



Volunteer Award Honours Ken Murray

As Ken Murray's first spouse, Helen, began her journey with Alzheimer's disease at age 60, so began Ken's journey as a dementia advocate and founder of the Murray Alzheimer Research and Education Program. In celebration of Ken's 85th birthday, MAREP hosted a special community event on October 26, 2009.

In 1992, Ken's personal experience as a partner in care lead to a discussion with the dean of the University of Waterloo's Faculty of Applied Health Sciences. A year later, he made a generous personal contribution and pledged to raise \$400,000 to support a research and education initiative. He wanted to ensure that research would be translated into practice, thereby enabling optimal care and support of persons with Alzheimer's disease and related dementias. And the rest is history! The Alzheimer Research and Education Project (AREP) was launched. In 1998, the project was renamed the Murray Alzheimer Research and Education Program (MAREP) to honour Ken's continued contributions.

MAREP's director, Dr. Sherry Dupuis, noted, "MAREP is improving the lives of so many persons and families with dementia because of Ken's vision and his willingness to give so generously not only of his money but his expertise and, most importantly, his time. It is because of Ken's dream that we are changing the face of dementia using our authentic partnership approach. With the help of so many persons with dementia and their partners in care we have demonstrated to the world that people with dementia have an enormous contribution to make to their own care and the care of others."

On the occasion of Ken's milestone birthday, an award was created to celebrate the vision and leadership he has given MAREP since its inception. The Kenneth G. Murray Partnership in Dementia Award will be presented annually to a person living with dementia and to a family partner in care who have made significant contributions to MAREP and its initiatives.

"Ken is such a tireless advocate for the dementia cause and his award will recognize others who give of themselves to enhance the lives of those experiencing dementia," observed Sherry. She continued, "Our authentic partnership approach would not work if it were not for the many, many persons living with dementia and their family partners in care who, over the last several years, have been so willing to give of their time to become actively involved in our work. Partnering on research and education projects can be challenging enough for anyone, but the challenge is compounded so much when faced with an illness causing dementia. Yet despite these challenges, we have been blessed by so many who have given so much of their time and themselves to our work."

Ken presented the inaugural awards to Brenda Hounam, a person living with dementia, and Ken Hancock, a family partner in care (see details on page 2). He commented, "I have been involved now in this project for the last 15 years. It is wonderful what we have accomplished. But it has been accomplished only because of a whole host of dedicated people who continue to try to find the answer to how we can enhance the quality of life of persons with Alzheimer's disease and other related dementias. I guess, God willing, I will be at it for another 10 or 15 years."

Following the awards presentation, Vancouver resident Cathie Borrie delighted the audience with a moving account of her experiences while caring for her mother during her journey with Alzheimer's disease. This event also served as the platform for launching the sixth guide in the By Us For Us series, *Living and Transforming with Loss & Grief* (see story on page 4).

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Brenda Hounam: Living with Dementia

A single mother of two, Brenda Hounam worked as a registered industrial accountant. In April of 2000 at the age of 53 Brenda was diagnosed with early onset Alzheimer's disease.

Since her diagnosis Brenda has been an active and dedicated volunteer with MAREP. She began her service as a member of the planning committee for *A Changing Melody* in 2002. She has also played a role in developing an online education tool that is now housed on the MAREP website.

In 2006, Brenda was involved with the release of another new educational tool, a DVD produced by MAREP titled *Breaking the Silence - Giving Voice to Persons with Dementia*.

She also helped develop the CD-ROM titled *Dementia Care Education Series*, an interactive tool for front-line staff in long-term care facilities.

Brenda conceived the idea for a series of guides written by persons with dementia, for persons with dementia. She was instrumental in developing the series, appropriately titled *By Us For Us*. Currently, Brenda sits on the Dementia Diagnosis Resource Kit committee.



Ken Hancock: Partner in Care

University of Waterloo graduate Ken Hancock is a professional engineer. His wife, Tuula, was diagnosed with Alzheimer's disease in 2001 at age 54.

To facilitate homecare for Tuula, Ken relinquished his management position at Queen's University where he had worked for 36 years and reduced his work hours. He later chose early retirement to optimize care and reduce stress. Tuula passed away on April 10, 2008, after almost two years in a long-term care facility.

Ken recently became a co-facilitator for a new men's support group formed through the Kingston Alzheimer's Society Chapter. He remains active with the family council at Specialty Care Trillium Centre and with the Regional Family Council Network. Ken has been a member of the planning committee for *A Changing Melody* since 2003, and more recently joined the planning committee for the *A Changing Melody* forum in Kingston. He is currently working with us to develop a *By Us For Us Partner in Care* series to complement our *Persons With Dementia* series. Ken also participates in the Alzheimer Knowledge Exchange Design and Dementia Community of Practice.



Happy Holidays from everyone at MAREP!

Enhancing the holiday season for persons with dementia: for helpful tips for family partners in care and professionals working with persons with dementia, please visit the MAREP website at <http://marep.uwaterloo.ca/other/>

We are grateful for the generous contributions from our many friends — November 2008 to November 2009

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Mobilizing Authentic Partnerships

“This approach values me as a person and the contributions I can make to dementia care, to my own care. This approach stops the exclusion of persons with dementia by actively including us and our family members in our own care and in the process of developing our care plans.” ~ *person living with dementia*

Over the past several years, MAREP has worked to develop partnerships with persons with dementia, family members, and professionals with the goal of enhancing the well-being of all those involved in the dementia context and promoting the abilities and contributions of persons with dementia. Drawing on our direct experience and on systematic research that looked at a number of partnership initiatives, MAREP has developed an Authentic Partnership Model, one that views persons with dementia as equal partners in the context of dementia care, support, and formal services.

An authentic partnership actively incorporates and values diverse perspectives and includes persons with dementia, partners in care, and professional partners directly in decision making. This approach:

- recognizes how persons with dementia have been silenced and how they can harness their collective capacity to empower themselves
- seeks to work in partnership with others to promote equality and social justice
- views knowledge as power, and education and learning as vehicles for social change
- challenges expert knowledge by acknowledging the lived experience of our partners
- incorporates critical reflection and dialogue

It is this partnership approach that has provided MAREP with a moral compass in developing its tools and education resources. By capturing the partnership process, we hope to share with others this alternative approach to working with all those affected by dementia.

Thank you to our donors who have funded the development of knowledge translation tools so that we can share research with those who need it!

New knowledge often does not on its own lead to widespread implementation or impact. We can bridge the gap between what we know and what we practice by actively including those on the margins — such as persons with dementia, family members, and professionals — in the research process and working with them to translate research into effective tools.

A pioneer in partnership approaches in dementia care and knowledge translation, MAREP has developed many tools that have had enormous influence on raising awareness, expanding understandings of dementia, and enhancing the well-being of those whose lives have been touched by Alzheimer’s disease and related dementias.

New education tools created (and in progress) in 2009/2010, funded through generous donations, include:

- new **By Us For Us (BUFU)** guide – *Living and Transforming with Loss & Grief*
- new **BUFU** series for family partners in care
- **Recreation Resource Guide** – providing information to family care partners, activity professionals, and volunteers about supporting and enabling meaningful leisure experiences
- **Ontario Age Friendly Communities** – developing a web-based toolkit that will enable cities to create age-friendly communities
- **Dementia Diagnosis Resource Kit** – working with persons with dementia, partners in care, professionals, and physicians to determine information needs of persons with dementia and their families at the time of diagnosis, and to develop a prototype for a resource kit that family physicians can distribute upon diagnosis

Our donors – our partners who are helping us make a difference in dementia care!

2010 Wish List

Although MAREP is committed to several projects in the new year, with secured funding we could also begin work on the following initiatives:

- developing a new play on intimacy and enhancing relationships in dementia care
- producing a French-language version of *I’m Still Here*: the play, the DVD, and the teaching-learning guide
- working with persons with dementia, family members, and professionals to complete, publish, and duplicate the Recreation Resource Guide
- developing a new By Us For Us guide related to engaging in meaningful leisure activities
- translating all of our By Us For Us guides into French
- reproducing and distributing the Dementia Diagnosis Resource Kit

If you’re interested in supporting any of these projects, please contact Meredith McGinnis, Director of Advancement, at 519-888-4567, ext 33631, or at meredith@uwaterloo.ca.

A New BUFU Guide

On October 26, 2009, the sixth guide in the By Us For Us (BUFU) series was launched. *Living and Transforming with Loss & Grief* aims to guide readers through the ebbs and flows of loss and grief to a place of acceptance, peace, and hope. A practical resource, this new guide provides useful tips and strategies.

The five original BUFU guides were developed out of the desire and necessity of persons with early-stage dementia to access information that would help them enhance their well-being and manage daily challenges. In response, a dedicated group of individuals with dementia created the project. What makes these guides particularly useful is that they are created BY persons with dementia FOR persons with dementia. This tremendously successful series has had a huge impact on people with dementia, family members, and professionals all over the world.

Publication of this sixth guide marks a transition for the BUFU series because it incorporates the experiences of family partners in care. Loss and grief are felt not only by persons with dementia but also by their family members. This guide acknowledges these shared feelings and shows families how they can support each other.



"Living and Transforming with Loss & Grief" Development Team

Front row (L to R): Janet Knight, Ann Marie Wilson, Brenda Hounam, David Knight. Back row (L to R): Kim Gellatly, Lisa Loiselle, Carl Wilson.

Individual copies and bulk orders are available for \$1 per booklet plus shipping and handling through the MAREP website at www.marep.uwaterloo.ca or by calling (519) 888-4567, ext 32920.

Excerpt from the new guide: "Keeping a Positive Outlook"

I learned – be patient, remain calm, adjust, and accept.
I still have a very positive attitude – my favourite saying is,
"I am still on the right side of the grass!!" I went to friends' funerals this year...and they are not here to enjoy life!!!
Here and now are most important along with lots of laughter.
I also make time to do things I like and renew my spirit so I can continue to stay in the moment.

Kenneth G. Murray Alzheimer
Research and Education Program

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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