

Self-Management and Dementia



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*Healthy Living and Dementia: 3-Part Online Event Series (CDRAKE
and AKE)*

Thursday January 19, 2012

What is MAREP?

The Murray Alzheimer Research and Education Program (MAREP), a major division of the Schlegel-UW Research Institute for Aging at the University of Waterloo, is 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.



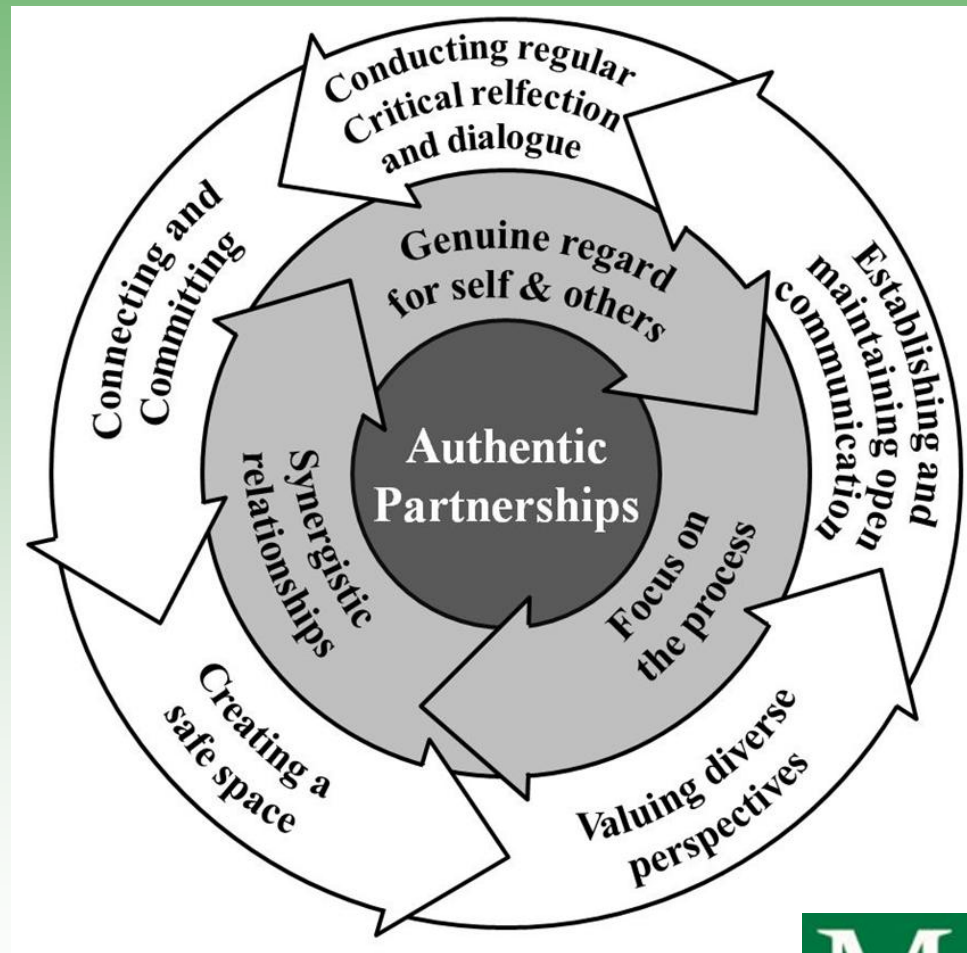
What is an Authentic Partnership?

An *Authentic Partnership*...

- Actively incorporates and values diverse perspectives and includes persons with dementia, partners in care and professional partners directly in decision making



Authentic Partnership



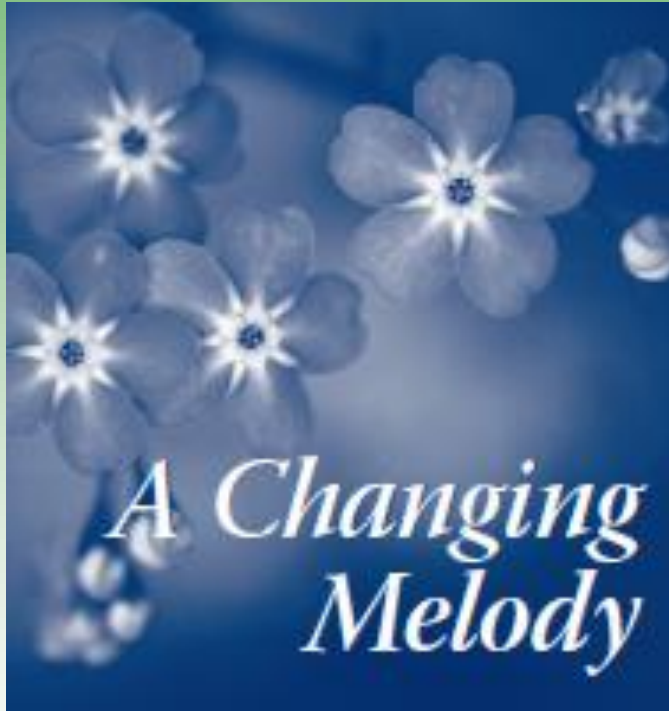
MAREP

Murray Alzheimer Research and Education Program
University of Waterloo

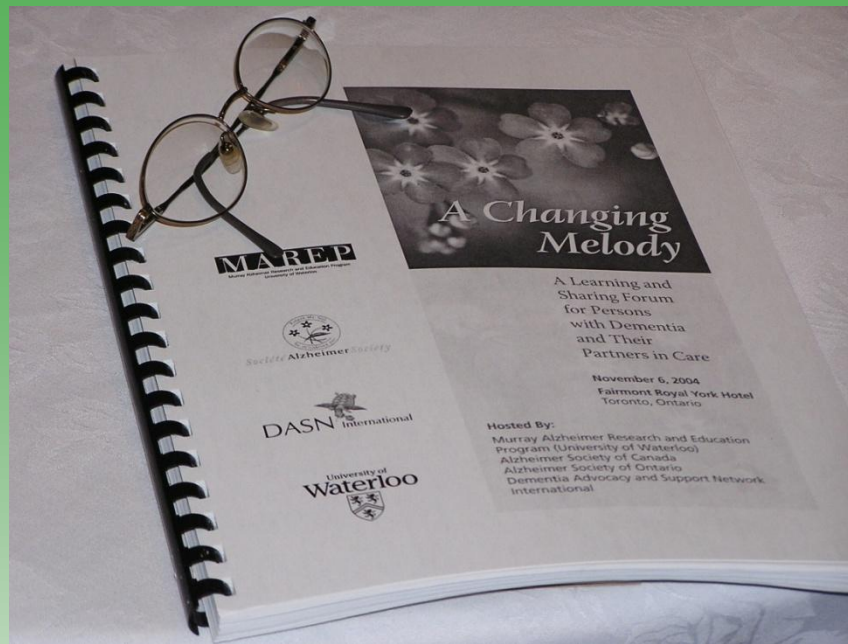
Partnerships in Practice

- Living with Dementia web tool
- Age Friendly Communities Initiative
- Recreation Resource Guide
- By Us For Us Series of Guides
- **A Changing Melody Forum and Toolkit**

Partnerships in Practice



*A Learning and sharing
Forum for Persons with
Early-stage Dementia and
their Partners in Care*



- hosted by MAREP in partnership with the Alzheimer Society of Canada, the Alzheimer Society of Ontario, local Alzheimer Chapters, and the Dementia Advocacy and Support Network International
- planned in partnership with persons living with dementia and family partners in care through direct participation in all decision-making



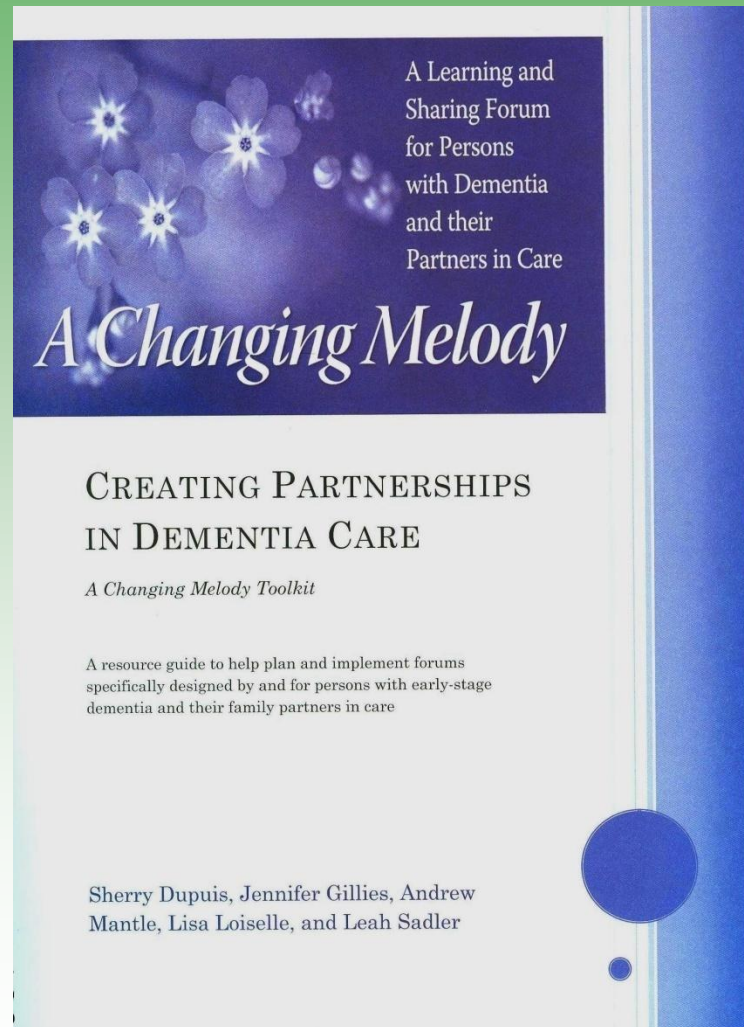
Full-day programs include:

- keynote and other presentations by persons with dementia and family partners in care
- facilitated group discussion and sharing
- use of art to express experiences (musical performances, play, art exhibit)

Why Implement A Changing Melody?

- persons with dementia have the *right* to be, and *must* be, involved in dementia care
- understanding the experiences of dementia from the perspective of those living with dementia is critical to QOL
- persons with dementia can continue to grow and learn but need adequate information, resources and support to do so
- good dementia care requires *strong partnerships* between *all* those involved in dementia care

A Changing Melody Toolkit



Connecting and Identifying with Others

A. Connecting and Standing Together in a Supportive Environment

“I would recommend EVERYBODY, especially people just getting diagnosed; get to some kind of forum quickly...I think for people who have never connected with people before, I just feel so sorry for them because I think support is so important.” – Person with dementia

“We’re all on this journey together and it’s just, it’s reassuring to know that you’re not alone.” - Partner in care

B. Learning With and From Persons with Dementia

“I got the most out of it, hearing others talk about their experiences...and I’ve never really had a chance to do that before...It really touched me to hear others talk about how they are coping.” – Person with dementia



Experiencing A New Awakening

A. Experiencing an 'Aha' Moment

"I'm standing now. Know what I mean? I think I have a better understanding of what's happening to me and what the future might be like, in that way it helped me a lot...It was an awakening." – Person with dementia

B. Transcending the Disease Through Acceptance and Hope

"If I'd of known this, three years ago, I could have done such a better job... at least I know from this point on, I will do so much better.since the forum, our last few get-togethers have been amazing. We just really enjoy each other's company...So I'm very thankful for that." - Partner in care

C. Becoming Empowered

"The more I know, the more empowered I feel... it reduces the anxiety that I might feel." – Person with dementia



Creating a New Face of Dementia

A. Reconstructing Meaning

“We are all converted people most of us...to know that we are breaking down the stigma, we are trying to change attitudes, there is a systemic kind of change that is going on.” - Professional

B. Becoming a Dementia Advocate

“And from that time on I just grew more and more positive about being more of an advocate, about being more myself, about enjoying what I’ve got... I had forgotten that I was me and that I could make a difference and now I’m back.” - Person with dementia

C. Reflecting Possibilities of “Living” with Dementia

“I really was amazed at how smart the people up on the stage with Alzheimer’s and telling their story. It’s not what I read about...I’m gonna live like I don’t have Alzheimer’s.” - Person with dementia





Thank-you for your interest and attention!

For more information about MAREP, please go to our website:

www.marep.uwaterloo.ca