

“Developing a Self-Management Program for People Living with Dementia”- Environmental Scan

The following is the second in a series that will look in detail at the CIHR-funded research project “Developing a Self-Management Program for People Living with Dementia” led by Dr. Elaine Wiersma of Lakehead University and David Harvey of the Alzheimer Society of Ontario. The research project, which has benefitted from the partnership and support of both the Alzheimer Societies of Ontario and BC, will be completed in multiple phases and will form the basis for the development of a self-management program for people living with dementia.

The first phase of the “Developing a Self-Management Program for People Living with Dementia” research project involved the completion of an environmental scan of dementia research, online resources, existing programs as well as other self-management resources for other chronic conditions. This environmental scan took place during the summer of 2012, and most of the information provided came from 26 health service providers, most of them affiliated with the Alzheimer’s Societies of Ontario and BC. These educators, facilitators, and administrators are already working with people who are living with dementia, and provide intake and support groups, develop education, facilitate workshops, deliver public education, and provide numerous other services and supports for people living with dementia as well as their caregivers and family members.

The environmental scan focused specifically on trying to understand certain factors that might either facilitate or act as a barrier to successful programs for people living with dementia. Key findings emerging from this work focused on the following:

- **“Fit”** was a common theme in trying to determine the appropriateness of the person attending the program, related to the progression of his or her dementia.
- **“Flexibility”** was described as central to encouraging group participation and providing a safe space that allows for adjusting to what comes up in the group, who they are that day, where they are at, and how they are functioning, or feeling that day.
- **“Boundaries”** were also discussed as challenging in balancing and meeting the needs of both the person living with dementia and their care partners in the group.
- **“Transitioning”** those that may no longer be appropriate for a program is seen to be very challenging for staff.
- **“Feeling Connected & less Alone”** were recognized as fundamental for people living with dementia who attend programs.

- **“Stigma”** was felt to be a significant issue in accessing services.
- **Key Successes !!!** encompassed the development of bonds and social connections where people feel understood and accepted, and core messages are shared that support individuals in finding a way to build on the skills that they already have and put strategies into place in their lives.

A key takeaway from the environmental scan was the importance of promoting empowerment in people living with dementia. Empowerment in this sense served dual purposes; one being to counter the stigma associated with living with dementia by being honest and open about it, and the other to remind those living with dementia that through the development of their self-management skills, they can still live well with dementia.

Taking into account all of the above, the environmental scan provided the researchers with a number of excellent best practice guidelines to consider as they are developing the content and delivery method of the self-management of dementia program.