



# Behavioural Supports Ontario Provincial Lived Experience Network

## Feedback: HQO Quality Standard – Behavioural Symptoms of Dementia

### Background:

The purpose of the BSO Lived Experience Network is to bring together people with lived experience from across the province to collaborate on key projects focused on system navigation and person and family-centred care. This network also advises and guides other BSO projects such as the Ontario Best Practice Exchange. This network is led by Sharon Osvald, who has recently expanded her role as South East Lived Experience Network Coordinator to Provincial Lived Experience Network Coordinator in collaboration with the BSO Provincial Coordinating Office and brainXchange.

Lived experience refers to the experience of living with dementia, mental health, substance use and/or neurological disorders or the experience of being a care partner with an individual living with one or more of these conditions. Examples of care partners may include family members, friends, etc., who play or played an active role in supporting an individual living with one or more of the above conditions emotionally and/or physically.

The Lived Experience Network connects via bi-monthly advisory meetings which take place via teleconference & webinar and also through bi-monthly online provincial lived experience advisory chats using the chat platform on [www.dementiacrossroads.ca](http://www.dementiacrossroads.ca). The first chat, hosted on June 15, focused on the provision of feedback regarding the HQO Quality Standard for Behavioural Symptoms of Dementia. Following early conversations with members of the network regarding the draft document, a decision was made to focus the chat on the following two questions:

*1) Language is a powerful means of communication and the use of person-centred language is believed to be pivotal in addressing the stigma surrounding dementia, mental health, substance use and other neurological disorders. What does person-centred language mean to you? Can you provide examples of both person-centred and non-person-centred language?*

*2) The Health Quality Ontario draft document (Quality Statement #12) suggests that all care partners of people living with dementia should be provided with the information and support services required to provide care. What information and education have you found to be most beneficial? What information do you wish you had known/knew now?*

The first live chat brought together 10 individuals with lived experience from across Ontario; including representation from Markham, Timmins, Brighton, Perth, Sudbury, Cloyne, Kingston & Brampton. The following sections summarize the feedback provided in the live chat. The recommendations provided are based on the conversations and developed by the BSO Provincial Lived Experience Network Coordinator in collaboration with the other BSO Provincial Coordinating Office Team Members.

**Feedback: Language is a powerful means of communication and the use of person-centred language is believed to be pivotal in addressing the stigma surrounding dementia, mental health, substance use and other neurological disorders. What does person-centred language mean to you? Can you provide examples of both person-centred and non-person-centred language?**

- **Emphasis placed on the importance of language used by healthcare staff in LTC as the way that they speak has an effect on the LTC culture and attitudes of others:**

- In one Ontario LTCH, staff refer to a dementia care unit as “the village”, which has a negative connotation.
- There is a need to retire terms such as “demented” & “feeders” (referring to those requiring assistance at meal times) “how hard is it so say ‘support someone with their meal, assist someone with dinner, help someone [or] give them a hand’”

- Healthcare staff should respect preferences of residents' regarding how they like to be referred to. One participant shared that staff would refer to her (the care partner) as Mrs. \*LAST NAME\*, yet refer to her husband (resident in LTCH) by his first name. Another participant echoed the above statement and shared "That is a big one, \*Name\*. It leaves my Mom feeling like she is being talked about in a negative way instead of included in the conversation."
- One participant highlighted the importance of respect and trust towards all persons providing care: "Not speaking to a resident like they would a child--Proper oral language -- Working with each resident instead of working for them. Let each person be part of their care plan if at all possible and have some choices even if it just is a little. Try to work and develop as much independence as possible"

**RECOMMENDATION – Quality Standards # 10 & 11:** "...providers of various disciplines who are specialized in dementia care is necessary." The term specialized is very general; it may be helpful to include core competencies that these specialized Interprofessional care teams should have that go **beyond education and emphasize other key elements such as respect, compassion & dignity.**

- **Importance of describing responsive behaviours rather than labelling people using general terms:**
  - One participant suggested that instead of saying that a resident is "non-compliant", healthcare staff should describe his/her responsive behaviours (e.g., facial expressions, grabbing, etc.)
  - "I have always been one to not get too too excited about this word or that word. It often feels like words are a fad that come and go. They are acceptable one generation and not the next, to one person and not the next. I attended a long term care resident's dinner and was surprised when a resident was about to have her plate taken from her, she spoke up and said "Jeez, why do the staff have to always say "Are you done, Are you done?" Why can't they say "Are you finished?" and a lightbulb went on for me - to some people, words matter... I think for the most part it's the presentation, a negative indication vs. a positive one. [Example:] Your dad seems agitated vs. your dad likes to walk around after dinner."
  - "The medical community might need a word, but the family does not. Why does there have to be word? Why not just describe what is [being] observed?"
  - "I think the concern is that we assign motive to behaviour, sometimes that is not accurate. Terms like agitation and aggression give a tone of the person is being 'bad'".
  - "The concern is the tendency to sum things up to quickly - without investigating further. That's when ONE word can become a problem."
  - The use of blanket terms is also problematic when attempting to translate into other languages. It is easier to translate descriptive words such as "kicking", "grabbing", and "tearfulness" vs. "agitation".

**RECOMMENDATION – All QS:** Avoid use of blanket terms that have a negative connotation such as agitation and aggression in document in order to **encourage healthcare staff to describe behaviours.** Consider use of other terms such as responsive behaviours, personal expressions, behavioural and psychological symptoms of dementia and ensure to include a definition.
- **Confusion regarding the use of term 'caregiver' for both professional healthcare staff and family care partners:**
  - "I love the words Care Partner, I always introduce myself as a friend when on the Memory Care Unit"
  - Differentiating between healthcare professionals and family care partners is important as their education and training needs are different.
  - Importance of asking care partners how they wish to be referred to reiterated.

**RECOMMENATION – All QS:** Differentiate between healthcare professionals and family care partners in the document by using separate terms.

**Feedback: The Health Quality Ontario draft document (Quality Statement #12) suggests that all care partners of people living with dementia should be provided with the information and support services required to provide care. What information and education have you found to be most beneficial? What information do you wish you had known/knew now?**

- **Importance of education & training for care partners in the community & in LTC:** (**Please note:** While some participants were aware that the document was focused on hospital & LTC, much emphasis was placed on the need for training/education while still residing in community settings (i.e., upon diagnosis).

Much of the following feedback may be better suited to the development of *Quality Standards for Dementia in the Community.*

- “Wish I knew what I was getting into. I mean there is this whole lack of education in regards to what a caregiver truly is responsible for (legally and otherwise). I mean, all of a sudden you find out you are a power of attorney and you are truly caught off guard.”
- “My husband could have been at home a lot longer if I'd had some training”
- “I tried to get training in GPA and P.I.E.C.E.S., not available to caregivers only ‘pros”
- Avenues should be created for care partners to access education and training through CCAC, primary care practitioners, long-term care and hospitals (i.e, the most common places people go to in order to receive care).

*Participants were provided with the list included in the document and asked to comment.*

- Positive feedback received on the list; very comprehensive.
- Missing: knowledge about how to apply to LTC. (*Consideration for QS for Dementia Care in the Community*)
- It is important to further strategize about how to spread the word about the availability of education and training.
- Enhancing knowledge at the primary care level about the complimentary supports that exist to assist with system navigation.

**RECOMMENDATION-QS #12:** The list provided is very comprehensive and includes important elements. Further consideration for how this education will be offered/delivered is key to ensure uptake and adoption.

**RECOMMENDATION – QS for Dementia in the Community:** While education and training opportunities for care partners are important to make available in long-term care, it is imperative to make training and education available for care partners upon diagnosis. Strategies for how to broadcast the availability of training/education is necessary. Consider enhancing knowledge about training/education opportunities in places where individuals most often seek care (i.e., hospital, primary care, home care services, etc.).