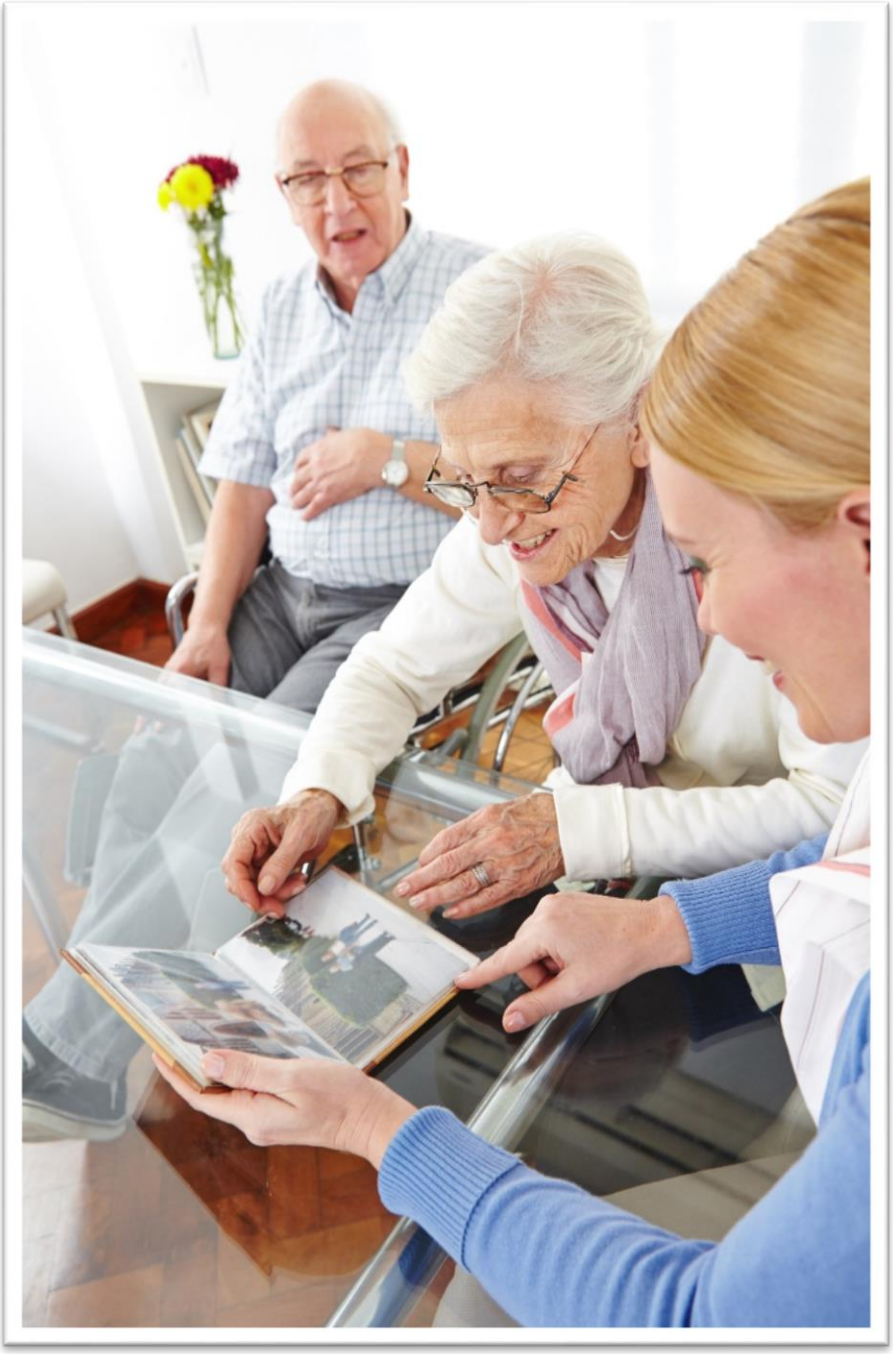
Behavioural Supports Ontario
Soutien en cas de troubles du comportement en Ontario



Making Connections:

Recommendations to enhance the use of personhood tools to improve person-centered care delivery across sectors

Behavioural Supports Ontario Lived Experience Advisory

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Developed by: The Behavioural Supports Ontario Lived Experience Advisory *in collaboration with the Behavioural Supports Ontario Provincial Coordinating Office*

About the BSO Lived Experience Advisory

The Behavioural Supports Ontario (BSO) Lived Experience Advisory (LEA) unites individuals with lived experience across Ontario to improve care for older adults and their families living with dementia, complex mental health, substance use and/or other neurological conditions. The BSO LEA develops projects of particular interest to its members in addition to advising on other BSO projects and related initiatives across the province. In the context of BSO, the term 'lived experience' refers to the experience of living with dementia, complex mental health, substance use and/or neurological disorders (i.e., the BSO target population) or the experience of being a care partner of an individual living with 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 the above conditions. The BSO LEA officially launched in January 2016 and is led by Sharon Osvald, Lived Experience Facilitator, BSO/brainXchange, Dr. Rhonda Feldman, Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, and Katelynn Viau, Project Coordinator, Behavioural Supports Ontario Provincial Coordinating Office (BSO PCO), with the support of brainXchange and the BSO PCO.

Personhood Tools Project

Upon the advisory's inception, a priority goal surfaced to develop recommendations to enhance the use of personhood tools in different clinical care sectors (i.e., the "Personhood Tools Project"). Members felt strongly that when caring for someone living with one or more of the conditions listed under BSO's target population, it is essential to remember them as people with their own values, interests, preferences and histories. Information about someone's personhood provides them with a voice regarding their care preferences and when they may no longer be able to verbalize their wishes.

In the context of BSO, information about an individual's personhood helps identify potential triggers and/or causes of responsive behaviours along with strategies to reduce their incidence and better support the individual through non-pharmacological interventions. The BSO LEA Members also suggest that leveraging personhood information in clinical care across sectors can reduce stigma, foster respect, increase safety, enhance empathy, promote care

continuity, and improve the overall care experience. Ultimately, the members of the advisory felt that information related to one's personhood could improve the delivery of person and family-centered care while also emphasizing dignity across all sectors.

Brief Literature Review & Evidence Base

The value of personhood information to promote better person-centered care is supported by international literature, best practice guidelines pertaining to the care of older adults, and in Health Quality Ontario's recently published 'Quality Standards for Behavioural Symptoms of Dementia'.

The concept of integrating information related to one's personhood in care planning for older adults is not new. In fact, back in 1986, Johnson stated that creating the conditions necessary to help older people tell their stories enables a more 'dynamic and authentic' picture of their lives which empowers health and social care staff to have greater awareness of the person's present day behaviours, beliefs and values (Johnson, 1986; Kindell, Burrow, Wilkinson & Keady, 2014). The provision of person-centered care for older adults extends beyond physical and medical needs and must consider their aspirations, concerns and relationships that are important to them (Ford & McCormack, 2000; Clarke & Hanson, 2003).

Kindell et al., (2014) studied life story work with people living with dementia. They found that different points of connection for biographical work could benefit persons living with dementia, their family and the care partners working with them. These connection points include: **emotional connections, practical care connections, building new connections and interactional connections.**

Emotional Connections

Documents describing one's personhood have been shown to be an enjoyable and beneficial exercise for an individual and their family. Engaging in this activity may help a person feel pride while reflecting on past accomplishments (McKeown, et al. 2011) and connect with their own identity in a positive way (Kindell et al., 2014). For families, engaging in these activities may result in a form of reminiscence therapy and help them with their relative's transition into new care setting (e.g., long-term care) or change in care needs. "Collaborating together in biographical work not only helped to strengthen the relationship between the care worker and the older person, but also between staff and the older person's relatives" (Clarke & Hanson, 2003, p. 702).

Practical Care Connections

Personhood documents help staff develop and implement tailored care plans, including day-to-day activities, based on an individual's particular interests and needs. (Kindell, et al., 2014). A growing number of researchers have noted that non-pharmacological approaches should be pursued first for people living with dementia, before considering pharmacological treatment (Douglas, James & Ballard, 2004). The acknowledgment of the principles of personhood is essential to the effective application of non-pharmacological interventions.

Building New Connections

Access to information regarding one's life experiences, hobbies, and personal preferences can assist staff in building new supportive relationships and partnerships. Biographical information can 'help staff to see the person behind the patient/resident' (Bakken et al., 2009; Gibson & Carson, 2010; McKeown et al., 2011) which Nolan et al., 2002 stress is especially important in geriatrics where practitioners may have limited awareness of the needs of older people. It is common for staff to have negative perceptions and stereotypes towards older people. Engaging staff in biographical work helps to challenge negative stereotypes about later life (Nolan et al., 2002; Gibson, 1998; Clarke, 2000).

Interactional Connections

Completed personhood tools provide staff with a physical resource to elicit memories and encourage meaningful conversation. Tangible objects related to one's personhood such as photographs, letters, or pieces of relevant memorabilia help staff better interact with patients/residents in personalized ways (Johnston & Narayansamy, 2016). These items may also assist in helping staff to engage with patients/residents in further 'legacy work', such as the creation of memory boxes or life story books which have shown to benefit both the individual and staff.

The Ontario Context

The principles of understanding patient/resident personhood to inform care planning and delivery have been widely encouraged in clinical practice. The importance of personhood has been recognized in The Registered Nurses' Association of Ontario's (RNAO) Clinical Best Practice Guidelines (BPG) for Delirium, Dementia, and Depression in Older Adults (2016) and Health Quality Ontario's (HQO) Quality Standards for Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes (2016). The RNAO's BPG acknowledges the uniqueness of individuals and that in order to provide person-centered care, care needs be individualized; this includes knowing and basing care plans on the person's preferences, retained abilities, interests, spirituality, etc. (RNAO, 2016). In HQO's aforementioned quality standards, individualized care plans and non-pharmacological intervention recommendations are stressed for individuals presenting with responsive behaviours (HQO, 2016). "Treatment approaches should include a combination of non-pharmacological interventions that are individualized based on the person's needs, symptoms, preferences, and history" (p. 13).

Project Methodology

Over the course of several meetings with various key partners, it became increasingly clear to the LEA that the use of personhood tools for the BSO target population varied significantly across sectors. While some members of the advisory had lived experience with completing personhood tools, others had no experience with their use. Despite the variety in experiences, all members saw opportunity in the development of recommendations to enhance the use of personhood tools across sectors. Members stressed the importance of developing a practical

document that readers could quickly navigate in order to locate tools relevant for their practice.

In the months following the initial conversations regarding personhood, the advisory focused on answering the following questions to assist in the development of recommendations:

(1) Which elements of personhood are most helpful to inform care planning and care delivery in the community, in adult day programs, at the hospital and in long-term care?

(2) When should information about personhood be documented and how often should it updated?

(3) Who would the information about personhood be most helpful for in the community, in adult day programs, at the hospital and in long-term care?

(4) Where should information about personhood be shared, displayed and/or stored?

(5) How can persons and families promote the use of information gathered from the tool amongst health care providers in the community, in adult day programs, at the hospital and in long-term care?

(6) What tools currently exist to promote elements of personhood that can be used in the community, in adult day programs, at the hospital and in long-term care?

The following recommendations were developed through discussions regarding lived experiences, presentations from various personhood tool authors, consultations with experts, and a live online chat on www.dementiacrossroads.ca.

(1) WHICH elements of personhood are most helpful to inform care planning and care delivery in the community, in adult day programs, at the hospital and in long-term care?

The following elements are included in one or more personhood tools recommended by the BSO Lived Experience Advisory members. These lists represent a compilation of factors that might be part of one's personhood. BSO Lived Experience Advisory members recognize that beginning these conversations with someone that you do not know very well may be challenging. They suggest starting the conversation by stating that you **would like to get to know them better as a person.** A British group made up of people with lived experience who are trying to spread the use of life story work also suggests starting with what the person wants to tell you; rather than a list of questions and to attempt to gather information through every day conversation (Told in South Yorkshire Resource Pack, n.d.).

A: GENERAL INFORMATION & LIFE OVERVIEW	

• Preferred Name
• Preferred Language and other Languages Spoken
• Birth Place & Other Cities Lived In
• Pets (Current & Past)
• Significant Dates and their Meaning
• Spirituality, Religion, Traditions & Other Cultural Considerations
• "What matters to you?"
• Past Life Role & Careers
	• What the person is most proud of and/or what they are most proud to be known for/as
	• Significant Persons in Life (Names of Family Members, Relationships)
	• Current Relationship Status (Single, Married, Widowed, Separated)
	• Sources of Hope, Comfort, Joy, Inspiration & Favourite Things
	• Happiest Memories (Vacations, Holidays)
	  ○ E.g., "*What was the happiest time in your life?*"
	• Significant Low Point(s) in Life/Trauma
	  ○ E.g., "What was the hardest time in your life?"

B: LIKES & DISLIKES

- Hobbies, Interests & Socialization Habits (Current & Past)
    - Music (e.g., Listening to Music, Playing an Instrument)
    - Reading
    - Sports
    - Arts (e.g., Painting, Drawing)
    - Television
    - Games (e.g., Playing Cards, Board games, Video Games)
    - Outdoor Activities (e.g., gardening)
    - Woodworking
- Dislikes & Fears

- Personal Care Preferences (including capabilities that the person can and wishes to still complete independently and preferred time of day)
    - Tub/Shower
    - Dressing
    - Dental Care
    - Eye Care/Glasses
    - Hearing Aid
    - Hair Care
    - Makeup
    - Shaving
    - Toileting
    - Use of appliances (kettle, stove, microwave)
    - Household tasks (sweeping, dusting, laundry)

C: ROUTINES

- Typical day (in the past and currently)
    - Wake up time and morning routine
    - Afternoon Routines
    - Evening Routines
    - Night Routine and usual sleep time
- Meal & Meal time Preferences (including eating capabilities that the person can and wishes to still complete independently)
    - Breakfast, Lunch, Dinner & Snack Routines
    - Hot & Cold Drinks and Alcohol Use
    - Use & Size of Cutlery
    - Food preferences (i.e., texture, variety, foods that are a source of comfort)
    - Use of Smocks and Aprons

D: ADDITIONAL CONSIDERATIONS

- Communication Tips (including information about vision, hearing and use of interpreters)
- Mobility & Use of Mobility Aids
- Coping Mechanisms/Validation Phrases
- Unsafe walking (patterns, safety precautions, ways to redirect)
- Tendency to hide articles or items
- Finance Management Capabilities
- Night time Restlessness (and strategies to mitigate)
- General Restlessness (and strategies to mitigate)
- Frequency of Repetitious Mannerisms (and strategies to mitigate)
- Other Safety Precautions
- Visual & Sensory Environment (e.g., use of call bells, doorbells, background music, etc.)

(2) WHEN should the information be documented and how often should it be updated?

An individual's interests and hobbies might change over time, particularly in the presence of certain illnesses such as dementia where capabilities may fluctuate and decrease as the illness progresses. Changes in primary health providers and transitions (e.g., moving from hospital to long-term care) may also propel changes which should be considered. The updating of information should involve ongoing exploration of an individual's change in interests, environments and routines.

IN THE COMMUNITY	AT ADULT DAY PROGRAMS	AT THE HOSPITAL	IN LONG-TERM CARE (LTC)
• As early as possible in situations where the individual may develop cognitive impairment in later stages of illness. • Updates to be made on an annual basis and/or upon any significant changes in health status, behaviour or personhood. • *Additional Consideration:* The completion of personhood tools early on in diagnosis may also be a form of reminiscence therapy for the individual.	• Prior to admission to the adult day program • Updates to be made on every 6 months and/or upon any significant changes in health status, behaviour or personhood.	• Prior to admission for a prolonged hospital stay. • Updates to be made upon any significant changes in health status, behaviour or personhood.	• Prior to admission into LTC. • Updates to be made every 6 months and/or upon any significant changes in health status, behaviour or personhood. *Note: The LTC act **requires** that all residents have a plan of care that details all aspects of care "including medical, nursing, personal support, nutritional, dietary, recreational, social, restorative, religious and spiritual care." These plans are required to be reviewed and revised every 6 months (at minimum).*

(3) WHO might the information be most useful for?

The following are a list of settings in which information gathered using a personhood tool may be helpful. It is of importance to note that this list is not exhaustive and that a person's circle of care may involve a wide variety of health care professionals beyond those listed below.

IN THE COMMUNITY	AT ADULT DAY PROGRAMS	AT THE HOSPITAL	IN LONG-TERM CARE (LTC)
• Family/Friends • Visiting health care providers (home care, allied health staff, BSO) & Physicians • Volunteers (e.g., Friendly Visiting Programs)	• Family/Friends • Adult Day Program Staff • Volunteers	• Family/Friends • Health Care Providers (Front-line Staff, Nursing/Allied Health Staff, Physicians) • Chaplaincy Staff • Volunteers	• Family/Friends • LTC Staff (Front-line Staff, Nursing/Allied Health, Recreation Staff, Behavioural Supports Ontario Staff, Social Work, Directors of Care, Physicians) • Volunteers • Other Residents of the LTC home to assist in the development of friendships between co-residents

(4) HOW can the information be promoted by family care partners?

While these recommendations are primarily focused on raising awareness about the importance of personhood tools and aims to increase an uptake in their use, it's also important to consider how to support the integration of the information into practice. Where possible, identify one lead individual who will have the responsibility of alerting others as to the existence of a completed tool and partner with relevant staff to assist in incorporating relevant content into care planning across sectors.

IN THE COMMUNITY	AT ADULT DAY PROGRAMS	AT THE HOSPITAL	IN LONG-TERM CARE (LTC)
• Ensure that visiting health care providers are aware of where the completed tools can be found. • Identify particular sections or items of the completed tool that are relevant to the visitor's scope of practice or reason for visit (e.g., provide PSW with information regarding bathing preferences, identify social preferences with friendly visitor program volunteers)	• Provide Adult day Program Staff with a completed tool upon first visit to the program. Invite staff to add information to the tool as they see fit.	• Provide staff with permission to share the completed tool with the health team by placing it in a secured binder. • Post a condensed version of a completed tool (e.g., 1-page profile) with items relevant to the hospital environment (e.g., personal care preferences, meal preferences/habits & items falling under 'special considerations'.) Consider avoiding the inclusion of sensitive information (e.g., low points in life) in this version.	• Provide staff with permission to share the completed tool with the health team by placing it in a secured binder. • In care conferences with family members where their input can become part of the resident's plan of care which is to be based on an assessment of that resident and their needs and preferences.

(5) WHERE might the information be shared, displayed and/or stored?

Every individual has the right to privacy and confidentiality with their own personal information. Individuals and their care partners must be consulted before sharing or displaying sensitive personal information, and consent must be provided on a case by case basis.

IN THE COMMUNITY	AT ADULT DAY PROGRAMS	AT THE HOSPITAL	IN LONG-TERM CARE (LTC)
• In a consistent location where all visitors can locate (e.g., on top of refrigerator, magnetized to the refrigerator, in a particular drawer/cupboard.) • 1-page laminated version can be left on dining room table that includes information about where to find particular items in the home related to the individual's personhood. • Specific elements can be written separately and posted in the living space most applicable to the items (e.g., have bathing or toileting preferences laminated and post them in the bathroom on the wall)	• Inside a binder accessible to all adult day program staff or wherever other information related to the person is located.	• Inside a binder accessible to all hospital staff or wherever other information related to the person is located. • Condensed version of tool (e.g., 1-page profile) can be posted above the bed, on a wall, on the inside of a closet door or inside a drawer.)	• In the resident's plan of care which is required to have interdisciplinary LTC staff collaboration and accessible to LTC staff to inform them of the needs, interests and preferences. • Interests Incorporated into a visual collage that is displayed in the resident's room to inform volunteers and visitors of the resident's personhood. • Specific elements can be written separately and posted in the living space most applicable to the items (e.g., have bathing or toileting preferences laminated and post them in the bathroom on the wall

(6) WHAT are the tools recommended by the BSO Lived Experience Advisory?

All tools are recommended to be completed by an individual who knows the person best, and, wherever possible, with the person that the tool describes.

IN THE COMMUNITY	AT ADULT DAY PROGRAMS	AT THE HOSPITAL	IN LONG-TERM CARE (LTC)

• All About Me *(Full Version)*
• "The Life Story Of" *(Reminiscence Therapy)*
• All About Me: A Conversation Starter
• PIECES of My Personhood
  ○ English
  ○ French
  ○ Indigenous Adaptation
• This is Me
	• All About Me: A Conversation Starter
	• PIECES of My Personhood
	  ○ English
	  ○ French
	  ○ Indigenous Adaptation
	• This is Me
		• All About Me: A Conversation Starter
		• This is Me
		• PIECES of My Personhood
		  ○ English
		  ○ French
		  ○ Indigenous Adaptation
			• All About Me: A Conversation Starter
			• This is Me
			• PIECES of My Personhood
			  ○ English
			  ○ French
			  ○ Indigenous Adaptation

Disclaimer: The tools recommended in this document are not inclusive of all personhood tools.

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