

Behavioural Supports Ontario Provincial Lived Experience Network Advisory

Summary of December 2016 Provincial Lived Experience Café Live Chat (www.dementiacrossroads.ca)

Our latest province-wide Lived Experience Café live (typed) chat took place December 14, 2016 from 6:30 -8:00PM on www.dementiacrossroads.ca . In this session, participants were invited to share their input on the following topic:

December's Live Chat Question:

What are the ways that you create meaningful engagement around the holidays when supporting someone living with dementia or mental illness?

- a. How have your holiday traditions changed/been modified to meet current needs?
- b. What are some practical tips and strategies that you've found to be successful?
- c. What are some of your key lessons learned and most valued supports during this time?

Participants:

This session involved 13 participants from Sudbury, Timmins, Kingston, Belleville, Toronto, Thessalon, Perth, Cloyne, Brighton and Waterloo, Ontario.

Key Findings:

- a. How have your holiday traditions changed/been modified to meet current needs?**

Simplifying the Holidays: Participants recommend various ways they had adapted previous activities like shopping, cooking, decorating and gift buying in order to keep things simpler and more manageable.

- "It helps to keep things simple as those with dementia are easily overwhelmed and stressed."
- "I have to be cautious not to fit too many activities into the day to keep the anxiety level at a manageable level."
- "In the past I have put a small 1/2 Christmas tree on the wall." (instead of a full-size real tree)

- “Adapting our visiting helped too. Everyone coming at once was too chaotic, so the tradition was adapted and I bring the grandchildren on a different day.”
- “Simple things like singing a song or a hymn was our way of connecting.”
- “We have gone to “cash gifts” this year. It is not as exciting but it sure is less stressful and I think the kids and grandkids appreciate the cash. That way they can enjoy the Boxing Day Sales.”
- I agree – cash as appreciated gifts. It is also really good for my blood pressure and for not having to make returns or exchanges.”
- Order Pizza and Sushi if that’s what you think you can handle. What law says we have to have turkey or ham?”
- “I hear from a lot of people that they just order Swiss Chalet, get their meal catered or ask the family to do potluck. Keeping it simple is less stress for already stressed out people.”
- “Embrace little mementos like a special ornament on the Christmas tree to honour the person we love when they can’t be present. These bring back warm memories we can cherish.”

Adjusting traditions: Participants shared ways in which traditions have been modified to meet needs such as family dinners, gift giving, decorating and the introduction of new activities

- “This is the first year we are shifting our Xmas eve and Xmas day activities to our daughter’s house. Fortunately, we all live in the same city so travel’s not an issue. It should be much less chaotic and if we need a break we can come back to our house.”
- Our family stopped giving gifts to each other a long time ago. If you’re coming for dinner you bring a wrapped gift of predetermined amount and then we play a draw game.”
- At our house the best gift of all is time with the family (seven grand kids ages 6 to 14).”
- “One thing we did was set a limit of \$5.00 plus tax for presents. They are really funny and pointed but easy for everyone to afford. Great to take my mom in the store and turn her loose. She loves the small jokes.”
- “When it comes to gifts, the gesture is the important things – a picture and picture frame with a label (without the glass) or a small ornament to hang on the door.”
- “We have a group of ten who go out for dinner every New Year’s eve. A couple have mobility issues, so this year we are going to someone’s house and ordering pizza. Nothing fancy but I think it will be more fun.”
- “Another suggestion was making Memory Boxes and changing them from time to time and the season.”... “I just found a link about memory boxes: <http://www.alzheimers.net/2014-02-06/memory-boxes-for-patients/>”
- “The long term care home has a Xmas market and everyone loves the shopping experience! In fact we find the shopping day to be time well spent together vs a Xmas dinner.”
- “This year our home did a “light the night” with hot chocolate and cookies and singing, then the lights in the backyard were switched on.”

- “In later stages be cautious with decorating and making sure the person does not feel disoriented in their environment.”
- “Last year, I left for the nursing home first thing Christmas morning, after my grandchildren had opened their gifts. I arrived just after Mom had breakfast, we spent the morning laughing sipping mimosa and I curled my Mom’s hair. She got all dressed up in her holiday attire ready for Santa to pay a visit to the nursing home. Residents, staff and family members gathered in the large activity room, the fireplace channel was set on the t.v. and presents spilled out from underneath the tree. Santa and his elves handed out gifts to each and every resident and then Santa took the time to take individual photos with all who wanted to participate. I sent the photo of Mom with Santa to all my Siblings and all her Siblings wishing everyone a Merry Christmas from Mom. That memory will stay with me forever, it is making me smile now as I type it, even a year later.”
- “It only takes two times to change a tradition.”
- “Once Mom moved here to LTC I would bring her to my place for late breakfast & our gift exchange. Then we would go out to Christmas dinner with all my in-laws. Each year we gave the great nieces & nephews a piñata - they decided to have it before opening family gifts because she might get tired. Mom really enjoyed watching & laughing with them.”

Knowing the Person Participants shared stories that emphasized the importance of truly knowing a person’s preferences and capabilities in order to adapt for the holidays

- One participant cautioned to decorate and un-decorate slowly. She shared that her parent woke one morning and the room was cleared of the decorations and she became frantic and disoriented. It took a long time to calm her down...lesson learned by the family involved.
- “Dad is now trying to eat anything he wants. I cannot give him wrapped candy because he doesn't know to remove wrapping.”
- “Holiday traditions are ever changing. It is hard, really hard, to set aside what I want to be doing with my Mom in my heart and what is best for her. As the dementia progressed, coming out [from the nursing home] for Christmas baking was the first thing that had to be changed, it became too overwhelming. The overnight visits shortened. Last year we had to change to a one day visit for supper only. This Christmas will be the biggest and most difficult change as I do not think Christmas dinner at my house is even possible.”
- “I think knowing what our loved one enjoys is key. In our case it was babies and young children. Our mother didn’t seem to know who her great grandchildren were, but concentrated on them with obvious pleasure.”
- “Help prepare visitors (especially children) ahead of time for what they may encounter- to adjust their expectations a little.”
- “Try not to say, “Do you remember when...” This can frustrate the person living with dementia when we are trying to reminisce. Try to rephrase that.”

Guilt, Grief, Loss and Isolation: Participants shared how the need to adapt holiday plans sometimes resulted in feelings of guilt, grief, loss and isolation

- “When we finally decided not to continue bringing Mom to our home, I felt so guilty! We realized we weren’t doing it for her benefit anymore, but our own needs and wishes. We had to adapt for her – but I still feel guilty about that every holiday.”
- “Holidays tend to increase the guilt, the grief and the loss as we reminisce more about the way things were.”
- “The guilt of not including her in everything we used to do as our family traditions is hard to control.”
- “I struggle with doing things without my husband, but am realizing I need that sometimes. Dementia is very isolating. Even when people want to help they have trouble understanding. Finding meaningful things to do with our loved ones is an evolving challenge.”

Strategies:

B. What are some practical tips and strategies that you’ve found to be successful?

Leaning on others for help:

- One family member shared that they book extra private care visitors to come and spend time with their parent in LTC when away travelling. This way they can know they are not all alone.
- “Early in Mom's journey with us my brother & I took turns hosting Mom for Christmas & New Year’s.”
- “I have a strong support system with my husband and children. The second great support is the nursing home, they go above and beyond to accommodate our family luncheons, brunches and suppers.”

Staying focused on the present moment:

- “I think it's about bringing the focus to this moment, this hour, this day.....and try not to want more than your loved one can handle. You/we are all dealing with the hardest job...caregiving for a loved one. Feelings really come into play.”
- “My key lesson is trying to find a proper balance between what my heart wants and what is best for Mom at this stage of her dementia.”
- “Things seem to always be changing. I think I just need to relax and try not to control the outcomes. They are SO out of my control.”

C. What are some of your key lessons learned and most valued supports during this time?

Strategies for Self-Care were:

- “1. Keep up exercise routine, 2. Make sure I get enough sleep, 3. Eat right and watch the extras this time of year. 4. Make time for family and friends and 5. Get out and enjoy the outdoors.”
- “I find talking about it with people who understand and have been there (or are there) is very therapeutic, especially when extended family doesn’t seem to be on the same page.”
- “I found great support from my sister, my husband and my family.”
- “I live in a small town but with lots of churches. They seem to be able to ensure that every resident has time with clergy and LOTS of singing. The kids from daycare & public school are in. Charitable Association pays for a school bus to bring the high school choir for a visit -really good because most residents will have at least one grand or great grandchild in each group. Volunteers keep treats like cookies available for "tea" and of course we get to send kids home well sugared!” (from someone who lives in LTC).
- “One coping strategy is to dig for humour to be found in a situation. It can involve very deep digging – but nuggets can be found.”
- “If it’s not fun, don’t do it...It if has to be done, make it fun.”