

Ontario BSS Project-Phase 1

“Keeping you in the know”

Individual Highlights:

Moving Forward Together 1

Grounding the Work in the Lived Experience 1

A Conversation With Joy Greenleese 2

Inventory of Projects next steps 3

Virtual Advisory Panel 3

In Short 3

Moving Forward Together

In this month’s issue we are taking the opportunity to update you on a number of activities designed to engage key project stakeholders.

The project is embarking on an important piece of work- engaging clients, caregivers and others who can ensure that our work is grounded in the lived

experience of those we intend to serve.

In order to help in this task, the newest member of the BSS Project Leadership Team Joy Greenleese shares a portion of her story as a caregiver. Joy will continue to provide advice and expertise as a member of the Leadership

Team and we appreciate her wise counsel.

As well, we update you on the Virtual Advisory Panel and the next steps on the very important Project Inventory.



Grounding the work in the Lived Experience- “Conversations about Care”

There is an opportunity for the Ontario BSS Project to provide leadership in expanding the view of behavioural supports systems; to unearth and clearly illustrate the systemic challenges experienced by the person, their families and health care providers; and mobilize the evolution of a strengthened health care system in the context of the behaviours associated with complex and challenging mental health, dementia or other neurological conditions.

We plan to engage existing community groups in “Conversations about Care” where, through a simple process, participants will be able to:

1. Share their perspectives on the health care system and how well its various components work together to support people with behavioural challenges; and

2. Contribute their ideas of what we all might want our health care system to do differently for this population.

Existing community groups would include, for example, caregiver support groups, mental health outreach teams as well as others.

We hope to be able to leverage knowledge from the lived experience of those involved in care to consider all perspectives and create a collective vision of a truly inspired health care system.

With permission from participants, information from these sessions will be collected and shared so that we can learn from those who have first-hand experience.

The conversations will be led primarily by facilitators from the Alzheimer Society of Ontario chapters. However, a discussion guide is currently in development that can be used by others who would like to host one of these conversations.

If you currently host, facilitate or participate in a survivor, caregiver, or care provider group and are interested in hosting a “Conversation about Care” please contact the Ontario BSS Project office at: bss@alzheimeront.org

Further information to come!

A Conversation with Joy Greenleese

Some moments have a way of imprinting themselves in the mind. Often they are moments of trauma and shock. They store in the memory like photographs – snapshots in time. I'll never forget the moment I took the phone call that told me my husband was dying.

Barry died last October, but I have no idea when I lost my husband. One day, he came home just a little less the man he was than when he left the house in the morning. That was the day I lost him, but I don't know its date. He didn't know either, of course, so he didn't say goodbye. He just went away, by tiny shreds, as if he unraveled, one thread at a time.

But it was so gradual that the change in his fabric was almost imperceptible, especially at first.

When dementia sets in, others compensate for the growing disability. You pick up more of the responsibilities and more of the load. You become a caregiver before you even realize what you're doing. And one day, you look back and wonder how you got to where you are.

Barry and I went through many challenges together as his disease progressed and although I am able to negotiate the system and get what I need, I have to tell you that when it came to getting services in place for my husband, I was overwhelmed and lost.

Quite apart from needing to find services, I was grieving the imminent loss of the love of my life who was, in every sense of the word, the ideal partner to me.

Despite all the challenges, I think the problems we ran into both at home and in LTC were systemic, and generally the professionals and programs we dealt with were excellent.

For example, at home I had trouble accessing respite care when I needed it. Because Barry went downhill so quickly, it was difficult to anticipate when it was going to be needed. I couldn't get transportation to get Barry to and from his day program, so I had to drive him myself. This included rushing from work to get him during what was supposed to be my lunch break.

The transition to long term care was also a challenge. You have to guess when the person is going to need it. One individual told me that it either comes too early or too late. I had to facilitate a crisis admission in order to ensure that he would get a bed before I totally collapsed.

Throughout the process of caring for him, I was constantly in a state of concern. I never knew if what we needed would be there when we needed it.

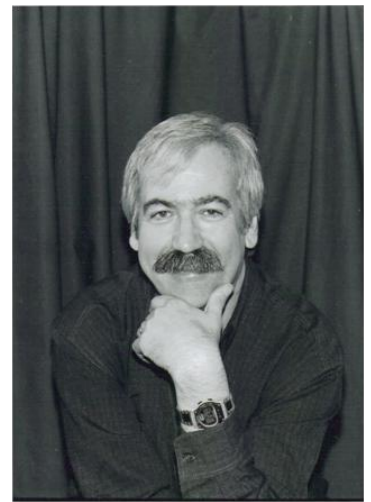
Barry became quite anxious, suspicious of the intentions of others and no longer had the ability to contain his responses. As the disease progressed, his usual calm demeanor changed and he became more impatient, angry and dramatic.

Humour was the best way to negotiate these problems but it didn't always work. Medications were used to try to solve the situation but these weren't always effective and the cost of medications was also an issue, again because of Barry's age.

Alzheimer disease (AD) is, essentially, the biggest problem-solving project I've ever been involved with. It tests your reserves to the limit. It expects you to be patient and giving and receive nothing in return.

But AD also had its back-handed gifts. I learned to live in the present and adjust my expectations to the abilities of others. I learned who my real friends were, and they were awe-inspiring. I learned that a sense of humour is indispensable. I learned that I had great reserves of strength I didn't know were there. I learned that most of the things we get upset about aren't that big of a deal.

And that I got lucky and married a great guy, because there is no covering it up when Alzheimer's comes along.



Barry Benness

"You become a caregiver before you even realize what you're doing."

Joy's husband Barry died in October 2009 at the age of 58. Three years earlier he had been diagnosed with early onset Alzheimer disease. Joy has kindly shared a portion of their story in this article.

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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



North Simcoe Muskoka Local
Health Integration Network
Réseau local d'intégration
des services de santé de
Simcoe Nord Muskoka

BSS Inventory of Projects – Next Steps



The first phase of the inventory of BSS projects was completed on March 22nd - many thanks for those of you who took the time to enter proposed, ongoing or recently completed projects. We have some wonderful information and contacts for a varied group of

projects.

We have decided to keep the inventory link open for the duration of the project so please feel free to continue to post your ideas. We will continue to update the list.

The results thus far have been posted on the www.bssproject.ca site.

Some folks have commented that they aren't sure if their ideas or approaches fit the "criteria" for the inventory. Please try not to feel constrained by the

structure of the survey and add whatever you feel would be important for the project team and your colleagues to learn about- be sure to include contact information!

If you have submitted a project and feel that there is an error in the content please send an email to bss@alzheimeront.org and we will make the correction.

Again many thanks for your efforts and continue to share your innovative ideas!

Virtual Advisory Panel

We would like to express our thanks to those of you who have volunteered to be members of our Virtual Advisory Panel. To date we have 41 volunteers from a variety of roles, settings, sectors and backgrounds.

You will each be receiving a communication soon which will be your confirmation that we have received your contact information. Our plan is to

provide you with opportunities to review some of the draft products of the project and have built in this into our timelines.

It is never too late to volunteer since each time we send out an opportunity to review we will use the most updated list. So if you are interested and have not volunteered yet the link is on the www.bssproject.ca website.



In short...

- The BSS Project Team is pleased to announce that it has engaged The *Distance Learning Group Inc.* to create the proposed BSS Model. The team will include Scott Dudgeon and Patti Reed who both have strong experience and interest in the area.
- *Remember-* keep moving forward with your projects and initiatives! We are learning together so don't wait for us before you get started.
- *A Network of LHIN Leads* have been identified- stay tuned for more information on their role in supporting the project