



Below is feedback from BSO Provincial Lived Experience Advisory participants. These answers were collected in a group teleconference/webinar discussion as well as email contributions. There were 13 people in total from across Ontario. (For more information about this advisory, visit the Ontario page on www.dementiacrossroads.ca).

1. What question(s) about living with dementia (or living with someone with dementia) would you like to see answered by research?

- What causes "wandering"? Is there an area in the brain that is damaged and if so is there research to try to fix it?
- Are there truly medications available that can slow down the progress?
- Sleep disturbances and the need for proper sleep and a routine.
- The positive effects of keeping the diagnosed person active and busy, the effect of increasing quality of life
- The connection to UTI's and all that goes along with that
- WHY the diagnosed person FALLS so much?
- How to increase your odds of remaining in your home vs institutions
- The person living with dementia believes that they can still do most of the things they always could and that keeps them independent. As dementia continues its journey it is frustrating (for both the family/caregiver and person with dementia) to have to assist with daily living tasks. Could research be done to determine how to handle the fine line of independence and dependence to manage daily living tasks?
- Advisory member states that she would like to see more research on how to keep their loved one safe in an inexpensive way. Research into building an environment that would allow someone with dementia to continue living at home that is not excessively expensive.
- Would like to see research based on how to reduce wandering within a LTCH. What kind of triggers are there that can cause wandering? What kinds of activities can be used?
- Research into supporting those living in the community rather than only LTC.
- Research into physiotherapy to help improve balance.

2. What question(s) about the barriers to living well with dementia would you like to see answered by research?

- Is it better for residents in LTC who have dementia to be all together in a separate unit? I mean, if they are all together continually surrounded by others

with dementia - what is normal for them? Or is it more of an irritant to be mixed in with the cognitively well.

- Communication methods that could be improved upon, maybe word boards? as well as how the family can best communicate with the person
- How to deal with the necessities of life when the driver's license is taken
- Show society that a person with dementia has capabilities still. e.g. can make decisions about basic issues like pain, dislikes, likes etc. but not a complicated medical issue.
- Huge improvement on phone usage, like auto diallers, etc. Study on Skype
- Studies on the need for long term care to provide WAY MORE things to DO to keep the mind active and prevent responsive behaviours
- When hearing aids are not accessible it affects the persons mood and whole day. Many, many seniors are going without hearing due the expense, the loss and the lack of knowledge on how to use them properly.
- A big barrier is abuse and most likely abuse by a family member. This needs to be fixed.
- Another barrier is attorney's for personal care who have no clue what their duties truly are and more importantly WHEN those duties actually kick in
- Perhaps research could determine that education about dementia helps to remove barriers. If people are not educated they will not understand the effects of dementia.
- Living in an institutional environment is a barrier to living well with dementia.
- Does mixing patients with dementia with patients with other cognitive disorders have a negative impact on patients with dementia?
- Do residents lose their level of skill due to lack of stimulation in LTC homes?
- How can we engage people with dementia into the community to improve their quality of life such as some communities in Holland have done? Getting services in your home for a person with dementia can be very difficult

3. What question(s) about preventing dementia would you like to see answered by research?

- Is there a "common denominator" amongst people presenting with dementia? It seems the disease attacks people of all lifestyles and abilities. If you knew the cause you might find the prevention - or vice versa?
- Often I find that the solutions are a fad that is constantly changing. I tend to ignore this because there is not enough science to come up with a cause, and people tend not to be proactive. You can tell me all you want to do brain games but I don't (it is kind of like exercise) I find that food trends come and go so everything in moderation. I need cold hard facts like cigarettes cause cancer.
- I am not sure at this stage that it can be prevented. I would like to see research done to prove or disprove that certain mind games help or do not help keep the synapses working. Also can we prove or disprove things like coconut oil helping or not.

4. What question(s) about the treatments for symptoms of dementia would you like to see answered by research?

- a) Is any kind of electroconvulsive therapy being studied in Canada - for dementia? What are the results?
- b) Is there a "go to" place for doctors (general practitioners) to find out what treatments seem to work?
- The use of psych meds, such as respiridone etc. vs other behavioural modification methods such as identifying triggers etc.
- UTI's
- FALLS

5. What question(s) about diagnosing or being diagnosed with dementia would you like to see answered by research?

- A) Right now, is there a way of collecting evidence on " something" that seems to work best in the prevention or treatment of dementia? I mean, what is the best overall approach?
- B) If people suffering from dementia would agree to donate their brains for scientific research purposes, getting proper permission of course, would the information gleaned not point sooner than later to a cause and perhaps a cure?
- The "mini mental test" are out of date and don't apply to today's ever changing world. Who can draw a clock anymore? Counting backwards by 7's stresses me out! (Is there a better method?)
- Society, long term care in particular diagnoses residents by guessing, lumping all seniors into one big category of being incapable and that generalization needs to change. (Better research into how to diagnose people accurately.)
- Is there a conclusive test and if so, how accurate is it? Can a blood test determine early onset in some way. How about DNA indicators?

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