

# Self-Management and Dementia



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

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# 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



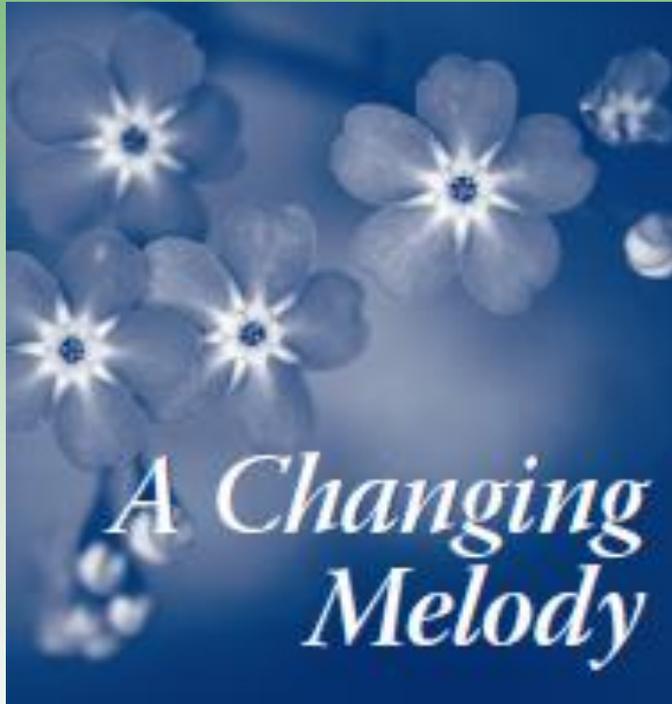
**MAREP**

Murray Alzheimer Research and Education Program  
University of Waterloo

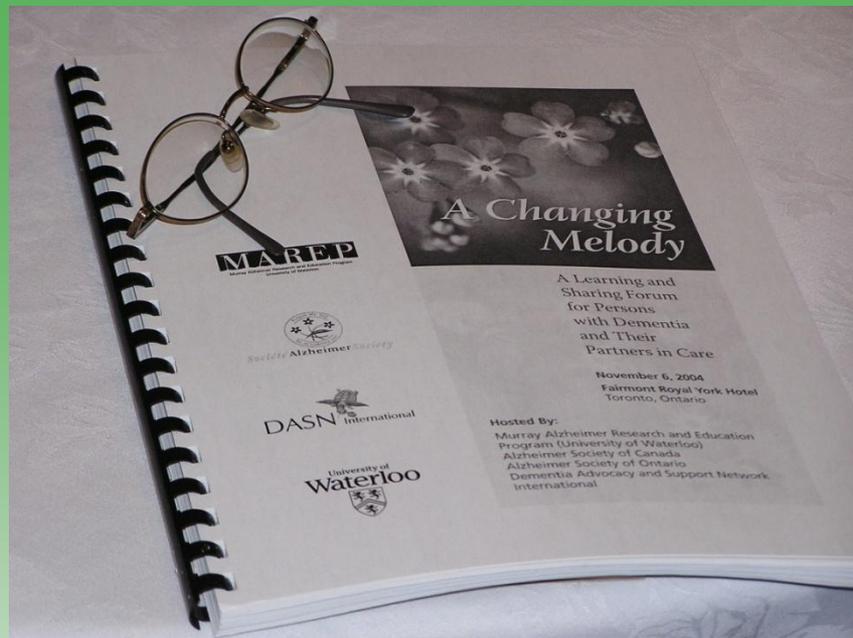
# Partnerships in Practice

- 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



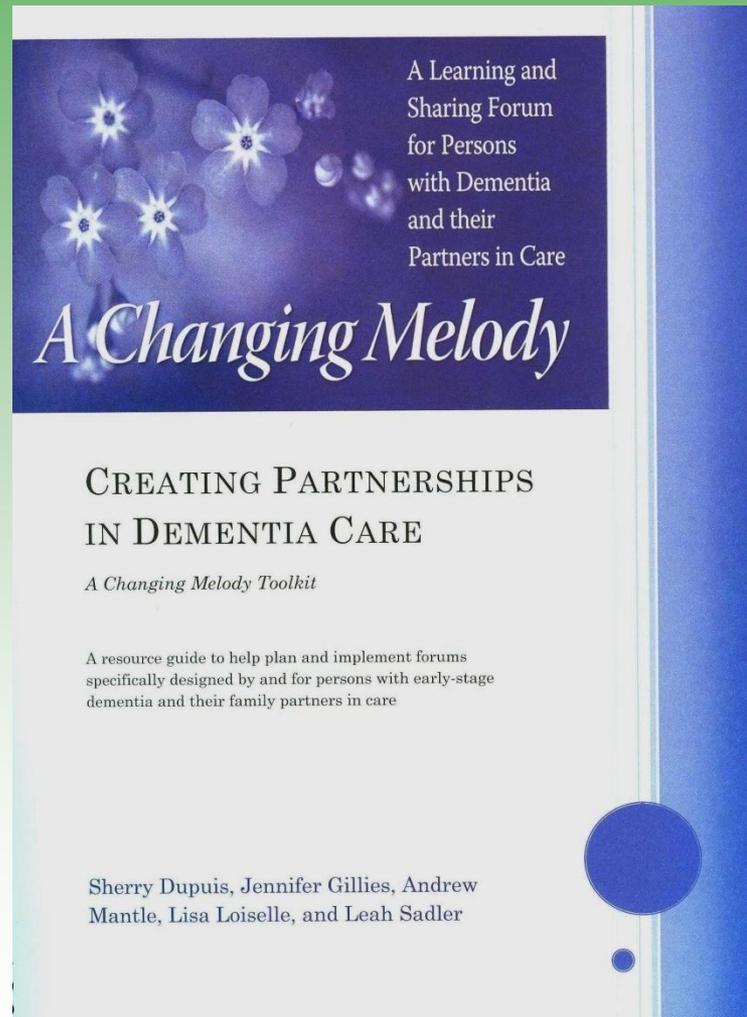
## Full-day programs include:

- 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](http://www.marep.uwaterloo.ca)