



# Behavioural Supports Ontario Provincial Lived Experience Network Advisory

## Feedback: Developing Ontario's Dementia Strategy

### Background:

The purpose of the Behavioural Supports Ontario (BSO) Provincial Lived Experience Network Advisory is to join voices from across the province to establish a provincial network of individuals with lived experience. The advisory also guides BSO projects and participates in an accessible virtual platform to connect people through shared experiences. Lived experience in the context of BSO refers to the experience of living with dementia, mental illness, 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 BSO Lived Experience Network Advisory is co-chaired by Sharon Osvald, Lived Experience Network Coordinator for the BSO Provincial Coordinating Office & Rhonda Feldman, Mental Health Clinician with the Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training.

In an effort to engage individuals with lived experience in the provision of feedback on the 'Developing Ontario's Dementia Strategy' Discussion Paper, the network hosted two events with tailored discussion questions:

- 1) Live Chat (hosted on [www.dementiacrossroads.ca](http://www.dementiacrossroads.ca)) on October 19, 2016
  - a. What would make it easier for people with dementia and their care partners to navigate existing available services and supports?
  - b. What existing services or supports are most effective in assisting care partners of people with dementia?
  - c. What would an ideal dementia friendly community look like?
- 2) Teleconference Meeting on November 8, 2016
  - a. What are some characteristics of high quality programs that help people with dementia and their care partners to live well?
  - b. What existing services or supports are most effective in assisting care partners of people with dementia?

### As a result of the discussions, four key themes emerged:

- **Access** – how to find, qualify for, and connect with needed resources; how to promote public education to reduce stigma
- **Consistency** – knowledge and training for front line care staff; regulation of required education for all care partners and other residents in LTC; referral process to services; single “case manager” point person for system navigation and advocacy
- **Flexibility** – needs-based services instead of rules-based services; focus on strengths and not weaknesses of person with diagnosis
- **Accountability** – when there are challenges in communication between care partner and care provider; regulating privacy in social media

A more detailed review of the themes that emerged is provided in the sections following:

## 1. What would make it easier for people with dementia and their care partners to navigate existing available services and supports?

### Key Findings:

- **Family Physicians/Specialists need to be Well Trained about Dementia and Able to Share Resources:**

- “Family physicians/specialists should be well trained in regards to the services/resources available in the community for those with dementia and their family in order to point the patient and caregiver in the right direction”. On the same note, another participant added that it would be helpful if doctors would provide navigation tools upon diagnosis.

- **Local, Consistent, Coordinated Approach to Care and having one point of contact- Advocate/Care Coordinator:**

- “Local, consistent, coordinated approaches to care including having one point of contact for family care partners such as an Advocate or Social Worker would be helpful when navigating the healthcare system and to become aware of which services are available”. On this note, another participant added that often family care partners are pointed in the direction of services such as CCAC by a family physician, however do not know what questions to ask or what to expect.
- “It would be nice to have a “go-to” person after diagnosis, someone to call and help figure out what is next as the dementia progresses.”
- “I went to a workshop and got introduced to a BSO worker who has stayed with our case all along. That is better than the inconsistent service provided by PSW organizations. This is important to those living with dementia.”
- “I think having “a” person is important, even better if it's the same person every time.”
- “I have (seen a counsellor) once Mom came here for long-term care. I was not coping well and after discussion with my General Practitioner she suggested going to the Alzheimer Society for help. They in turn helped me start with a psychologist who stayed with me until well after Mom had passed away. I am lucky I have private insurance that paid for it. This is a big deal”.
- “What worked well were supports that travel alongside the “person and family” throughout their entire experience - not just a one-time service but ongoing support.”
- The benefit of living in a smaller community was noted. Things were simpler, relationships were better and this improved navigation. A participant stated “I think Family Doctors & Nurse Practitioners in small communities have more information through their office staff; everyone has a friend or family member who is on the road. In cities it may be more complicated. I know my brother (who lives in an urban community) had more trouble finding help for Mom.”

- **Easy to Access Paper and Internet Resources:**

- One participant suggested easy access to paper or online resources would be helpful when seeking information as it is sometimes difficult for family care partners to find resources when they are not yet aware of the services available.
- “We need a navigation tree: ABCD and what happens if you get stuck out on a limb.”

- “Many web sites show you places - and in some ways they show you what you need to consider, but they are talking about help for physical issues and children’s issues not just dementia. It is confusing.”

- **Educating the Public and Tackling Stigma:**

- One participant noted that educating the public in order to address stigma in regards to mental health and dementia would help eliminate barriers for those with dementia and their care partners.
- “I think that over the past few years "Let's Talk" has really helped make the general public have a better understanding about mental illness. We need a public forum similar to make everyone in general more aware about dementia and give everyone tools to "Let's Talk" about dementia.

- **Peer to Peer Support and Education:**

- “Peer to peer support and education for family caregivers” was suggested by a participant as it was noted this would provide family care partners with the advice they need when difficult problems/questions arise.
- “I feel that helping others through the maze is best done by those who have had to experience it themselves, along with service providers.”
- “A few years back, I attended a day-long seminar called "In My Shoes". That type of seminar where family care partners and medical providers come together was a great eye opener for me and it lifted the dark veil I was walking behind.”

- **The Use of Technology and Access To Services in More Remote Areas:**

- “The use of technology and access to services in more remote areas such as webcam based chat availability for consultations/education by physicians and specialists are important”.
- “There are great advantages of technology in visiting with spouses and family in long-term care like Skype and FaceTime. Maybe those technologies can help people to access supports too.”

## 2. What existing services or supports are most effective in assisting care partners of people with dementia?

### Key Findings:

- **Day Programs, Respite and Social Work for Care Partners:**

- “We have ‘Nora's House’ in Mississauga. My mother stayed there for 2 weeks while we went on a cruise. It is a house owned by Alzheimer Society of Peel (donations are provided to keep it running) and it has 10 beds and is staffed by nurses that are trained on dementia. My mother did not want to come back to her apartment. It cost me \$75 per day and I got a tax receipt for it. The best part is that I could go away and not have to worry.” Another participant added “We need more Nora's houses for sure. The respite beds in long-term care are often scary for people to go to the first time.”
- Participants indicated that home care and access to consistent services across the province is an issue at present. There are areas that do not have consistent services across neighborhoods at the moment; some services are only available in particular cities.

- A participant noted that brief respite services would be helpful as she stated “For a while I didn't need help from home care, I just needed time to do groceries and take a break.”
- “I found that another frustration with my Mom was when I left town. The long-term care facility would NOT permit a paid PSW from an agency to come and socialize with my mother while not providing personal care, but if I paid a long-term care PSW staff member off duty they could to it.”
- “There needs to be more respite services available, i.e., respite beds so caregivers can get a real break.”

• **Home Care and Access to Consistent Services across the Province:**

- “Home care is confusing. It was hard to know what we qualified for and it was always someone different which was confusing for me and my dad. We got really tired of telling our story. We need information on changing needs as the disease progresses. Next, we need help for the caregiver as long as client is at home - everything from a night's sleep, going for groceries and meeting a friend for tea.”
- “One issue that I know comes up a lot when talking about home care is the stipulation that the care receiver MUST accept bathing in order to qualify for other in-home services. My grandmother had this challenge as she was very uncomfortable with the idea of a ‘stranger’ bathing her, but since my mother (as the primary caregiver) needed help, they had to take it or leave it altogether.”
- “Existing services differ by area. We are fortunate to have many services in Mississauga/Halton that are not available in Etobicoke (Toronto) even though it is next door.”
- “Qualifying for in home services is a nightmare.”

**3. What would an ideal dementia-friendly community look like?**

**Key Findings:**

• **Compassionate, Empathetic, Knowledgeable and Stigma-Free Communities Searching for Creative Solutions:**

- “There would be easy to access to information regarding how to obtain services in the community for both the family care partner and individual with dementia”.
- One participant suggested that places of business (shops, banks etc.) would be made more accessible to those with dementia by training staff on how to assist individuals with cognitive impairments. The subject of accessibility was discussed further as another participant suggested that a sticker could be added to shop windows that would indicate that the shop is accessible for those with dementia or other age related disorder.
- “Some European cities have dementia friendly towns in which individuals with dementia can be more independent and involved in the community as people within the community are educated on the disease”.
- “Affordable programs that would assist those with dementia in becoming more involved in the community should be easily accessible and available.”
- “An adequate amount of staff members would be required in order to provide services other than personal care such as multiple recreational activities daily in long-term care to keep residents engaged and socially active”.

- One participant suggested a dementia-friendly community would engage in activities that would reduce stigma regarding age related disorders such as the Bell “Let’s Talk” campaign did for depression and other mental health disorders.
- Participants agreed that having accessible, knowledgeable and trustworthy care partners that family care partners can go to for information and help regarding the patient is key. These individuals would need to keep personhood in mind when assisting with the coordination of services for the patient. This point of contact could be a social worker, case worker, or long-term care home staff member.
- “Mandatory training for long-term care staff members in regards to dementia that they can actually utilize. Often, staff members are trained and they cannot utilize these skills because there is not enough staff present, making personal care the only thing there is time for. This does not cater to the patient’s social or spiritual needs”.
- “Processes regarding volunteering at long-term care homes needs to be improved in order to lessen barriers for volunteers”.
- “Affordable transportation for patients with dementia needs to be made available so patients can spend more time in the community or attend appointments/ events without barriers”.

#### **4. What are some characteristics of high quality programs that help people with dementia and their care partners to live well?**

##### **Key Findings:**

- “Consistency in regards to follow up with a patient’s progress”.
- “A program that fosters autonomy and the individual’s strengths in order to keep the individual involved within their community and engaged”.
- “Proper dialogue between family care partners and healthcare providers to ensure expectations are being held consistent for all persons involved”.
- “Respite care would be helpful, particularly when the respite worker has the option of taking the patient out of the home to engage in activities. This would provide the patient with a sense of autonomy. The program should be directed by the patients individual needs and interests and be flexible”.
- “High quality training for all staff in regards to person-centred approaches in dementia”.
- “Offering education to other long-term care residents so they know how to interact with an individual with dementia”.
- Strict regulations in regards to what a respite/home care worker can do in the home. These regulations would require some degree of flexibility as what is appropriate may differ between families”.
- “Regulations in regards to the use of social media and technology used by respite/ home care workers (such as emailing the patient, assisting them with the use of social media, taking photos, etc.)”.
- Accountability and transparency of programs and services was a common theme among participants.

- “Programs should offer a variety of activities for patients to choose from”.
- “Effective strategies would transfer between programs/services to ensure consistency in care, particularly in regards to long-term care, behaviour support transition units, and respite programs”.
- “Consistency in regards to staff members in order for staff to get to know the patient and their family. This way patient-centred care can be provided without important details slipping through the cracks”.
- “Availability of a consistent, respected and knowledgeable staff member who family care partners/ patients can go to if there are any issues in regards to care that need to be resolved at a higher level”.

## **5. What existing services or supports are most effective in assisting care partners of people with dementia?**

### **Key Findings:**

- One participant stated that the Behaviour Support Transition Unit (BSTU) has been effective in providing strategies for care partners in regards to medication adjustment and responsive behaviours to improve the quality of life of the patient and their family. She also added that there was consistency in regards to dementia educated staff and doctors. Emphasis was placed on personhood and individualized care plans. Doctors were willing to trial new interventions and medications to discover what worked best for the patient. There were issues in regards to the transfer of these effective strategies to long-term care as the home did not have the staff, resources or training in order to follow this effective care plan created by the BSTU.
- “The use of story boards, particularly later in the disease process. This often assists with finding triggers for responsive behaviours as the patient’s life story and experiences are taken into account. The use of these strategies in regard to the patient’s personhood needs to be consistent between staff. These existing strategies therefore can be improved”.