

## **Self-Management Program for People Living with Dementia- General Overview**

*The following is the first 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's 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.*

Dementia is increasingly becoming a subject of discussion and debate within governments, the media, and the general public the world over. Various studies are reporting that with the increase in an aging population across the world over, a simultaneous increase in the number of people diagnosed with some form of dementia will occur. The 2010 Rising Tide study predicts that by 2038 1,125,200 Canadians will be living with dementia, the equivalent of 2.8% of our population. This research evidence highlights the importance of developing a well-researched, authentic, effective self-management program to improve the lives of those who are currently living with dementia, as well as preparing for those who will one day be diagnosed.

While self-management programs have been successful in chronic disease prevention and management, (for example, with people living with diabetes), very little has been done to develop a self-management program for people living with dementia. The recent CIHR-funded research project "Developing a Self-Management Program for People Living with Dementia", led by Dr. Elaine Wiersma of Lakehead University, has started the process of developing a self-management program directed by researchers, health care representatives, the Alzheimer's Society and perhaps most importantly, people living with early dementia and their care partners. The goal of the "Developing a Self-Management Program for People Living with Dementia" project is to develop, implement and assess a self-management program for persons with early dementia based on previous research, current practices in the field of dementia care, and the perspectives and input of people with dementia, partners in care and families, and health care providers.

The research is using participatory action research (PAR). PAR is understood to be a research methodology that aims for change in the lives and practice of those involved, respecting local knowledge and the lived experiences of people, and focusing on action. While research in dementia has often focused on clinical interventions for people with dementia and their care partners, engaging people with dementia in the development of services and programs is novel and innovative. By including the experiences and inputs of people living with dementia, it allows for a self-management program that will actually work for those individuals, their caregivers, and all of those people who are personally or professionally affected by dementia. The research has been occurring in the following phases:

- An environmental scan of dementia research, online resources, programs and other self-management resources (summer 2012)
- Interviews with 26 health service providers working with people living with dementia to understand more about successful programs (summer 2012)
- Focus groups in Ontario and BC with people living with dementia to understand more about successful programs (summer-fall 2012)
- Advisory hub meetings in Thunder Bay, Waterloo, and Vancouver where people living with dementia, care partners, and health service providers provide input into the content and areas for inclusion into the self-management program (fall 2012-spring 2014)
- Curriculum development that is given to the advisory hubs to review and comment on (winter 2014)
- Piloting the program in three sites and providing opportunities for the participants to comment on the content and structure of the program (spring 2014)
- Finalizing the program (late spring 2014)
- Developing resources and guidelines on engaging people living with dementia authentically and effectively (late spring 2014)

We will be sending out communications on a regular basis about the findings, development, and key learnings from the research. Future plans involve exploring how to engage people living with dementia as peer leaders to support others in their dementia journey, making use of the collaborative model used in phase one. The research team will explore how to develop guidelines, opportunities, support and training for people with dementia to be peer leaders. The research team believes that the peer leaders will play an integral role in the final delivery model developed for the self-management program for people living with dementia.