

Ontario BSS Project-Phase 1 "Keeping you in the know"

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Focus on the Lived Experience

Hot off the press! We have just recently received the results of our Conversations about Care initiative and would like to share them with you.

You may recall that over the last few months individuals in caregiver support groups have been asked to provide us with advice about what they

feel would be important for an ideal Behavioural Support System in Ontario.

Their ideas and suggestions will be discussed as the BSS Model is developed.

Soon we will post a report outlining the results in more detail on the BSS website. In the meantime,

please take a look at the highlights provided in this month's communiqué.

The ideas of the people in the field are critical to ensuring the model is grounded in what is important to the community we are trying to serve.



Conversations about Care- advice from caregivers

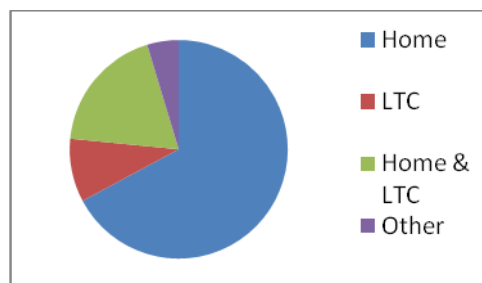


The BSS Project team has designed an approach called "Conversations about Care" to hear from the individuals, families, health care providers and caregivers who are living the experience day by day.

Over the last several months facilitators of caregiver support groups were approached by the Alzheimer's Society of Ontario and asked if they would be willing to participate. Each group was given a participant's package and members were asked to provide their advice on how to make our system work better to meet their needs.

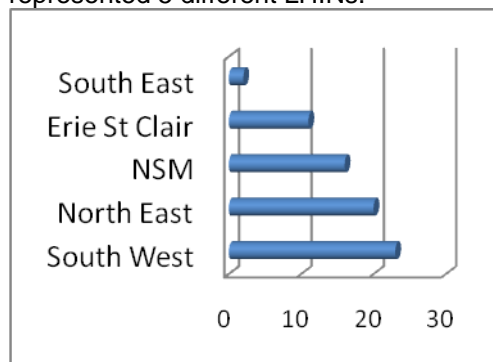
A total of 107 people participated in the conversations and 72 individual and group responses were received.

Participants were asked to share the location of their experiences with individuals with behavioural challenges. Many had experience with more than one location.



The majority of participants described themselves as unpaid care providers, but a small number of paid care providers participated as well.

Results came from across the province and represented 5 different LHINs.



Ontario BSS Project- Phase 1

Do you have questions or comments?

Send them along to:

E-MAIL:

bss@alzheimeront.org

We're on the Web!

See us at:

www.bssproject.ca

Alzheimer Knowledge Exchange



Alzheimer Society
ONTARIO



Summary of Key Suggestions from the Field

Respite Services: Increase hours of respite and the flexibility of respite hours

Education: Increase knowledge of ADRD signs and symptoms for GP's, Staff need to learn the history of ADRD residents

Streamline Referrals: Simplify but ensure comprehensive communication of community services available to people impacted by dementia, Refer to the Alzheimer Society earlier

Finances: Financial resources be made available to offset the cost of losing time at work and increased costs of medications and other expenses related to ADRD,

Staffing: Increase staff in nursing homes (time to learn about resident, reminders to eat, time to bathe, consistent supervision etc.), Keep staffing consistent (new faces are difficult)

Offer a hotline for crisis call 24/7

In their own words.....

From family members:

- ✓ *"In the mid stages (my wife) would experience mood swings going from calm quiet and loving to extreme violence attacking me without warning. The only way to get through this was to try to hold her, talk quietly telling her how much I loved her. My advice would be that when the doctor is told about the condition that besides a pill a reference to someone who could have offered advice would have helped."*
- ✓ *"I have not had any problem with our health care clinic/ hospital. Only 1 situation, 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."*
- ✓ *"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. A lot has been done but a lot more needs to be done."*

From Staff:

- ✓ *"The personal support workers who are front line workers do not know anything about their client with dementia because they do not have access to that info. When I look into the residents charts that registered staff often write incident as behavior and no appropriate action to intervene. We have to have knowledge when we work in a locked unit. My advice... learn to know the history of your patient hopefully it will be accessible to our front line worker. Share with the other workers what intervention was successful and what you should avoid."*

In Short:

Behavioural Support System Model- We would like to express our sincere thanks to the members of the Virtual Advisory Panel who took the time to review the draft model. They have provided invaluable advice and their comments are informing the next draft.