



Comments and Tips from *A Changing Melody* Forum 2007

General Comments on the Forum

The forum facilitates learning and an increased awareness

It was even better than the ones before, if that's possible. I continue to learn so much and enjoy attending Changing Melody conferences.

Each year just seems to get better than the year before. WELL DONE! Everyone I spoke with said they had learned so much (myself and my staff included) and had such a positive day. Thank you for all your hard work!"

Thanks so much in the library filled with books – now I don't know what aisle to go down – There's just so much knowledge. "Confusion at its best"

[Alz. Soc. staff member] The day was fantastic, very well organized and informative. Thank you.

This was a tremendously informative session, very instructive and constructive both for those with dementia and caregivers.

I liked very much the forum & have no single regrets of attending it. I've learned a lot. I am a live-in caregiver from the Philippines.

The facilities, services and overall the personnel should be lauded by all. Topics were covered thoroughly, explicitly, and simply

A powerful, dynamic conference; relative to many diversities of the growing nb/r of dementia afflicted persons + their families, who daily undertake supportive care + the potential awareness of their own window into the foreseeable future of hereditary disease.

Very informative. We have a wonderful support group up in Fenelon Falls + Lindsay both for partners in care and persons with Alzheimer. They are so helpful kind and loving and encouraging.

So valuable, enjoyable, educational. Heart, hugs!

Very good information.

Learning experience.

Searching for me and the citizens we (Ontario Senior Citizens Organizations) serve in Ontario

Very good to hear personal points of view. It makes it more realistic about how serious the disease really is.

Our first Forum, very informative. We will attend again!

I find the Forum very informative and well discussed especially in dealing with person with dementia. As a caregiver, I learned new ideas and techniques in coping with dementia. I hope there will be more forums like this in the future Thank you!

Gaining new insights

I came to support my Mom in her role of directly caring for Dad. I walk away appreciating my role as an advocate and an educator both to professionals and to the community where I live. Thank you!!

Positive, informative. Learned new tactics re: exercising your mind, body and soul.

Excellent forum. This is my third forum and I thank you so very much. It continues to teach me how I can be a more effective support to persons with dementia and advocate for persons with dementia. What a privilege!! THANK YOU.

Very positive. First time and I was very well informed on coming, but have gained knowledge and have some ideas how I can help.

Thanks for helping me face some of my shortcomings as a caregiver. I am sure that the personal sharing by the caregivers that spoke will help me on our journey.

[Yellowknife chapter] More than I expected. Will be taking/sharing all this information back to the Yellowknife Chapter. Being a long distance caregiver gave me the knowledge to communicate with my mother in-law because she also attended.

Great to be among such a variety of perspectives. Will take many of them back to my practice.

I have learned great ideas how to help my dad and 86 yr old mom have the best “rest of their lives” as I can.

I agree that all people should not be ignored – they all should be respected for who they are. I have some ideas how I can help and will work with my local society where possible.

There is far too much denial about this illness, an attitude that dementia is disgraceful and something to be hidden and kept a secret. We need more emphasis on educating the public. we need to erase the stigma so that it isn't seen as a shameful disgraceful condition.

“ I AM A “BOOMER” HEAR ME ROAR!
19-20% OF THE POPULATION
7,500,000
IN 5 TO 10 YEARS
750,000 TO 1,000,000
NEW PATIENTS
WE HAVE THE #S TO INFLUENCE POLICY
WE HAVE THE \$ TO INFLUENCE POLICY

Exhilarating, positive, respectful. I have so very much to take back with me in my role (Early Stage Program Co-ordinator)

Plan to arrange a support group at our church. We know people who have dementia but have not gone “public”.

Am going to try to get friends and family to speak (include) Jack in everything they say.

A form of support from a growing community

A valued forum growing in numbers! Also, an encouraging – sometimes tearful – testimonial and network sharing opportunity. Many thanks for your collective efforts in changing our future.

This is my second Conference. I also attended last year. My youngest daughter is here again with my husband and I. My “middle” daughter, who was with us all last year, is away. My eldest daughter is working through breast cancer at the moment. I am praying for her. I am lucky to have such a “great support group.” I am looking forward to next year’s Conference. It is wonderful! Keep it up!!”

I was very inspired by the people who spoke, and the people I met at my table [T&T – volunteer and guest of AlzCan]. Very satisfying. This is my second year with the Changing Melody Forum and I can see that it’s quite grown and possibly growing even more. Good luck and all the best.

I am never disappointed when I come to A Changing Melody. I know MAREP has helped a lot of Dementia Patients including my wife.

Many new thoughts and how to help others and meet with a great bunch of interested people.

I am always pleased with the quality and dedication of the people that help Alzheimer patients especially at MAREP and Alz. Society.

A positive and open environment

The most positive event I have attended in a while. Bravo and congratulations to you all. I will return and bring others.

2nd year attending, positive, uplifting experience – need more of this throughout the year.

Forum – “Great” – Keep it going. Hard to find this type of positive approach everywhere.

Love this forum and look forward to it each year. Always find it so refreshing to have the disease spoken about so honestly – getting rid of shame!

As someone who has been touched by neurological disease in family and personal ways, I find the conference to be upbeat and I appreciate the tone of hope that is presented.

Thank you for providing a safe comfortable forum for PWD. And their caregivers.

First I wish to say how much I enjoyed the day receiving so much support. I enjoyed all speakers for different reasons. I loved the way we were greeted arriving make you feel so welcomed. Food very delicious. Here I am at the end of our day, I say your speakers are all wonderful. I Shall be back with my husband.

Great day – thank you! I found especially useful the time available for attendees to ask questions and share experiences. Very emotional.

Terrific guidance from the many ASK ME guides!

Plentiful and good food. Breaks well spaced.

An inspiration and gift

Very inspirational! Truly enjoyed the personal experiences with dementia. Will carry the experience with me and be an advocate for supporting those with dementia and their caregivers.

Today has been an inspiration. Thank you.

This is my second time attending and inspiring it is for me as well for others.

In work – see the middle to end stages of disease – very inspired to hear about life in early stages. Keeps it real!

This forum is the gift of time

The gift is my life [Person with dementia]. Friends for years + now it just gets better.

Still searching for answers

A lot of emphasis is on “early” diagnosis, what if diagnosis is in later stages and “sprung” on family.

There was a lot of emphasis on Alzheimer's which is not my husband's disease. We are still dealing with his unwillingness (inability?) to accept his dementia and my difficulty in interacting with him successfully – this forum has given us some “thinking points” – we need to help expand out knowledge.

What do we do about all of our questions?

Support groups are too far away. Scarborough area for both persons with Dementia + caregivers needs to be more readily available. How do we go about this? How do we find them? More support groups around all cities in Canada including suburbs, i.e. Ajax, Pickering for example. Making access more readily available

When my mother was diagnosed with terminal cancer 12 years ago, I was put in touch (through a hospital social worker) with an organization whose name I have forgotten. The family was immediately assigned a case manager who oversaw every aspect of her care for the next year: we were linked to several services who could help us right up to her admission to a palliative care facility. My husband has dementia –not Alzheimer's – he suffered brain damage as a result of radiation received as a teenager for a brain tumour. It has been 8 years since his diagnosis and tho' we regularly see 2 neurologists (one to deal with epilepsy; one for memory) as well as our family doctor and I have contacted both the ABI and Alzheimer's associations, we have not received the assistance I feel we need! Each doctor & organization seems to work in a vacuum – There are no perceived links. Where is the help we (and many others) need to negotiate the tangled web of health care. I am so discouraged by the shoulder shrugs and “I don't know” answers to our questions. If you can point me in the right direction, I'd be so grateful!!

I am going to try to find a better support system for my Mom and Dad. And myself too – The only one of their children (of 4) in Canada. They live in Ajax- west of Pickering Village. Their geriatric Dr is at Markham Stouffville Hospital and does not have a very warm, caring, helpful manner. Mom did not get much satisfaction re: there being support groups available for them with local Alzheimer's Assoc. If you have any ideas to help us, please call me at: Thank you very much.

Comments on speakers/sessions

Well organized. Very informative, Knowledgeable presenters.

The doctor's session was very informative, but there was a bit too much to “take in”. Perhaps one segment & more details on that.

Fabulous panel discussion on communication – loved the different perspectives.

The variety and quality of speakers was very educational and provided us with optimism.

Very well organized with excellent speakers who are obviously concerned and caring people.

Dr. Le Clair's presentation was excellent, very informative and of great benefit to all.

Dr. David Knight's presentation: directly meaningful, inspiring, informative and beautifully delivered.

Someone like David Knight should be speaking all over Canada about this disease. Doctors + professionals (Medical) especially should come + hear him.

David Knight - Most inspirational.

David Knight was wonderful. He explained the different steps ahead of us. He gave us courage to carry on.

Address by David Knight was truly inspiring, totally awe inspiring – dignity worth fighting for.

Christine Baum Van Ryzin – Excellent medical approach – Block's- her presentation was so good and well done.

Christine – Truly inspirational warm and open encouraging awareness.

Marija – Excellent, clear and easy to understand

Ann Marie – Clear, to the point (a good review for me). Excellent +++

Excellent!!! It was so informative to have a combination of professionals as well as individuals with dementia discussing valuable information and providing enhancement of understanding re coping mechanisms with this illness. I was very impressed with the positive and uplifting information received.

It was wonderful. I look forward to next year. Speakers were so encouraging.

Joan McConnell- Interview – very natural, charming in her approach

I am the eldest daughter of my 81 year old Dad who has Alzheimer's. I found it very helpful to hear Joan McConnell's coping strategies (especially re. calendar of activities which is shared daily with family members.

Brenda Hounam – Safely Home – Very well done.

Christene Gordon – very light, fun, easy to listen to- good humour

Jeanne Bentley – Very brave, even with short term memory impairment.

Song (I'll Walk You Home) - Excellent and Moving.

I got so much from every speaker.

The panel was very instructive and open. Communication works.

Panel was superb and meaningful.

Ken Leclair shared great info but his slide presentation was different from the one printed in the pkg- this made it challenging to follow along.

Dr. Kenneth LeClair – while an approachable and knowledgeable man, the presentation was disjointed and confusing

“Pantyhose session” jumped from the book (Powerpoint) to the envelope handed out.

Dr. Le Clair’s presentation should have been aimed at non-professionals, focus on advancements in team building.

Dr. Le Clair – very informative, stats #s I had not heard before – (a passion for persons with dementia) (too much information – too little time to present, not following slides) this would have been difficult for persons with dementia to follow. (Everyone enjoyed the “Last tip” – (Not what you say, but how you say it).

Just plain excellent

An excellent occasion – worth attending, enjoyed every minute. Very well organized, professional, and friendly.

Excellent!

Forum was great and informal. Great work. Thanks to everyone

How valuable to be here!

Great job!!!

Well organized. Extra signage was good and helpful.

Very worthwhile.

Extremely well done. Keep up the good work!

An excellent Conference!! Thank you.

An excellent forum – keep up the good work.

The content of the Forum was excellent and well presented

Excellent forum! Diverse.

Very well done! Excellent!

Great day!

Thanks for having it on Sat. Wonderful forum ++++++

Excellent – really enjoyed

Excellent.

WOW!!

Excellent, enlightening, wonderful day.

Absolutely Excellent.

What a wonderful day it has been. I thank you.

Very well organized.

CM and MAREPS forums we've attended and we do hope their's another in the plan!

Very helpful. Very professional. Very satisfactory location. Good adherence to advertised schedule.

Tips and Strategies for Persons with Dementia and Partners in Care

As a caregiver, my coping strategies are enhanced by my husband's acceptance of his diagnosis and he is not in denial. It makes things so much easier.

Joan's advice on focusing on making each day a "good day" is most inspirational and great advice for us all.

I am caring an 81 yr/old woman with undiagnosed Alzheimer's Disease. I said undiagnosed because nobody said it but I believe she has it. Sometimes, she has tantrums of a dominant attitude. I just try to listen, ignore, & try to let go of it rather than fight back because I know it will just make it worse.

Keep busy, senior's groups helpful, (All in same boat, not just with Alz.)

H.O.W. – Honesty, Open-Minded, Willing. (Similar to 12-step Program approach)

Celebrating small successes is so important, dignity and self-worth. The speakers who are living with dementia are invaluable.

Tips and Suggestions for next forum

Same place every year would help. Then I can program it.

As you find more people with “functioning” dementia, use them in a greater portion – in all your programs, there was a greater percentage given to non-AD people.

Podium was too short [tall] for some presenters.

More displays in celebrating accomplishments.

This is my first visit to this Forum – in some ways, the amount of information was overwhelming.

More info. for those who are caring for family members with dementia in the home – day by day coping mechanisms

Would like to have seen a “book table”.

There needs to be given information and support for all stages.

I noticed in the afternoon my friend with AD could not sit still or pay attention. Too much information/communication/verbosity for these folk?

Too long – clients are falling asleep. Me, too!

[child attendee] It was very interesting and good, but maybe there could be more hands-on things to get more involved in dementia and family!

Maybe too long for some of us. Too much “material” for PWD (some). More table interaction?

Suggestion → end time of day at 3:30 or 4:00pm would be workable especially when have approximately 1½ drive afterwards when bringing a group.

Maybe more about new meds & treatments.

As I look out across attendees it strikes me that the audience is not reflective of Canada’s diversity. I suggest considering initiatives to reach out to people living with dementia + their caregivers (e.g.,) consider translating some materials into Chinese, Italian, Portuguese, moving next year’s forum to a high school in a community comprised of Canada’s diverse background,

also often people who are away or most newcomers live in low income communities. A willingness to engage with these populations in their world is needed.

Would like to hear more info about the latest research and updates or clinical trials.

Lapel mike much more difficult to hear than hand or stationary mike.

Speakers without dementia reminded to speak clearly and slowly.

Great conference but a lot of information for one day. My husband, who has Alzheimer's, found it difficult to stay focused in the afternoon. What about two half days?

Personal care books given in packages.