

Developing a Self- Management Program for Dementia



Integrating Research, Care Practices and Client Perspectives through Partnerships

Meet the Research Team

The research team consists of diverse partners - with specific expertise and experience who have a vision to see people with dementia have the opportunity to direct their care and decisions of their lives and who are committed to finding ways to enhance the quality of life of people with dementia and their care partners.

The research sites include Vancouver, B.C., Kitchener-Waterloo & Thunder Bay, ON.

About the project

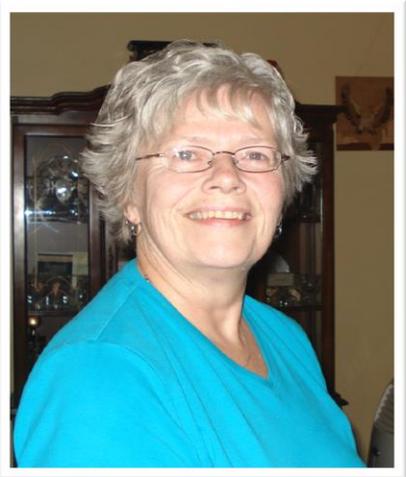
The goal of the study is to accelerate the translation of knowledge into action by developing a self-management program for people living with dementia, and examining the process whereby people with dementia and other knowledge users are involved in the program development process.

Personal Advocates



Bill Heibein

Bill was diagnosed in January 2000 at the age of fifty-nine with early-onset Alzheimer's and, after a thirty-eight-year career in accounting, retired. He and his wife Heather, continue to own and operate "Amethyst Farms", under which name they have bred, trained and shown registered Quarter Horses. As he has for the past thirty-seven years, Bill continues to play bass with the popular local swing and dixieland band "Bottom of the Barrel." He is involved with both the Thunder Bay and Ontario Alzheimer Societies as a spokesperson and Champion for Dementia and was a member of the planning committee for the International Changing Melody conference held in Toronto during March 2011.



Brenda Hounam

In April of 2000 at the age of 53, Brenda was diagnosed with early onset Alzheimer's disease. Brenda worked as a registered industrial accountant. She has been an active volunteer with MAREP. Since 2003, she has served as a member of the planning committee for *A Changing Melody*. She assisted with the development of an online education tool which is housed on the Alzheimer's Research Exchange website. In 2006, Brenda was involved with the new educational DVD produced by MAREP entitled, "Breaking the Silence – Giving voice to persons with dementia", and assisted with the development of the Dementia Care Education Series on CD-ROM, an interactive education tool for front-line staff in long-term care facilities. Brenda spearheaded the development of the *By Us For Us Guides* written by persons living with dementia.



Jim Mann

Jim was diagnosed with Alzheimer's disease in February 2007 at the age of 58. He is now an advocate utilizing his experience and expertise in the business and volunteer sectors and as a care partner for his mother who also had the disease. He is an active volunteer with an emphasis on Alzheimer's and related dementias. Nationally, Jim is a board member of the Alzheimer Society of Canada where he is also co-chair of the public policy committee, and is also a member of the Board of Directors, Canadian Dementia Knowledge Translation Network. In BC, Jim is on the board for the provincial Alzheimer Society and a member of its advocacy committee, and is a community advisory committee member with Centre for Research on Personhood in Dementia.

Principal Investigator



Elaine Wiersma,

Elaine is an Associate Professor in the Department of Health Sciences, Lakehead University, Thunder Bay, ON, Elaine's research is focused on dementia in three main areas: self-management and dementia, aging and dementia in rural northern communities, and dementia care. Elaine is the lead for the division of Dementia and Geriatric Mental Health, Centre for Education and Research on Aging and Health (CERAH), and the Program Coordinator for the Interdisciplinary Dementia Studies Certificate at Lakehead University.

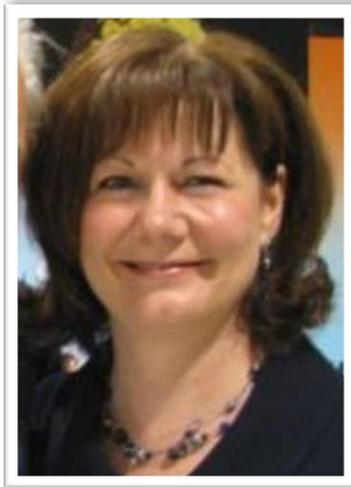
Principal Knowledge User



David Harvey

David is the Chief Public Policy and Program Initiatives Officer with the Alzheimer Society of Ontario. In this role, David leads the Alzheimer Society of Ontario in influencing public policy change to secure improved and targeted care for people living with dementia and their families. David also co-chairs the Alzheimer Knowledge Exchange (AKE) that serves the broad dementia community in Ontario.

Researchers



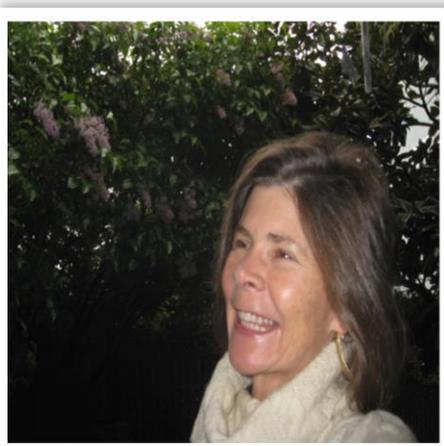
Sherry Dupuis

Sherry is the Director of (MAREP), and a Professor in the Department of Recreation and Leisure Studies at the University of Waterloo. Guided by an *authentic partnership* approach and a number of years experience working in long-term care, Sherry's research program has focused primarily on identifying ways to improve the quality of the lives of persons living with dementia and their families and to ensuring that the voices of persons with dementia and their partners in care are represented in research, education, and practice. She is also interested in exploring creative approaches to research and alternative representations of research results that make research findings more accessible and more effective in shifting images, understandings and actions in dementia care.



Mary Lou Kelley

Mary Lou is a Professor of Social Work and Gerontology at Lakehead University and professor at the Northern Ontario School of Medicine, Thunder Bay, ON. Her work focuses on promoting interdisciplinary research and interprofessional education in gerontology and palliative care for health care professionals nationally. Her research expertise is in community-based and applied health services research, using ethnographic and participatory methods including techniques such as photovoice. Her current projects focus on developing palliative care programs in rural communities, long term care homes and First Nations communities. . In 2011 she was co-chair of the OMHLTC committee that worked to create a vision for palliative care system integration in Ontario research.



Deb O'Connor

Deb is a social worker by profession. Her work in the area of dementia has had three main foci: understanding the experience of living with dementia; exploring family care and the use of support services; and developing person-centred, relational approaches for assessing decision-making capacity. She is the founding Director of the Centre for Research in Personhood and Dementia (CRPD)— an interdisciplinary research centre located at UBC - and a Professor in the School of Social Work, UBC .

Researchers continued....



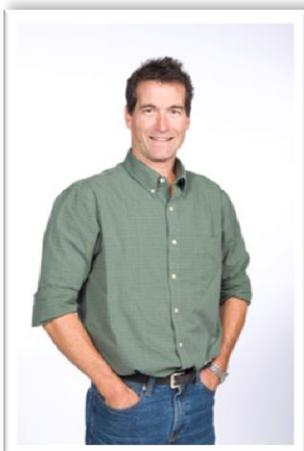
Carrie McAiney

Carrie is an Associate Professor in the Department of Psychiatry and Behavioural Neurosciences at McMaster University and is the Director of Evaluation and Research for the Geriatric Psychiatry Service at St. Joseph's Healthcare Hamilton. Carrie has been conducting research on dementia for over 15 years. Her focus is on enhancing care and support for individuals living with dementia and their family members, and improving the quality of work life for staff involved in their care. She was the lead researcher on the evaluation of the First Link™ Programs in Ontario and Saskatchewan .



Ken LeClair

Ken is Professor and Chair of the Division of Geriatric Psychiatry, Queen's University and Co-Chair of the Centre for Studies in Aging and Health, Providence Care, an affiliate of Queen's University. His major interests have been in learning and development, knowledge exchange and health service delivery models for older persons with complex health care challenges with associated behavioural, mental health and cognitive disorders in terms of the development, dissemination and delivery of new knowledge to inform policy and practice. He is the Scientific Co-Lead of the Canadian Dementia Knowledge Exchange Network (KT Division), and co-chairs the Alzheimer Knowledge Exchange of Ontario.



Michel Bédard

Michel is a Canada Research Chair in Aging and Health and is a Professor in the Department of Health Sciences and the Northern Ontario School of Medicine at Lakehead University. He is also the Director of the Centre for Research on Safe Driving at Lakehead University, and Scientific Director, St. Joseph's Care Group, a rehabilitation hospital network that provides services to older adults. Michel's main research focus is on aging, with a particular interest in automobile driving, family caregiving, and mental illness. His work on driving was the basis for the Canada Research Chair award he holds, for a Premier's Research Excellence Award (PREA) he received in 2002 from the Province of Ontario, and for the R K Dewar Medical Research Award, he received in 2003.

Researchers continued....



Lisa Loiselle

Lisa Loiselle is the Associate Director of Research for MAREP, the Murray Alzheimer Research and Education Program, a major division of the Schlegel-UW Research Institute for Aging at the University of Waterloo. Her educational background includes an undergraduate degree in Psychology from Brock University and a Masters degree in Community Psychology from Wilfrid Laurier University. Since 1999, she has been conducting research which focuses on the social critical aspects of Alzheimer Disease and related dementias, with the goal of translating the research results into practical, accessible way in which to educate persons with dementia, partners in care and professionals working in the field of dementia care.



John Puxty

John is currently an Associate Professor, Chair, Division of Geriatric Medicine, Dept. of Medicine, Queens University, and Director of the South East ON Regional Geriatric Program. He is co-Director of the Centre for Studies in Aging and Health at Providence Care. He is an experienced academic geriatrician who has an extensive list of publications and academic presentations. He has special interests in the development of eldercare services, and the use of information technology both as an aid to learning and strategies for effective knowledge and information transfer.



Shannon Ferguson

Shannon graduated from Lakehead University in 1993 with a BA majoring in Psychology, and returned in 2010 to study Gerontology and complete an Honours Degree. I will begin studies this fall in the MHS program and plan to conduct research in the Gerontology field. I have spent many years working in emergency services which has greatly contributed to my interest and concerns in ageing and health and prompted my return to University for further education in this area. I will be involved in the Self Management of Dementia Program as a research assistant.

Knowledge Users



Kathy Hickman

Kathy is an Education Manager for the Alzheimer Society of Ontario and led the design of the Society's Frist Link Learning Series for people living with early stage dementia and their care partners. As a Certified Dialogue Education Teacher, Kathy used this approach to create a learning experience for this group. Kathy has also worked as a Knowledge Broker with the AKE since 2009, facilitating communities of practices including psychogeriatric resource consultants, supporting family caregivers, primary care, health care consent, advance care planning and self-management in dementia. She supports these groups to identify and capitalize on successful practices and to assess and address areas of need through knowledge exchange and transfer activities.

Kathy Kennedy

Kathy has over 30 years of management and service delivery experience in health and social services organizations. She has developed and implemented numerous educational and support programs for such diverse groups as parents, women in abusive relationships, hospice patients and caregivers, as well as designing and facilitating training programs for staff and volunteers. Since 2000, Kathy has been with the Alzheimer Society of British Columbia. As the Director of Programs & Services, she is responsible for the development and delivery of the Society's province-wide educational and support programs for individuals and families living with dementia.



Alison Denton

Alison became the Executive Director of the Alzheimer Society Thunder Bay, in June 2009 and was able to together her front-line experience in long-term care, her academic interests and her experience in non-for-profit management. She has also been able to pursue teaching and has been a part-time lecturer at Confederation College for the last ten years teaching Sociology, and teaches various courses for the Women's Studies Department, Lakehead University. Alison enjoys reading, hiking, kayaking and walking her dog.

Knowledge users continued....



Jennifer Gillies

Jennifer Gillies is Executive Director for the Alzheimer Society of Kitchener-Waterloo and Cambridge. Jennifer earned a BA, MA, and PhD from the University of Waterloo's Department of Recreation and Leisure Studies. She earned a second MA from York University's Critical Disability Studies. Jennifer worked with the Murray Alzheimer Research and Education Program for seven years while completing her PhD and later as a Postdoctoral Fellow. Jennifer has expertise in Participatory Action Research and is interested in working collaboratively to create accessible and inclusive environments that promote engagement, empowerment, and self-determination.

Project Manager



Ruth Wilford

Ruth Wilford is an Education Planner with the Centre for Education and Research on Aging and Health. As such, she helps to plan and facilitate educational programs for formal and informal care providers of older adults with mental health needs. This work is done in collaboration with many local, regional and provincial partners of CERAH. Ruth is also the project coordinator for the Thunder Bay Age Friendly Project as well as the co-chair of the Caregiver Support Committee

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