

A Changing Melody Forum

November 6th, 2004 will go down in Canadian history! It was the day “*A Changing Melody – A Learning and Sharing Forum for Persons with Dementia and Their Partners in Care*” took place in Toronto, Ontario, Canada. Together the Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo, the Alzheimer Societies of Canada and of Ontario, along with DASN (Dementia Advocacy and Support Network) International co-hosted this momentous event.

It took almost two years in the planning with people with dementia being included on the planning committee, but the results were well worth the wait. The day started with a plenary session by Dr. Les Sheldon, a geriatric psychiatrist from Vancouver entitled “Getting the Most out of Today”. His talk centered on broadening our perspective and being proactive instead of reactive when it comes to being diagnosed with dementia. By doing this he feels quality and quantity of life can be improved. It was a talk filled with knowledge, optimism and hope. He also spoke of how we can lobby with our Alzheimer’s Associations and governments to get better help for people with the early stages of dementia.

Brenda Hounam, a person with dementia and Linda Westbrook, a partner in care gave the second session. They talked of their journeys with dementia from each personal perspective.

Brenda has the honor of having a song called “One More Memory” written and recorded on CD for her. The words tell what it is like to have Alzheimer’s Disease. Singer, Sara Westbrook performed the song live at the forum. It was a very moving emotional experience to say the least. Information about the CD can be obtained at www.onemorememory.com

After lunch, Marilyn Truscott, a person with dementia spoke on “Adapting and Enhancing Leisure Activities”. It was a very informative session about what creative activities a person can do to make their life more meaningful.

The next session was called “Advocacy and Dementia”. It was presented by Marge Dempsey and Lynn Moore care-professionals from Alzheimer Society offices in Ontario. They spoke about the code of ethics for advocates and of the importance of keeping records. We learnt a lot of useful tips and ways of advocating for ourselves.

The last session was entitled “Planning Ahead”. Judith Wahl, a lawyer who works at the Advocacy Center for the Elderly in Toronto spoke of the importance of Advance Care Planning and made us aware of the options available.

The whole day was very informative, enlightening, inspirational, and insightful to say the least.

The day was capped off by the premier of a brilliant play called “I’m Still Here”. It is a research-based play based on the experiences of people with dementia. Christine Jonas-Simpson and Gail Mitchell, along with playwright, Vrenia Ironoffski captured exactly what it feels like to go through getting a diagnosis of dementia, how the person with dementia feels, how their friends and family react. It was so true to life that there were many tears in the audience afterwards – not so much because the play was sad, but because it was so real. It will be an excellent teaching tool for the general public to show exactly what it is like to live with dementia.

In all, the day was a huge success judging from the comments and evaluations received afterward. Hopefully this forum will be the first of many of it’s kind to come.

Additional information:

Murray Alzheimer Research Education Program (MAREP

<http://www.marep.uwaterloo.ca/>

Alzheimer Society of Canada <http://www.alzheimer.ca/>

Alzheimer Society of Ontario <http://www.alzheimerontario.org/>

DASN International www.dasninternational.org