Consider what worked well, what didn't work well and share with us what advice you would give someone who is trying to create a system that would meet your needs. Perhaps a particular event comes to mind that triggered a behaviour and you have an idea that could have avoided the behaviour, its duration or intensity"*

The **Discussion** gave participants an opportunity to hear from the experiences of others, including those shared through provided case examples. After hearing from their peers, the participants may have gained further insight into what they would like to see in the Health system that supports those with behaviours associated with mental health, dementia or neurological challenges.

The **Closing Reflection** gave participants an opportunity to make revisions or additions to their ideas based on the insights gained from the dialogue that just occurred.

The facilitators were also asked to provide basic information including: number of participants, number of completed Personal Reflection forms and the LHIN location.