![Behavioural Supports Ontario / Soutien en cas de troubles du comportement en Ontario](logo)

October 2018

Behavioural Supports Ontario Person-Centred Language Initiative

Report

Prepared and presented by

Behavioural Supports Ontario Provincial Coordinating Office
and the Person-Centred Language Initiative Expert Panel Members

Project Background and Description

Behavioural Supports Ontario's (BSO) Knowledge Translation and Communications Advisory reignited a conversation on language with intentions of fulfilling one of its terms of reference objectives: to critically reflect and provide recommendations regarding language and communications used by BSO and its key stakeholders. Leads were assigned to the initiative and a time-limited expert panel comprised of persons with lived experience and others with various expertise was formed. Over the course of a year, the expert panel was able to create a living document in the shape of Person-Centred Language Commitment Statements informed by the authentic voice of persons with lived experience to promote the consistent use of person-centred language that is appropriate, respectful, life-affirming and inclusive when talking about individuals served by BSO's mandate. This mandate includes older adults presenting with or at risk of responsive behaviours/personal expressions that may be associated with dementia, complex mental health, substance use and/or other neurological conditions and their care partners. This document also includes relevant resources in the form of a toolkit to further awareness and knowledge regarding person-centred language and communication.

The collaborative leads of this project are listed below in alphabetical order:

- Kate Ducak, Project Officer, Schlegel-UW Research Institute for Aging
- Gagan Gill, Public Policy & Programs Analyst, Alzheimer Society of Ontario
- Tina Kalviainen, Strategic Communications Specialist, Provincial Coordinating Office (PCO), Behavioural Supports Ontario (BSO)

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Acknowledgements

We wish to extend our sincere gratitude and appreciation to the expert panel and leads for kindly dedicating their time and knowledge by taking part in and supporting this initiative throughout 2017-18. Central to this initiative are the unique perspectives of our members with lived experience who were invited and included in the process of shaping the Person-Centred Language Commitment Statements. We would also like to thank those we reached out to for their contributions along the way.

Pictured above are expert panel members that were able to meet in-person on November 15, 2017.

The BSO Provincial Coordinating Office would like to acknowledge the following individuals and organizations for their contributions as the Expert Panel:

"Through his own personal experience, Ron had much to offer and said he was thankful to have been asked to join the group alongside Pat Smola and Brittney Krooger from University Gates and David Kent from Erin Meadows. His sense of self-worth as someone living with dementia rose, he says, knowing that his opinions were valued among those offered on the expert panel."

Excerpt from the January 16, 2018 Schlegel Villages' Village Voice monthly newsletter Rethinking Language to Tackle Stigma article. (http://schlegelvillages.com/news/rethinking-language-tackle-stigma)

> Throughout this document, the term **individual** refers to an older adult presenting with or at risk of responsive behaviours/personal expressions that may be associated with dementia, complex mental health, substance use and/or other neurological conditions as served by BSO's mandate.

Why do we need appropriate language?

The best response to this question is succinctly and powerfully provided by Dementia Australia:

> "The words used to talk about dementia can have a significant impact on how people [living] with dementia are viewed and treated in our community. The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person [living] with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person [living] with dementia experiencing stigma or discrimination." (Dementia Australia, 2014, p. 1)

What is language?

Language has been described as "a powerful and ever-evolving force for social change" (Whitehouse, 2013, p.107), with keywords sometimes capturing our imagination, conjuring up vivid images (especially through the use of metaphor) and even serving to achieve strategic goals. On the other hand, people sometimes use words out of habit, without reflecting on the meanings. Language use is also dependent on numerous factors such as who is speaking and to whom, the context, the mood or atmosphere, the person's feelings about dementia, whether the person is comfortable with the topic, as well as factors linked to specific cultures (e.g. history, traditions, literature, beliefs and linguistic norms) (Alzheimer Europe, 2013).

Variations in Terminology

Members of various cultures share a common philosophy and may use different words and languages to refer to the same thing (Bowman, Ronch, & Madjaroff, 2016). Despite this shared understanding, many leaders and advocates tend to be selective about the words they choose as language is central to the culture and identity they shape in collaboration with others (Bowman, Ronch, & Madjaroff, 2016). Culture change in Canada typically is defined as an ongoing, holistic journey toward incorporating relational living within institutional settings where values, beliefs, attitudes, language,

practices and policies are explored to collectively transform the culture into a community where everyone thrives (Schlegel-UW Research Institute for Aging, 2015, p. 7).

The commitment statements and other resources affiliated with BSO's Person-Centred Language Initiative acknowledges that different organizations have certain terms or language that they use as shaped by their organizational mandate, culture, policies and related regulations. For example, one organization might have a congregate living culture because of the services they provide and, therefore, prefers to use terms typically associated with a personal expressions philosophy rather than a responsive behaviours framework to objectively describe interactions with persons they encounter. See the Resources sections near the end of this report for more information and examples.

Cultural Awareness

As per Dementia Australia's Dementia Language Guidelines (2014), terms and words may not always be appropriate when talking to people from culturally and linguistically diverse communities or in translation as it may be seen as offensive or disrespectful. Words and phrases that are appropriate in one community may be offensive or of no meaning in another community. It is important to be aware of the cultural background of the person, family and/or community so that you can use the most appropriate language. Also keep in mind that "culture" refers to any group that the person identifies with, such as their ethnicity, religion or spiritual beliefs, gender identity and expression, sexual orientation, ability, socioeconomic status, etc. (Ontario Centres for Learning, Research and Innovation in Long-Term Care, 2018). It is always advisable to seek guidance from the person and their care partners as well as members of and/or organizations representing culturally and linguistically diverse communities on appropriate terminology whenever possible.

How do We Communicate?

We all need to communicate; it is part of our identity. Communication continuously influences and strengthens who we are as individuals and in relation to others (Alzheimer Society of Canada 2016). We tend to think about communication as talking, yet over 90% of communication happens through non-verbal communication such as facial expression, gestures and touch (The Alzheimer Society of Ireland, 2018). We share our ideas, needs, experiences, emotions and values in many ways, such as:
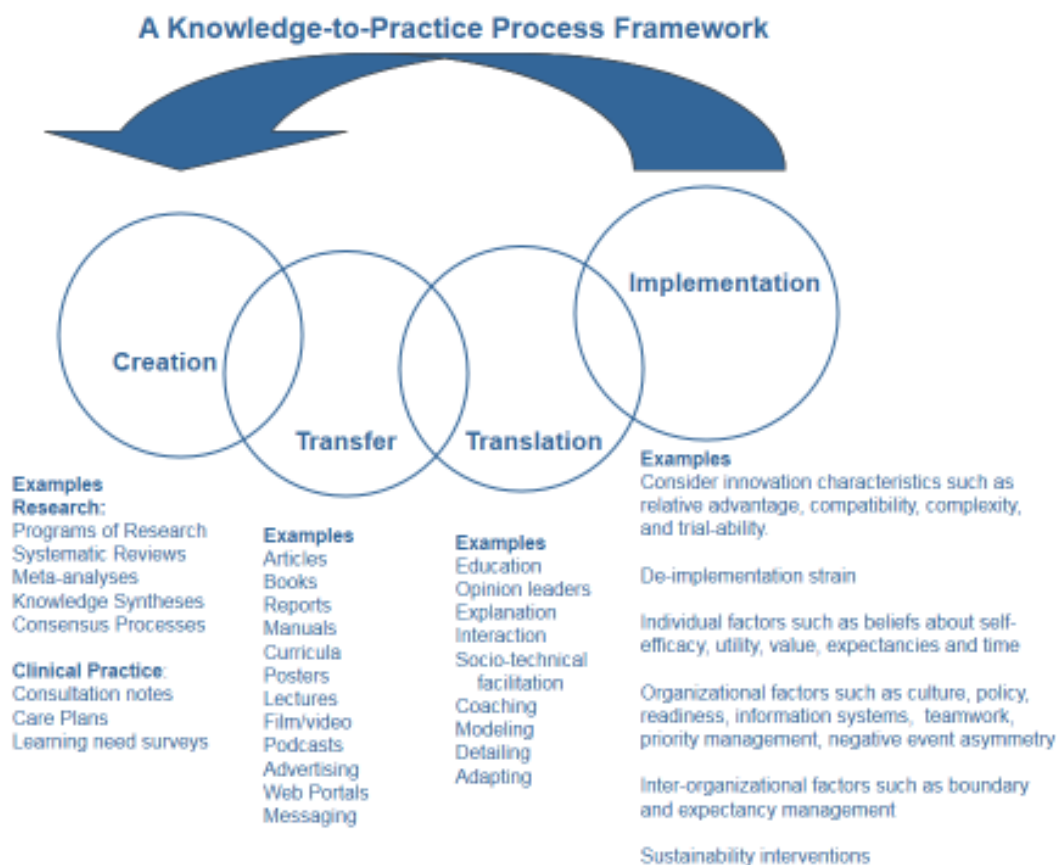
- Verbally: words we use
- Vocally: sounds we use
- Non-verbally/vocally: body language (facial expression, posture and gesture)
- Para-verbally/vocally: tone, pacing and volume of our voice

Bringing Person-Centred Language into Practice

BSO's Knowledge Translation & Communication Advisory selected the Knowledge to Practice Process Framework (Ryan, et al., 2013) to be utilized provincially to support BSO's pillar: 'Knowledgeable Care Team and Capacity Building'. In an effort to revolutionize how to implement practice changes, the framework was developed to consider multiple factors that need to be contemplated in bringing knowledge into practice. In order to drive change and enable the implementation of new knowledge, a four element, also thought of as a four step, process was derived.

As pictured below, the four steps include: Creation – Transfer – Translation – Implementation.

The expert panel considered the four elements/steps of the process to better equip individuals in their efforts to practice and promote person-centred language. The following pages will include some concepts that were explored.

A Knowledge-to-Practice Process Framework

Creation

Transfer

Translation

Implementation

Examples
Research:
Programs of Research
Systematic Reviews
Meta-analyses
Knowledge Syntheses
Consensus Processes

Clinical Practice:
Consultation notes
Care Plans
Learning need surveys

Examples
Articles
Books
Reports
Manuals
Curricula
Posters
Lectures
Film/video
Podcasts
Advertising
Web Portals
Messaging

Examples
Education
Opinion leaders
Explanation
Interaction
Socio-technical
   facilitation
Coaching
Modeling
Detailing
Adapting

Examples
Consider innovation characteristics such as relative advantage, compatibility, complexity, and trial-ability.

De-implementation strain

Individual factors such as beliefs about self-efficacy, utility, value, expectancies and time

Organizational factors such as culture, policy, readiness, information systems, teamwork, priority management, negative event asymmetry

Inter-organizational factors such as boundary and expectancy management

Sustainability interventions

(Ryan, et al., 2013)

Creation

First, the expert panel collected and reviewed available literature and resources that would inform their work. Then they spent the bulk of their time together as a group deliberating in the **Creation Phase** to arrive at a consensus and land on the following four Person-Centred Language Commitment Statements:

1. I will focus on the person's wholistic well-being by respecting the role of culture and other influences such as personal experiences and the environment.

2. I will be open and compassionate about each person's unique experiences and establish a trusting relationship by honouring what matters to them and their care partners.

3. I will develop a strong understanding of the person's health condition(s) and consider verbal and non-verbal means of communication (e.g. responsive behaviours/personal expressions, vocal expressions, body language) to be forms of meaningful communication.

4. I will continuously reflect on and advocate for person-centred language and its potential impacts. I will be open to discussions regarding language choices for myself and others, respectfully challenge those that are not person-centred and celebrate positive language choices.

Transfer

The **Transfer Phase** included rich discussion on how the commitment statements may be presented in various ways to optimize its availability.

We are pleased to provide the following tools:

✓ This **report** to disseminate the work accomplished.

✓ The BSO Person-Centred **Logo** which was designed to represent the three kinds of knowledge as described by Carmen Bowman and colleagues;

> "Leaders and teachers need to keep reminding people that the new language requires three kinds of knowledge: **know that** (facts/information), **know why** (motivations and beliefs) and **know how** (the new words/concepts/language are spoken). All education needs to promote all three kinds of knowing if the new language is to take hold and become the dominant way of speaking" (Bowman, Ronch, & Madjaroff, 2016, p. 94).

Based on this, we collaboratively created a logo with the expert panel and others with relevant experience to symbolize how one's thoughts (know that), heart (know why), and actions (know how) connect and communicate with others in person-centred ways.

We hope the logo representing BSO's Person-Centred Language Initiative inspires the alignment, engagement and implementation of language transformation.

✓ A **poster** version of the commitment statements available in both English and French (See p. 15 for poster).

✓ A **certificate** highlighting the commitment to the pledge available in both English and French (See p. 15 for certificate).

✓ An **online pledge** to reside on the Behavioural Supports Ontario website.

✓ An **educational webinar** that will be recorded and archived to the Behavioural Supports Ontario and brainXchange websites. (Coming soon!)

Please note the tools are available for download by visiting the following:
http://www.behaviouralsupportsontario.ca/Pledge

The tools have also been translated in French and may be accessed by visiting:
http://www.behaviouralsupportsontario.ca/Pledge?lang=french

Translation

The third phase of the Knowledge to Practice Process Framework is that of **Translation** where it is recognized that many tools and strategies are needed to help people understand and to support practice change. This is where our efforts merge and we ask that you consider ways to support the use of person-centred language!

Below is a list of supporting strategies to consider:

☐ **Review Policies / Documentation**
- ✓ Review and update your policies and documentation to incorporate/reflect person-centred language.

☐ **Employee Handbook**
- ✓ Add a section on Person-Centred Language in your employee handbook.

☐ **Job Description**
- ✓ Add specific items related to person-centred language to job descriptions. Samples:
  - Contribute to the delivery of person and family-centred care by utilizing communication strategies that demonstrate compassion, validate emotions, support dignity, and promote understanding.
  - Pledge to use person-centred language that is appropriate, respectful, life-affirming and inclusive.

☐ **Recruitment Questions**
- ✓ Add specific items related to person-centred language to your recruitment questions. Samples:
  - Please provide us with your understanding of Person-Centred Language. Please give us an example of how you might apply these concepts in the role of _____.
  - Can you give us an example of a term (words/language) you've changed/stopped using in an effort to practice person-centred language?
  - Tell me about a time where labelling occurred during a conversation. What did you do or consider doing to redirect the conversation?

☐ **Onboarding Staff / Orientation**
- ✓ Add person-centred language to your onboarding checklist to be discussed during orientation.

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✓ Beware of the herd effect in language, when people enter the organization and adopt the prevailing language to lose their newcomer status. Encourage your informal leaders to model what you want to hear said. Start at orientation (Bowman, Ronch & Madjaroff, 2016).

☐ **Training and Development**
  ✓ Engage staff at all levels of your organization in person-centred language initiatives. It is essential that all staff, including contractors (janitorial services, cooks, drivers, etc.) understand their role in delivering good care and increasing the quality of life of residents (Alzheimer Society of Canada, 2011).

☐ **Employee Performance Review / Evaluation**
  ✓ Add specific items related to person-centred language to your employee performance review/evaluation form. Sample:
    ▪ Provide an example where the staff member has demonstrated the use of person-centred language (Have they been objectively describing the responsive behaviours/personal expressions rather than labelling?).

☐ **Review Charting / Audit Charting**
  ✓ Apply language comparison to charting on a monthly or annual basis. See Resources listed at the end of the document to assist in the reviewing process.

☐ **Reward and Recognition**
  ✓ Reward and recognition are important components of culture change. When individuals are recognized for their actions, they feel a sense of satisfaction and achievement and are thus more motivated to continue to maintain this effort. This principle can be applied as a tool to ensure individuals remain committed to person-centred language. Some methods of recognition include:

    ▪ Practicing Positive Reinforcement: The act of recognizing/providing praise for the use of person-centred language in the moment can help to increase the commitment to person-centred language.

    ▪ Highlighting Examples: Highlighting positive examples of when individuals have used person-centred language helps to provide motivation and encouragement to others to also apply more person-centred language. These examples or key person-centred words could also be featured in newsletters or displayed on bulletin boards for visibility.

Implementation

The fourth phase of the Knowledge-to-Practice Process Framework is that of **Implementation**. Ultimately, the actual use of person-centred language happens when individuals and teams have the resources, environment, culture, and processes that enable important practice. This involves all levels embracing and supporting language that is person-centred. Personal and societal values shape language and therefore need reflection and critique.

Below are examples to support such reflection:

Organizational Self-reflection - Questions to consider:

- What would encourage the spread of person-centred language?

- Are there individuals in our organization, such as formal or informal leaders, who already advocate for person-centred language?

- Is there something in our mission, vision, values, policies and procedures that supports or limits the use of person-centred language?

- Are there forms of education we currently provide or other initiatives underway we can build upon to enhance the use of person-centred language?

- What external resources can we use to encourage the use of person-centred language?

- Is there something we can do as an organization to inspire personal and societal change that includes the use of person-centred language? Are there partnerships we can strengthen or form, or initiatives we can join?

Personal Self-reflection – Questions to consider:

Commitment statement #1: I will focus on the person's wholistic well-being by respecting the role of culture and other influences such as personal experiences and the environment.

- Does culture mainly pertain to a person's cultural or ethnic background, or can culture be interpreted more broadly, such as regarding language, religion, gender identity and expression, sexual orientation, physical and mental ability, socioeconomic status, current or former occupation, and so on?

- What does wholistic well-being mean to you and how is it affected by your personal experiences? How might wholistic well-being differ for people you interact with?

- Is the environment mainly or more than physical surroundings?
- What else could influence your and other individuals' wholistic well-being?

Commitment statement #2: I will be open and compassionate about each person's unique experiences and establish a trusting relationship by honouring what matters to them and their care partners.

- What does it mean to be open and compassionate about each person's unique experiences?
- How do you establish a trusting relationship?
- How do you honour what matters to other people?

Commitment statement #3: I will develop a strong understanding of the person's health condition(s) and consider verbal and non-verbal means of communication (e.g. responsive behaviours/personal expressions, vocal expressions, body language) to be forms of meaningful communication.

- How do you develop a strong understanding of someone's health condition(s)?
- How are responsive behaviours/personal expressions, vocal expressions, and body language verbal and/or non-verbal means of communication? What are some other forms of verbal and non-verbal communication?
- How are verbal and non-verbal means of communication meaningful to you? How might verbal and non-verbal means of communication differ for people you interact with?

Commitment statement #4: I will continuously reflect on and advocate for person-centred language and its potential impacts. I will be open to discussions regarding language choices for myself and others, respectfully challenge those that are not person-centred and celebrate positive language choices.

- What does continuously reflecting on and advocating for person-centred language and its potential impacts mean to you?
- How can you be open to discussing your language choices and the language choices of other people?

- What are some ways you could respectfully approach potentially challenging discussions regarding person-centred language?
- What are some ways to celebrate positive language choices?

We recognize that there are many factors that will fully influence the true implementation of person-centred language, but have been encouraged that our conversations thus far with various groups have been well-received. It is our hope that individuals and organizations are ready to embrace the person-centred language commitment statements and put their commitments into practice.

Impact of New Language

Changing our language is an evolving process. It will take time and concerted effort. It goes beyond making changes to the words we speak. It is a change in the way we treat people in our daily lives. By making an effort to change our language, we are committing to changing a life-long practice. The impact of this change will have a positive effect in how individuals feel, how they are viewed, and how they are treated. Changing language and changing culture are thought to be a complementary process (Bowman, Ronch, & Madjaroff, 2016). By committing to person-centred language we are changing our practice and actions to create a culture that is dignifying and respectful to all individuals.

Conclusion

Applying and promoting person-centred language is complicated and will require perseverance and ongoing efforts. We invite all health care sectors, care and organizational partners, all levels of government, the community at large, media, educational settings and research to answer the call for culture change by becoming advocates for person-centred language. Let's demonstrate our willingness to change and make a pledge to transfer knowledge into practice by means of adopting and adapting the person-centred language commitment statements and accompanying toolkit to promote the consistent use of person-centred language that is appropriate, respectful, life-affirming and inclusive when speaking to and/or about older adults presenting with or at risk of responsive behaviours/personal expressions that may be

associated with dementia, complex mental health, substance use and/or other neurological conditions and their care partners.

The Person-Centred Language Commitment Statements are part of a living document. We are hoping this document will kindle motivation for language transformation. We invite feedback on the usefulness/applicability of the commitment statements and the accompanying references and practical resources. Should you be aware of other relevant resources or have any suggestions, please forward them to our attention for consideration in future revisions.

We encourage the wide distribution of this document in the hopes that many successful uptakes of the person-centred language commitment statements will take place and support the implementation and sustainability of this initiative.

SHARE WITH US.

Please keep us informed by contacting us through our provincial coordinating office email address at provincialBSO@nbrhc.on.ca.

We encourage everyone to kindly inform us by sharing your ideas and projects demonstrating how you have taken your head, heart and hand knowledge and transformed them into actionable steps to connect with and adapt this document into your environments.

BSO Provincial Coordinating Office: Contact Information

Call: 1-855-276-6313

Email: provincialBSO@nbrhc.on.ca

Visit: http://www.behaviouralsupportsontario.ca/

Subscribe to the BSO Provincial Pulse quarterly newsletter by visiting: http://brainxchange.ca/bsopnewsletter.aspx.

Provide your contact information and click "Subscribe Now" to stay current on the latest BSO developments and other related news.

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Appendix A: Person-Centred Language Commitment Statements and Pledge Certificate

The Person-Centred Language Commitment Statements are available online for download at http://www.behaviouralsupportsontario.ca/Pledge. Please note, we have two versions to select from, a comprehensive and an abridged version.

We also invite you to take the pledge online and generate a personalized certificate for your records.

Appendix B: Practical Resources

The following documents serve as a repository of information holding more in depth knowledge, web links and practical resources to guide the use of person-centred language. The resources listed in the pages below are a collection of suggestions/responses received from various BSO advisory and expert panel members. Please note, the list is not an all-inclusive listing of all the resources available. We are offering/sharing them to further your knowledge and the possibility of creating meaningful discussions around person-centred language.
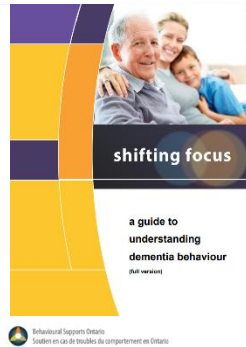
Each resource below may be accessed by clicking the image or related text.

Person-centred Language Guidelines
Alzheimer Society of Canada
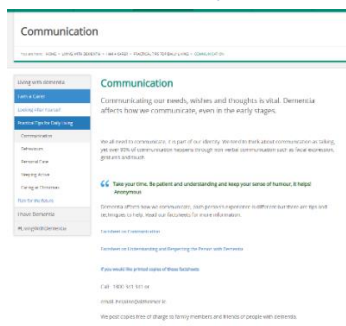
*Practical Tips for Daily Living: Communication*
The Alzheimer Society of Ireland

Shifting Focus
Alzheimer Society of Ontario

Making Connections: Recommendations to Enhance the Use of Personhood Tools to Improve Person-Centred Care Delivery Across Sectors
Behavioural Supports Ontario
Lived Experience Advisory

Recovery Oriented Language
Canadian Mental Health Association Edmonton
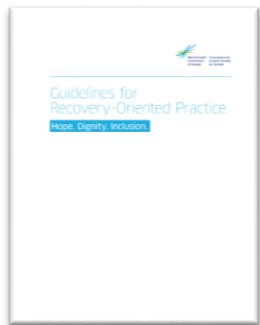
Guidelines for Recovery-Oriented Practice
The Mental Health Commission of Canada

News and Issue

Defining Agitation

Agitated, aggressive, frustrated, angry, stubborn, restless – adjectives that are often used interchangeably to illustrate comparable clinical presentations, but words that can bear very different meanings to different people. It is well documented in the literature that individuals with cognitive disorders regularly suffer from a plethora of neuropsychiatric sequelae during their illness course. Syndromes such as depression, anxiety, and agitation are common, and agitation is frequently considered the most disruptive as it is often associated with increased rates of institutionalization. Specific diagnostic criteria for depression and anxiety in certain cognitive disorders such as Alzheimer's disease have been outlined in the literature. However, agitation remains an ambiguously defined term that is often muddied by the individual's, caretaker's, or provider's interpretation of the clinical manifestations. Creating a standardized, validated diagnostic definition of agitation in individuals with cognitive disorders could prove beneficial to clinical and research environments seeking to advance treatment options, as well as, facilitate accurate communication among clinicians and patients and their support.

Defining Agitation
International Psychogeriatric Association

Recovery Oriented Language Guide
Mental Health Coordinating Council

Enhancing Communication Guide
Murray Alzheimer Research and Education Program

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Responsive Behaviours
Murray Alzheimer Research and Education Program

Personal Expressions
Partnerships in Dementia Care Alliance

Communication Health and Aging Brochure
Speech-Language & Audiology Canada (SAC)

Speech and Language Disorders Tip Sheet
Speech-Language & Audiology Canada (SAC)

Person-Centred Language for Responsive Behaviours
Toronto Academic Health Science Network

Related Webinar Recording and Slides
The Evolution of Person-Centred Language with Responsive Behaviours

<u>Cue Cards as Visual Reminders</u>

St. Michael's Hospital, Toronto ON

The following cue cards were a component of the hospital's education program focusing on prevention and management strategies for responsive behaviours, with person centred language and care being a module within that curriculum.

The wallet sized card was designed to attach to staff's name cards in order to provide a visual reminder of preferred language in an effort to encourage positive language habits.

BEHAVIOURS COMMUNICATE NEEDS: LET'S COMPARE LANGUAGE

Instead of...

Agitation → unable to sit or lie still, resisting personal care, reaching out/grabbing

Impulsive → did not wait for assistance, getting out of bed quickly, not using call bell

Exit seeking → trying to get home or somewhere familiar, pacing, looking for people or missing belongings, walking to elevator, packing up belongings

BEHAVIOURS COMMUNICATE NEEDS: LET'S COMPARE LANGUAGE

Instead of...

Physical Aggression → hitting, kicking, spitting, grabbing, throwing objects

Verbally Aggressive → calling out, yelling, screaming, repetitive requests for help, frequent crying, swearing, verbal threats, worry, anxiety

Self-harm → pulling at lines or tubes, refusing to eat or drink, self-injury, eating or drinking inappropriate substances

Slide from Relational Understandings of Personal Expressions

Sherry L. Dupuis, Ph.D. Professor and Co-Principal Investigator Partnerships in Dementia Care Alliance

Reframing "Actions" in the Dementia Context

Problem-Based Discourse	→	Possibilities Discourse
Anxiety	→	*Eagerness*
Agitation	→	*Energy*
Wandering	→	*Exploring*
Garbled, repetition	→	*Poetry*
Disruptive/Challenging	→	*Communicating*
Hoarding	→	*Collecting*
Aggressive	→	*Protecting self*

(Adapted from Fazio et al., 1999)

Appendix C: Report References and Resources that Helped Shape the Person-Centred Language Commitment Statements

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