Incorporating the Philosophy of Responsive Behaviours into LTC


As the first in the country to challenge dominant and stigmatizing assumptions about, and approaches to, behaviours in the dementia context, MAREP’s research program on behaviours has had a significant impact on provincial policy. MAREP’s responsive behaviour language and philosophy have been adopted and incorporated in recent revisions to the Long-Term Care Home Act through the LTC Bill 140.

Words, gestures, and actions may be used to express important aspects of one’s personal, social, or physical environment. To represent how their actions, words and gestures are a response, often intentional, to something important to them, persons with dementia originated the term Responsive Behaviours (RB). RBs adhere to the following principles:

1. All personal expressions (words, gestures, actions) have meaning.
2. Personal expressions are an important means of communicating meanings, needs, and concerns.
3. Care partners require a multidimensional lens that seek understanding of others’ expressions.

Rather than the current focus on pathology/disease as the root cause of all actions, words, or gestures, a multi-dimensional lens/approach helps partners in care develop a broader and more comprehensive understanding of what the person with dementia is subjectively experiencing, which personal expressions they are communicating, and how best to offer compassionate support.

In other words, RB philosophy requires and encourages care partners (both professionals and family) to:

- focus on understanding the meaning of personal expressions (words, gestures, actions)
- understand the layered nature of personal expressions:
  - individual/personal level: subjective experience of the physical body, cognition, emotional experiences, spirituality, and cultural beliefs
  - social environment: the nature of caring and interpersonal relationships and broader cultural issues, e.g., organizational policies and practices
  - broader physical environment: built environment, temperature, lighting, heating, layout, etc.
- develop skills in active listening, be truly present, and use alternative ways to communicate
- be open, non-judgemental, and compassionate

In addition to adopting MAREP’s definition of RB, the Ontario government has recently invested $40 million in funding and in-kind resources to enhance services and supports in each of the 14 Local Health Integration Networks (LHINs) across the province as part of the Behavioural Supports Ontario (BSO) initiative (www.akeresourcecentre.org/BSOAbout). BSO aims to improve the lives of Ontarians with behaviours associated with complex and challenging mental health, dementia, or other neurological conditions who live in LTC homes or in independent living settings. Each LHIN is working to apply quality improvement strategies to inform tailored and local plans of action. MAREP currently supports Waterloo Wellington LHIN’s action plan.

For more information regarding MAREP’s definition of RB, please refer to www.marep.uwaterloo.ca. For additional educational support regarding RB, please contact Jessica Luh Kim at 519-888-4567, ext. 36880, or jluh@uwaterloo.ca.
Update on the Partnerships in Dementia Care (PiDC) Alliance

Over the next several issues of Innovations, we will provide updates on the PiDC Alliance project. This issue features each of the four Culture Change Coalitions (CCCs) and highlights their recent accomplishments.

What is a CCC?
Established in long-term care (LTC) and community care settings with representation by persons with dementia, family members, staff, researchers, and students, the CCC makes all decisions related to the culture change process.

Bloomington Cove Speciality Care
Culture Change Coalition

Bloomington Cove Specialty Care is a 112-bed LTC home in Stouffville devoted exclusively to dementia care. The Fall 2011 issue of Innovations highlighted the official launch of this CCC’s partnership with MAREP on the PiDC Alliance project. Currently in the Discovery phase of the Appreciative Inquiry (AI) process, the Bloomington Cove’s CCC is gathering positive accounts of the care experience from residents, family members, and staff. The coalition is working with the family and resident council to run focus groups in which family members and residents can identify Bloomington Cove’s strengths, suggest ways to enhance the care experience, and plan strategies to more fully engage family members and residents in the Bloomington community. The CCC has also distributed the CARE Profile (also highlighted in the Fall 2011 issue of Innovations) to residents, family members, and staff in order to better understand the care experience from a variety of perspectives. Information booths and presentations to family council have helped engage the community in the process and showcase the valuable work of the CCC.

Huron County Culture Change Coalition

The Huron County CCC comprises clients with dementia, their family members, researchers from the University of Windsor and MAREP, and community care representatives from the South West Community Care Access Centre, Saint Elizabeth, the Alzheimer Society of Huron County, and ONE CARE - Home and Community Support Services. Currently planning activities to discover what is positive about their current home and community care services, the CCC will subsequently move into the Dream phase of AI in which they will imagine even better possibilities for the future. The Discovery process, which will take place in May 2012, offers a variety of ways for clients, family members, and staff to share their positive experiences of community care, including discussions, questionnaires, phone interviews, and home visits. The CCC is currently brainstorming ways to engage the larger Huron County community in their AI process.

Yee Hong Centre for Geriatric Care

Yee Hong Centre for Geriatric Care is a 200-bed LTC home that serves older adults with various cultural backgrounds including Chinese, South East Asian, Filipino, and Japanese descent.

Yee Hong formed a CCC in January 2012; it is in the initial stages of the AI process, now called the Dawn phase, in which the CCC is working to establish strong, trusting relationships among members that will set the foundation for a positive culture change initiative.

The Village of Wentworth Heights

Part of Schlegel Villages, the Village of Wentworth Heights is a 120-bed LTC home in Hamilton. Schlegel Villages recently underwent the initial phases of the AI process through an organization-wide culture change initiative, including the development of six aspiration statements. Each village has created its own Village Advisory Team (VAT) responsible for designing strategies to implement three of the aspiration statements.

The Village of Wentworth Heights VAT is our fourth culture change coalition. In 2011, this village distributed the CARE Profile to residents, family members, and staff to better understand the care experience from a variety of perspectives. Wentworth Heights is looking forward to working collaboratively to enhance its care experience.

Stay Tuned!
Each CCC provides a unique perspective. We have had opportunities to reflect on and map out the process with each of our CCCs. We look forward to seeing what each coalition will discover and aspire towards, and we will keep you informed on their development.

For more information, including contact details and the new PiDC newsletters, please visit www.pidc.uwaterloo.ca. For up-to-date reports and related articles, please visit our new blog at http://pidc-alliance.blogspot.ca.

The PiDC Alliance

The purpose of this project is to change the culture within LTC and community care settings to better reflect a relationship-centred/partnership approach. The PiDC Alliance focuses on improving the care experience and support for persons living with Alzheimer’s disease or a related dementia, their family members, and staff working in those settings.

We ensure the involvement of all key stakeholders in the culture change process.

We focus on the experiences of all involved in the care context.

We incorporate the voices of all involved in dementia care in all decision-making in the culture change process.

We use appreciative inquiry to uncover and work towards new possibilities in dementia and LTC.
MAREP is pleased to announce a new By Us For Us (BUFU) guide titled Food & Mealtime. As the second guide in the Partnership series, which incorporates the experiences of persons with dementia and family partners in care, Food & Mealtime follows the inspirational guide titled Living and Transforming with Loss & Grief.

Creation of this guide was made possible through the Eating Together Study led by Drs. Heather Keller, Sherry Dupuis, and Lori Schindel Martin, which was funded by the Social Sciences and Humanities Research Council.

Food is an essential part of living — it allows the body to function well. Whether shopping, preparing meals, or going to eat at a restaurant, it is important to acknowledge and accept changes around food and mealtime for both persons with dementia and partners in care. This guide presents strategies for adapting to the changes associated with living with dementia that are specific to this crucial aspect of daily life.

A valuable addition to the eight previously published BUFU guides, Food & Mealtime was developed by a dedicated group of individuals with dementia and family partners in care. Individual copies and bulk orders can be purchased online at www.marep.uwaterloo.ca. A PDF copy can also be found on our website.

For more information regarding the BUFU guides or other MAREP products, call Jessica Luh Kim at 519-888-4567, ext. 36880, or contact her by email at jluh@uwaterloo.ca.

Food & Mealtime: Another New Publication in the Partnership Series

food & mealtime

An inspirational guide for persons with early-stage memory loss and their partners in care

Living with Dementia:
Resources for Living Well

MAREP presents a new web-based tool that offers information and resources to persons with dementia and their family partners in care. Searching for current and reliable information is easy! Everything is collected in one place.

Created by persons living with dementia, family members, and professionals working in dementia care, this website is intended to help enable those diagnosed with dementia and their families to live well and prepare for the road ahead. Four key areas have been identified by persons living with dementia:

- health care
- living well
- care and support
- planning ahead

Want more information?
Call 519-888-4567, ext. 35040
“It is wonderful that everything you need to know about the disease is right on one website”
— person with dementia

www.livingwithdementia.uwaterloo.ca
Kim Gellatly: Portrait of a Partner

I was introduced to MAREP back in 2008. I had little formal knowledge of dementia, but what I did have was a great deal of experiential knowledge from caring for and supporting my father who had Lewy Body dementia. As a family, we did not pursue a great deal of community support and information. I think we were just overwhelmed and struggling to manage on our own.

Our journey was a difficult one. My father’s hallucinations were the most challenging aspect, and responding to the behaviours related to the disease became a daily stressor. We too began to change as my father’s behaviour changed, and it was at this point that I realized we were all in this journey together.

It was only after my father’s death that I realized I had been through a very profound experience, yet I was just starting the process of understanding it. I had approached dementia at the end and was working my way to the beginning by first living the experience, then accessing research, support, and community contacts afterward.

MAREP was one of my first contacts in this process of understanding. I was invited to join the core committee, working with Brenda Hounam and four others on the first By Us For Us guide in the Partnership series, Living and Transforming with Loss & Grief. After completing this project, I continued to participate by lending my experiences and my artistic abilities to the Before/Early Diagnosis guide and to the subsequent covers for the Partner in Care series.

The desire to apply my experiential knowledge led to my attending MAREP’s 2011 international A Changing Melody forum. As part of this event, I helped construct an art installation candle called “This Little Light of Mine.” Audience members were encouraged to share messages, words, or phrases of hope and resiliency that provide a “light” for them in their lives. As the day progressed, the candle grew in intensity and the collective voice of all those who had put their thoughts to paper was a powerful sight. It was a visual reminder of their solidarity in continuing to live their life fully and with purpose.

MAREP represents a valued partnership in my life and in the community. I continue to use and promote MAREP’s resources and educational tools as a means for eradicating stigma, and to promote further compassion, awareness, and support for partners in care and individuals living with a diagnosis of dementia.