



Comments and Tips from *A Changing Melody* Forum 2008

General Comments on the Forum

The forum facilitates learning and an increased awareness

Excellent sharing for people with dementia. Very moving experience, understanding what it feels like to have a memory loss. Excellent workshop. Thank you!

Every year I gain new knowledge.

Thanks for all the input – a big learning day for my dad.

This is my 1st exposure to this forum. Excellent! I found this extremely enlightening and at times an emotional release. We as caregivers are not alone and isolated as I discovered today. Networking was high on my priority list. I have been searching for answers to unknown questions or actions of my mother to which I had difficulty dealing with. The guilt of having to resort to placing our mother in a long term home was devastating to all of us. Our need to find support as children (adults) was difficult because we felt the need to be with our mother 7 days a week 16 hours a day. How could we abandon her after all she had done for us? The two ladies from the booth of Circle of Friends listened to our personal concerns and I truly felt my concerns were validated, so important. I purchased Richard Taylor's book, he was fabulous. My mother always finds comfort in music and my sister purchased Joanne Does CD. My other sister purchased *Treasure the Journey* by Betty Lane. My sisters are my support network, but we were always searching for answers how and what. Today some of those questions were answered. Thank you and we will be here next time.

I enjoyed the day. Completely! This is my 3rd forum and each one is very educational in different ways. I have worked in an adult day program for ten years and I am always learning.

We work with the late stages of dementia so listening to ones with early onset, it makes me stop and think how rapidly memory diminishes in dementia.

Good techniques have been discussed and learned today.

This is my 3rd time at this forum and have personally grown so much because of what I have learned. I have been encouraged to come out of my seclusion and start speaking out.

We also learned from Christine Jonas-Simpson to focus on what it is that we need – and to reach out and ask for help.

Gaining new insights

It is my nature, if you will, to always “go that extra mile” when caring for my family members. More recently I have been able to step back, assess my situation, and establish boundaries if I feel overwhelmed. The training I received while working as a professional health care worker (16 years) has helped me in my own personal situation, and I can honestly say that I am a better caregiver today.

Keeping a stiff upper lip? Makes it difficult to share. Of all the things I’ve lost, it’s my mind I miss the most. I don’t grieve loss. I feel sorry for people who don’t know what I’ve become.

The marbles of my life are all over the place – now I try to find 1 marble at a time. Then with luck I can learn to understand my life again and my past history. As a child playing the game of marbles was easy – now the game gets harder – but I do find the marbles I’m lucky – I am a child and adult at the same time.

Networking

Every year I gain new knowledge and meet amazing people.

I met many interesting people.

Networking was high on my priority list.

Personal Challenges

It’s hard to socialize because I don’t fit...My processing speed isn’t there.

One person with dementia present at the forum today stated how depressed he felt at the ongoing dialogue sessions (because of the continuing talk of lack of support some individuals are feeling).

Becoming a Dementia Advocate

What an inspirational day! There is much to be done to continue the building of supportive dementia communities. I am inspired to do more.

I look forward to helping start A Changing Melody in my own community with persons with dementia, staff, volunteers and partners in care. Thank you for a great day.

My father has agreed to help others to learn about his experiences with Alzheimer's, both difficult, challenges and positive experiences - starting with small groups at his church. My mother plans to contact the Pastoral Care Nurses at their church

Have everyone create a personal/family/community action plan.

Offer services of MAREP for new initiatives – become an incubator.

Design and start an advocacy school for persons with dementia.

Grow leaders! Open a leadership center for people with dementia.

Now that you are clear about what “it” is – write a strategies plan with goals, objectives and timelines.

Harness the energy and interest created here.

Create the model for individual/couples/families/communities and sell it to these folks.

Next Steps

Housing – develop a ‘village’ concept for folks with early on-set, providing support as required as dementia progresses.

Provide the book by Dr. Taylor on audio CD. My father's dementia affects his ability to read but really enjoys audio books.

Use of technology with late stage Alzheimer's – somewhat like approaches used with autistic kids to help them communicate.

Promise in the areas of stem cell research and implementation.

Research & Development.

Sad Farwell

Deeply saddened by the “final” 5 yr annual run of compassionate and extremely necessary forum organized by MAREP @ u.waterloo. This conference opportunity has been a welcomed discovery in our family 3rd (if not 4th) Alzheimer/dementia journey. The future as a family

member caregiver is scary and a bit bleak without this vital annual symposium of encouraging and positive attendees, motivational speakers and contributors.

As a 12 year old, I am very disappointed. I wish the MAREP forum wouldn't end.

My mom, grandpa and I have been coming for 4 years. I sort of feel like you're giving up. Every year my family looks forward to this event.

Still searching for answers

What happens if/when I lose my drivers' licence? My wife has MS and cannot drive and we live in the country?

Define stigma and advocacy – they were unfamiliar words and used a lot.

What happens if my caregiver dies before me!

Employment rights of people with dementia particularly prior to diagnosis.

Access to ADP for visual aids where dementia (not blindness) affects vision.

Comments on speakers/sessions

Time for dialogue was a great addition to the forum.

Interactive questions were great for participating.

I enjoyed when the doctor said "Live your life today"; "Love me for who I am today"; you can't do it by yourself.

Dr. Taylor spoke with passion and drive; I was very moved by his speech.

Absolutely loved to hear the personal experiences of the people in attendance who are living with dementia.

Ken Murray is to be commended for his foresight – a great man.

Elaine was awesome!

Brenda Hounam demonstrates that people with Alzheimer's can be tremendous teachers and how important it is to have a sense of humour.

Talk by Christine Jonas-Simpson – body awareness reminded me of the techniques of focusing by Eugene Gendlin.

Advocacy was explained in a very simple way that was accessible.

Speakers were great.

The test for each speaker is invaluable.

The affirmations were the best interaction.

On the positive side (this after lunch and a short walk) audience was receptive to speakers for the most part – Dr. Richard Taylor's talk well done and inspiring!

Resources

By Us For Us booklet – are excellent; please print in a larger font. Print is very small for aging eyes.

In the toolkit or otherwise making it available – it may help to have some sample shelf letters/proposals for seeking financial support for ACM forums.

Just plain excellent

A wonderful experience – thank you!

Thank you for asking the caregiver to showcase the person with dementia in a celebration of his ordinary life at 85 years young.

The food and location is great.

Absolutely wonderfully organized. I met many interesting people. Very very glad that I attended – I'll come again.

Coming to this forum is good.

About the forum – excellent.

Thank you!!! Wonderfully done!

This forum was very successful in my opinion – also demonstrated by response from audience.

Another great year.

This has been an excellent forum – even better than last year – well balanced – more input by persons with memory challenges. Thank you all for the work and support that you have done. Keep in touch.

Catering service was well organized with good quality food and beverages.

MAREP members/staff very helpful.

Program books well done.

Tips and Strategies for Persons with Dementia and Partners in Care

Use simple recording device to remember significant do list.

Keep connected, don't isolate. Speak up about your needs. Keep active doing things you enjoy, for example, dancing!

Take one day at a time.

Have patience.

Speak out.

Group support.

Keep busy.

To be open about talking about Alzheimer's to friends and relatives and to be more patient and to pray for strength to care more.

Life with dementia is full of hope and expectancy – Life is meant to be lived to the fullest. We need to enjoy life and not worry.

I cope by keeping myself busy, doing things that are good for me, staying involved with Alzheimer's care, sharing my experiences with others, learning more through reading, internet, networking with others, facilitating men's group.

We both so enjoyed the day – I was here last year, brought my husband this year he did very well, he has had Alzheimer's since 2003 still doing well, we enjoy our Alzheimer meetings in Peterborough. I keep as busy as I can - my husband goes to VON Day Program 3 days a week and enjoys it.

Treasure the moment- even when communication is compromised, the underlying bond with your loved one is strong and can be nourished even in silence or quietly with holding hands, singing and music or just sharing time together.

Coping strategies from the position as caregiver – patience, positive support, understanding, loving compassion, to be a good listener, the need to set boundaries for the safety of all concerned.

If someone's appetite decreases, zero in on what they really like and buy or make that e.g. person with dementia stopped wanting breakfast so the spouse knew what food he really liked and she made sure that she provided that.

Suggestions for Future Events

Speeches needed to be shorter – people were exhausted.

One suggestion – have forums in places other than in downtown Toronto – talk about confusing and stressful to access! But well worth it!

People talk too fast. People need to slow down without exaggerating. More pauses between sentences.

Keep the planning committee alive.

Every year my family looks forward to this event. We can't travel very far, so the Toronto location is just perfect. Please reconsider having the national forum every 2-3 years!!

Program books – it would be helpful to have tabs for easy location of session notes.

My suggestion is to have a half hour a week for several weeks to do the same as you do here - which is very educational and much appreciated by us Alzheimer patients.

Think that while it is admirable to want dialogue, more time needed to be allowed for it to be effective. Perhaps choose between small table community sharing and large group sharing. Maybe these could be alternated.

Suggestion – cold drinks/beverages in addition to coffee and tea.

Needed more time to process these large ideas and feelings – shorter presentation and longer process time? Scramble the seating after lunch/play human beings or some people mixer.

Timelines! Shorter periods of speaking might be helpful – facilitator needs to guide people without feeling badly about moving the program along!

Closing session with all the thank yous was too long. These things are important but our group was definitely tired out. I would have liked to hear from Ken Murray at the beginning of the day, when we were fresh. Timing is always hard to judge, but it was just a bit too long at the end of the day.

Schedule intervals of events to enable people to engage more in one-on-one dialogue – can be a long day and people lose focus.

We need fans so the air can circulate.

Too much dialogue which interrupts the flow – leave this for more appropriate times – or keep the speakers talks to a minimum, please.

Need for a survey to be done regarding responses to the forum from participants as a way of educating planners around planning more effectively.

What happened to the idea of drumming session??

Idea for the forum is a good one, but needs to be modified, needs to flow more.