

PiDC Team Pilots Newly Revised “CARE Profile” Tool

The Partnerships in Dementia Care Alliance (PiDC), led by Dr. Sherry Dupuis, Director of MAREP, and Dr. Carrie McAiney, Psychiatry and Behavioural Neurosciences at McMaster University, has initiated a large-scale project that seeks to shift the culture in long-term care (LTC) and community-based care settings. The project aims to encourage and support a relationship-centred/partnership approach to care, with a focus on persons living with dementia, their family members, and staff working collaboratively in those settings.

The study unites over 50 partners representing an alliance of key stakeholders to facilitate and assess culture change using an Appreciative Inquiry approach integrated with the Alzheimer Disease and Related Dementias Planning Framework. To date, Culture Change Coalitions (CCCs) made up of persons with dementia, family members, and staff have been established in one LTC home (see article on page 2) and in one community-based setting. These CCCs are responsible for all decision-making related to the change process at each site. Two more will be established this fall.

To track changes over time, we found an existing tool called the Combined Assessment of Residential Environments Profile (CARE Profile), which was co-developed by Michael Nolan, the creator of the relationship-centred care philosophy. Originally used in LTC homes in the UK, three versions of a 30-item questionnaire explore the experience of care for residents, family, and staff in those settings.

To ensure the relevancy of the questionnaire in the context of this study, we worked with our CCC partners and consulted with some of the original creators of the tool to

develop two modified versions: one that reflects the Canadian LTC home context and one that is relevant to the Canadian community-based care context. This process involved:

- critically reflecting on the original items in the CARE Profile in light of the relationship-centred care philosophy
- ensuring that the items are accessible/understandable and relevant to the Canadian context
- critically reflecting on the original items in light of the community care context
- exploring a range of ways to support the involvement of those living with dementia
- determining the best way to present the items and selecting the most appropriate response categories

The review process has been exciting and very interesting. For example: Is it appropriate to develop strong, caring relationships with residents in dementia care? We found that we needed to critically reflect on notions of relationality in LTC and will continue to do this as we move forward.

MAREP is currently piloting the revised CARE Profile in the LTC home context throughout Ontario. Pilot sites include Waterloo, Kitchener, London, Guelph, Kingston, and Barrie. Data gathered will be used to determine reliability and validity, and will provide insights into modifications needed in the final version as well as the use of the tool in decision-making.

Piloting of the community-based version will likely take place next spring. MAREP is looking to connect with organizations offering community-based dementia programs and supports within the Kitchener, Waterloo, Cambridge, and Guelph areas that may be interested in taking part in the pilot study. If your organization would like to help, and/or you would like to hear more about the PiDC Alliance, please contact Dr. Jennifer Gillies at jljgillies@uwaterloo.ca or at 519-888-4567, ext. 36884.

Fall 2011: Volume 10, Issue 2

2 ... PiDC Celebrates Launch of First Culture Change Coalition

3 ... Welcoming Jessica Luh Kim and Zara Rafferty

4 ... The L.E.A.D. - MAREP Partnership

Partnerships in Dementia Care (PiDC) Alliance Celebrates Launch of First “Culture Change Coalition”

Bloomington Cove Specialty Care of Stouffville, Ontario, a long-term care facility devoted exclusively to dementia care, officially launched its partnership with MAREP on the Partnerships in Dementia Care (PiDC) Alliance Project on August 16, 2011. Currently serving as one of the project’s Culture Change Coalitions, Bloomington Cove has been working with MAREP and the PiDC Alliance since January.

The PiDC project unites researchers from five universities and 50 partners at the regional, provincial, and national levels representing all key stakeholder groups in dementia care including persons with dementia, family members, staff at all levels, policy makers, community organizations, and a multidisciplinary team of co-researchers and students. The project’s goal is to facilitate sustainable culture change in long-term care and community-based settings that reflects a relationship-centred/partnership approach to care and support (see article on page 1).

The official launch was celebrated with a wine and hors d’oeuvres social at the Bloomington Cove long-term care facility. Residents, family members, staff, and community members were invited.

Janet Iwaszchenko, Administrator for Bloomington Cove, offered the following words as part of her opening remarks: *“We see this partnership as an opportunity to work under the guidance of Dr. Sherry Dupuis and MAREP’s team in achieving the study’s goal of facilitating a culture change reflective of a relationship-centered approach. It has always been my view that quality care can only be achieved through working with all of one’s stakeholders.”*

A highlight of the launch was the support shown by local MPP, Dr. Helena Jaczek (Oak Ridges-Markham), who openly shared her experience of a relative with dementia. She said that although she comes from a medical background, this personal experience enabled her to better understand that needs extend beyond the medical.

Lois Cormack, President of Specialty Care, also showed her support for the work of the Alliance and Bloomington Cove by attending the launch.

Dr. Sherry Dupuis presented Ms. Iwaszchenko and Bloomington Cove with an award acknowledging their involvement in the PiDC Alliance. Dr. Dupuis expressed her appreciation for Bloomington Cove’s commitment to the project:

“We would like to express our excitement in having Bloomington Cove Speciality Care as a partner and official research site in the PiDC – one of four research sites that have been chosen from across Ontario. Since establishing the Culture Change Coalition here at Bloomington Cove, made up of residents, family members, staff representing various positions and levels in the organization, and MAREP researchers, Bloomington Cove has demonstrated time and time again their commitment to enhancing the care experience for all in this community. We have been particularly impressed with the willingness of so many in this community to volunteer precious time to work with us in planning a way forward for Bloomington Cove that builds on its existing strengths and assets and creates a culture that has strong relationships at its core.”

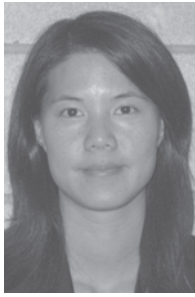
Dr. Dupuis also noted that as the Canadian population continues to age, more and more people will be diagnosed with an illness causing dementia. It is estimated that, by 2034, over one million Canadians will have some form of dementia. Many of these people will require support from community services and long-term care homes.

Dr. Dupuis observed, *“In the not-so-distant future, there will be few of us not touched in some way by dementia.”* This demographic trend demonstrates the urgency of the PiDC Alliance’s work; it also underlines the importance of innovative partnerships between research groups and progressive long-term care homes like Bloomington Cove.

... as more and more Canadians are diagnosed with an illness causing dementia, innovative partnerships between research groups and progressive long-term care homes like Bloomington Cove Specialty Care will become increasingly important ...



Jessica Luh Kim — Associate Director of Education



We are delighted to welcome Jessica Luh Kim back to the MAREP team in a new role.

Jessica has had a passion for working with older adults since the late 1990s. The seed for this passion was first planted when, as a teenager, she volunteered in a long-term care facility in the Niagara region. Inspired by the many meaningful interactions she had with the residents at the facility, including persons living with dementia, Jessica decided to focus her educational and professional career in the chronic care and long-term care field.

Jessica began her career path by earning an undergraduate degree in Gerontology and Psychology at McMaster University followed by working both in the community (e.g., VON Halton, Alzheimer Society of Peel) and in the long-term care field (e.g., Region of Peel Homes). During this time, Jessica became interested in learning more about facilitating opportunities for meaningful experiences for the older adults in her care. To deepen her knowledge, she undertook a Graduate Diploma in Therapeutic Recreation from Georgian College.

After working in long-term care for some time, Jessica decided to pursue a Masters degree in Recreation and Leisure Studies from the University of Waterloo to enhance her understanding of the needs of ethnic older adults living in the long-term care context. Her experiences at the university and her work with Dr. Sherry Dupuis led her to become part of the MAREP team from 2002 to 2006, first as a Research Assistant, then as a Research Associate. She worked on a number of MAREP's research and educational projects, including:

- Ontario Dementia Caregiver Needs Project
- Institution-Based Caregiving Across the Caregiving Career
- Gentle Persuasive Approaches in Dementia Care Evaluation
- Understanding Responsive Behaviours in Long-Term Care Settings – Phases I to III
- Family Transitions
- *A Changing Melody* Forum
- Managing and Accommodating Responsive Behaviours
- Gentle Persuasive Approaches in Dementia Care – Certified Coach
- MAREP Education Series and CD-ROM

Leaving MAREP in 2006, Jessica worked in the chronic care industry, developing and offering educational workshops and training on best care practices related to chronic care medical devices, and managing projects and client accounts. Now, after a number of fruitful years in chronic care, Jessica has rejoined the MAREP team as Associate Director of Education.

Jessica is very excited to continue working with the wonderful MAREP team and alongside persons living with dementia, family care partners, formal partners in care, community and long-term care organizations/facilities, and policy makers to pursue her passion: *to enhance the understanding of dementia, to listen and give voice to the perspectives of persons living with the illness, and to enhance best care practices.*

Zara Rafferty — Knowledge Translation Specialist



We are pleased to announce that Zara Rafferty has joined the MAREP team as our Knowledge Translation Specialist. In this role, Zara's primary responsibility is to develop tools and resources for the Partnerships in Dementia Care Alliance (PiDC) project, funded through the Social Sciences and Humanities Research Council CURA (Community University Research Alliance) Program, which focuses on changing the culture in long-term care to improve the care experience for persons with Alzheimer's disease or a related dementia, their family members, and care staff (see article on page 1).

Since beginning her position in August 2011, Zara has attended the partnership launch of the Bloomington Cove Culture Change Coalition (see article on page 2), and is currently working on developing the PiDC Alliance website and newsletter.

Zara has a longstanding relationship with the University of Waterloo as both a student and staff member. She completed both her undergraduate and Masters degrees in the department of Recreation and Leisure Studies. During her undergraduate years, Zara spent time as a Volunteer Companion for the Kitchener-Waterloo Alzheimer Society. Her Masters thesis focused on the experience of inclusive arts practitioners; Dr. Sherry Dupuis served on her committee.

Zara left UW briefly to complete a Bachelor of Education at Wilfrid Laurier University. After graduation, Zara returned to UW and spent a year teaching undergraduate courses in the Department of Recreation and Leisure Studies. Prior to joining the MAREP team, Zara was working as an e-Learning consultant for UW's Information and Systems Technology Department.

“Leisure, Empowerment, Achievement, Dignity” Demonstrating Partnerships in Dementia Care Work



In 2008, the L.E.A.D. (Leisure, Empowerment, Achievement, Dignity) program at the John Noble Home in Brantford, Ontario, was established. This program aims to improve quality of life for individuals who have started the journey related to short-term memory loss by offering friendship, entertainment, laughter, fellowship, conversation, and togetherness.

Led by Carol Howarth and Lisa Hayes, the program runs once a week and incorporates a support group component, a recreation program, and supper. How the program is run and what activities are offered is determined by the members themselves, helping them to maintain an optimal level of physical ability, intellectual function, and social interaction.

Over the past decade, MAREP has worked to develop partnerships with persons with dementia, family members, and professionals using an “authentic partnership approach” that views persons with dementia as equal partners in care and support. This approach includes them in decision-making regarding the design of programs and tools meant for them.

As partners of MAREP, the L.E.A.D. members at John Noble have been directly involved in many of our projects. Serving as the advisory committee for the Recreation Resource Guide project, the L.E.A.D group worked with us to gain a better understanding of the meanings of leisure for those living with memory loss and to use that knowledge to create “Living and Celebrating Life Through Leisure” – the sixth guide in the By Us For Us series, written by persons with dementia for persons with dementia. Members of the L.E.A.D. Program were present at the *International A Changing Melody Forum* to launch the new guide, which was published in March 2011.

The group has also contributed to the development of our education tools by acting as graphic consultants, reviewing research tools, discussing research results, and being profiled in a new MAREP video on Authentic Partnerships in Dementia care.

MAREP is honoured and proud to call the members of the L.E.A.D. program our partners. We have learned so much from their experiences and we appreciate their willingness to share their stories so openly. Without the contributions of the L.E.A.D. members, and other partners with dementia, we would not be able to do the work that we do...*nothing for them, without them!*

For more information about the L.E.A.D. program, please contact Carol Howarth at chowarth@jnh.ca.

Kenneth G. Murray Alzheimer
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MAREP

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Innovations: Enhancing Ability in Dementia Care is published quarterly by MAREP, an innovative program that adopts a partnership approach and integrates research and educational activities in an effort to improve dementia care practices in Canada and beyond. The goal of MAREP is to enhance the ability of all involved in dementia care, including persons with dementia, their family partners in care, and professional care partners, to respond to the needs of persons with Alzheimer’s disease and related dementias and ultimately improve the quality of life of all those experiencing dementia.

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This newsletter is designed to provide accurate information. Although the information presented and the opinions expressed are gathered from sources thought to be reliable, their accuracy and correct interpretation cannot be guaranteed.

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