



## Comments from *A Changing Melody* Forum 2006

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### *Tips and Strategies for Persons with Dementia and Partners in Care*

Always remember: What you don't remember you don't know and never be afraid.

As a caregiver to a person with MCI, I try to take care of my own health and well-being. This I do by developing my own interests and hobbies as much as possible. If I am living a balanced life, my resources for coping with my partner's situation will be better, and we will both benefit.

Coping Strategies: Endorse the effort-not the outcome!

Much like AA groups -- What about a "sponsor" (with dementia) who could help in transition with peers. After all this is life altering. And who knows better the issues and problems faced than someone who is going through this disease themselves.

Participating in an Alzheimer's Society (of Guelph) support group - which meets every second week - has been invaluable. It helped me come to be able to say "I have Alzheimer's" which then opened up new horizons for me. I am thus deeply grateful for that group.

Coping strategy for gentle reminders for person with Alzheimer's: Write important info or reminders on 8x10 sheets in bright magic markers and put in prominent place.

Fundraising - follow steps made by the cancer society. Use of technological tools that have helped children with autism and similar neurological diseases - crossover research and sharing of information and tools. Pressure to step-up stem cell research and applications.

### *Making Connections*

There is no support group in my area. I would be interested in a panel from other areas who would be willing to share some of their good ideas and activities. ([john.bateman@sympatico.ca](mailto:john.bateman@sympatico.ca))

### *General Comments on the Forum*

A friend's mother passed away earlier this year, she had Alzheimer's. Her doctor spoke at her "Celebration of Life." The doctor had asked her how she was doing. She replied that it is difficult some days. "Sometimes I wake up and I don't know where I am." The doctor responded that it must be difficult. My friend's mom (a beautiful, unique mother) replied, "No not really, I just think of each day as a *new adventure*."

This year was much more relaxed than last year. The quiet room was very helpful.

The forum has been an extraordinary experience for me. I am a front-line worker, but also a caregiver (14 yrs ago) for my mother. When there were no support groups, no help in a much needed way. Thank you.

Great location and room setup. This was exceptionally well organized and a wonderful learning, networking and supportive environment. The people sitting with us had never reached out for help before and I think it was a great experience for them. They even made contacts back in their home town of Ottawa. Great work! Thank you for sharing.

A wonderfully uplifting day. Personal touch, stories and experiences of people living with AD made my experiences/job real and reassured me I'm in the right job for the future. Thank you.

A great forum - very interesting and informative. The speakers with dementia were very powerful and interesting.

It opened my eyes even more from a worker who works at an adult day centre in Oakville.

As a care provider (professional), I cannot comment on 1st topic. However, I found the forum very educational and uplifting on overall info re: AD, having worked and presently working with people in much worse shape as a result of the disease (and lack of success with present drugs) than those I heard speak today. Most encouraging!

Wonderful forum. Lots of valuable information to take back to support group.

A good day for me, thanks again.

An excellent forum. The speakers were exceptional in their presentations and heartfelt sharing of their experiences. A lot of great encouragement.

Great, perfect.

It has been a good day for me because of the forum. It motivates me to continue to care for my mom-in-law who is going through a later stage of dementia. Thanks.

The Forum: Congratulations! The flow of information was interesting and understandable - time went very quickly! Very well presented and timed. You've come a long way!

I think it is very important for both people with cognitive impairment as well as their caregivers to know that they are not alone. Forums like this one are an excellent way to network and even form support groups. It is important for people to know that when someone with cognitive impairment lashes out or becomes agitated that it is the disease talking not the person.

I do not have any pertinent questions at this time, but I did find the forum extremely informative. Keep up the movement toward knowledge and awareness. Thank you for the enlightenment. I found it very helpful. It is so nice to be treated like a person and not a number.

As a caregiver I teach others my way of coping with AD. I find the forum very informative also the regular breaks would have made those affected by the disease more relaxed.

As a health care provider, I believe it is important to have a greater understanding of the challenges and limitations that person's with dementia face in their daily lives. We need to use this understanding to increase these individuals' quality of life at all stages. This forum was an excellent experience. Thanks so much.

Enjoyed and learned so much from people with Alzheimer's -- really appreciated their honest sharing.

Absolutely marvelous symposium; attending for the 2nd year. Appreciate in-room exhibits and info booths; practical to attend with visibility of entire area (in case of wandering attendee needs, if a caregiver. Valuable handouts and materials.

Wonderful conference. We are new into the subject and it helped us a great deal, identifying with others. Provides hope for the future.

Thank you for a great day. I have just been diagnosed with the disease. It is very frightening and I feel this day has helped me greatly. I have been accompanied by my husband and my two daughters. I am very grateful that they saw fit and took the time to support me.

Enjoyed personal experiences of the speakers. As always, excellent program, great information and networking. Congrats to all in the planning committee!

Lunch was superb! I especially enjoyed the soup - a nice touch - as well as the numerous offerings of sandwiches, desserts. Thank you!

### ***Tips and Suggestions for Next Forum***

Have a caregiver and person with dementia talk about their experience as a couple.

More physical stimulation - to get people to move in their chairs - tai chi, etc. Simple movements at regular intervals, i.e. each hour. Overall great info.

No more Sundays, spiritual part is very important.

I want to mention that some of the individuals at today's forum found the presentations too long. While the presenters had valuable information to share, I think we must be mindful of time. Again, let me stress the importance of break times.

Kleenex at the tables please.

A box of Kleenex at each table for those of us who become a bit teary-eyed.

Suggestions: provide Kleenex at tables for "tears."

Venue parking @ \$30 was a shock; luckily a hotel employee suggested 2nd lot past the adjacent boat restaurant @ \$8 (1st lot @ \$10). Affordable; perhaps next year area parking would be beneficial advised in advance.

I am here to support my mother (recently diagnosed with early stage) and father (care partner). My son (14 yrs) has ADHD (diagnosed when he was 8 yrs) and Asperger's Syndrome (diagnosed @ 12 yrs). I have noticed so many similarities in coping strategies and feelings (shame) and reactions of others (ignorance). I wonder if sharing of strategies would be helpful.

Comments re forum: Having Kleenex boxes available. Out of curiosity and information sharing, knowing if any involved in trial drugs.