



PERSON CENTRED LANGUAGE GUIDELINES

What is dementia?

Dementia is an overall term for a set of symptoms that is caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour.

Many diseases can cause dementia, including Alzheimer's disease, vascular dementia, Lewy Body disease, fronto-temporal dementia, and Creutzfeldt-Jakob disease. These conditions can have similar and overlapping symptoms.

The Alzheimer Society has developed these language guidelines as a tool for anyone who lives with, supports or works with a person living with dementia. The Alzheimer Society hopes that they will promote consistency in the use of respectful language.

Introduction: The power of words

Language is a unique human gift and our very powerful means of communication. Words can influence our feelings, actions, mood, and self-esteem. Words also help us communicate to others our needs and desires. We react physically and emotionally to what is said to us and about us. How language is used can affect us as strongly as physical actions. This is the power of words.

Language used to describe dementia has historically been largely negative, focusing on the losses experienced by the person living with dementia. While these losses are real, this negativity has contributed to the development and persistence of stereotypes and approaches to care that focus on weakness rather than strength, illness rather than wellness and victims rather than whole persons. This approach influences how others view dementia, and can add to the stigma and discrimination experienced by people living with dementia and their caregivers.

Statement of purpose

By consciously using language in a more sensitive manner, we can avoid reducing individuals with dementia to a series of labels, symptoms or medical terms. Person-centered language focuses on the person, not on their condition. The use of person-centered language helps us deal with the fear and stigma surrounding dementia. By reducing the fear associated with dementia, people are more likely to acknowledge, learn and have discussions about dementia. These guidelines will introduce you to preferred person-centered terms that are meant to maintain dignity and respect for all individuals.

How to use these guidelines

These guidelines have been reviewed by people living with dementia and have been developed for use by all individuals involved in the care of people with dementia. To promote person-centred language, we encourage you to share these guidelines with organizational partners. Consider using these guidelines when writing and reviewing policies and procedures, information resources, website content, promotional materials, media releases and educational presentations. The guideline includes terms listed alphabetically under 'Language to be avoided' for easy reference (refer to page 5 of the guideline). Language is a living thing, as are these guidelines. The

Alzheimer Society invites feedback on the usefulness of the current guidelines and suggestions of terms that might be included in future versions. Please email us at info@alzheimer.ca with the subject line "person centered language guidelines" with your input.

Principles and definitions

Person-centred language

The purpose of person-centred language is to recognize the impact of language on thoughts and actions, to ensure language does not diminish the uniqueness and intrinsic value of each person and to allow a full range of thoughts, feeling and experiences to be communicated while supporting the following principles:

I. Personhood

A standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust. -Kitwood, T.M. Dementia Reconsidered: the person comes first. p. cm.-(Rethinking Aging series)

II. Dignity and respect

Create positive conditions where the person can live without fear of shame or ridicule; where people are treated with warmth and authenticity, listened to without judgment and are given opportunities for independence and self-expression.

III. Acceptance and understanding

Accept each person with unconditional positive regard. Accept behaviour as a form of communication that expresses unmet needs or emotions and helps the person continue to enjoy basic personal freedoms.

IV. Relationships

Support and preserve relationships. Support the person in the development of new positive relationships.

V. Recognition and individuality

Recognize the individuality of each person's unique life experiences, personality, culture, values, beliefs and opinions. Respect and incorporate these factors in the person's future care planning.

VI. Relationships of trust

Provide the conditions necessary to satisfy fundamental needs and create a climate for personal growth and understanding by providing a relationship based on trust. In a relationship of trust the person knows confidences are respected, choice and control are maintained and the person will not be abandoned.

Human rights for people living with dementia

The principles outlined in this document reflect that people with dementia have the same human rights as everyone else. It is important that the language that we use when talking about dementia reflects the following general principles¹:

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination
- Full participation and inclusion in society
- Respect for difference; acceptance of disability as part of human diversity
- Equality of opportunity
- Accessibility
- Equality among genders

Language and behaviours

Dementia affects people in different ways, and in some cases a person with dementia may also experience changes in behaviour. Changes in the brain, a person's physical and mental health, their environment and medications can cause behavioural changes. Dementia may also cause sensory changes, such as difficulty with spatial awareness, hypersensitivity to noise and certain tones, and a decreased sense of taste which could affect the person's appetite. Changes in the senses may make it difficult for the person to interact with their environment, which could also result in behavioural changes. In most cases, these behavioural changes are a way of communicating distress, pain, frustration, loneliness, boredom, and unmet needs (such as thirst). "Responsive behaviour" and "reactive behaviours" are terms commonly used in the dementia field. Responsive behaviours refer to behaviours exhibited by a person with dementia as a way of responding to something negative, frustrating or confusing in their environment. When talking about behaviours it is important to remember that:

- All personal expressions (words, gestures, actions, body language) have meaning.
- Behaviours are often used to communicate needs and concerns.

When talking about responsive behaviours it is important that the language we use is respectful, specific and objective. A better understanding of the person encourages more appropriate care planning and responses.

Cultural Awareness

Using the term dementia may not be appropriate when talking with people from other cultures. It is important to know the person's cultural background, so that you can use words that they will not find offensive. If possible, learn about appropriate terminology from people with the same cultural background as the person you are working with.

¹The human rights of people living with dementia: from rhetoric to reality. Dementia Alliance International. 2016. Available at <https://www.dementiaallianceinternational.org/wp-content/uploads/2016/05/Human-Rights-for-People-Living-with-Dementia-Rhetoric-to-Reality.pdf>

What terms should you use when talking with and about people with dementia?

Language to be avoided	Why should you avoid it?	Person-centered language
<ul style="list-style-type: none"> • Adult Day Care Centre/ Day Care 	<ul style="list-style-type: none"> • More appropriate for children's services than for adults. 	<ul style="list-style-type: none"> • Adult Day Centre/Programs • Provincially-specific term • Support program
<ul style="list-style-type: none"> • Acting out / Aggressive behaviour • Agitation • Challenging behaviour • Difficult/Problem behaviour • Hoarder/Hoarding • Violent • Screamer • Sundowning/Sundowner • Wandering/Wanderer 	<ul style="list-style-type: none"> • These terms are not specific, suggesting that the behaviour is a result of a problem with the person. They do not support a person-centred response. 	<p>Describe the behaviour. Be as specific as possible, giving examples:</p> <ul style="list-style-type: none"> • e.g. person strikes out when asked to undress • e.g. the person paces and appears upset, frustrated, restless • "Responsive behaviour" can be used for general situations, but specific descriptions (such as above) are preferred. • Alternative to "sundowning" - e.g. person with the disease seems to become restless at approximately 5-6 pm most days • For "wandering," consider using: <ul style="list-style-type: none"> • Getting lost • Losing one's way <p>Reference: For more information about wandering, visit www.medicalert.ca/safelyhome.</p>
<ul style="list-style-type: none"> • Bib 	<ul style="list-style-type: none"> • The term is reflective of products used in the care of children. 	<ul style="list-style-type: none"> • Clothing protector • Apron
<ul style="list-style-type: none"> • Burden of caregiving • Caregiver burden 	<ul style="list-style-type: none"> • Implies that caregiving is always a burden • The individual interpretation of caregiving should be up to the caregiver. • The term can help validate the burden some caregivers experience, but should not be assumed and should be avoided when speaking in generalities such as public presentations. 	<ul style="list-style-type: none"> • Effects of caregiving • Effects of providing care • In the context of caregiving, there may be difficult issues. It is important to be specific and name the issues. e.g. Caregiver states she is exhausted. Has not slept for three nights. • Caregiver stress • Caregiver challenges • Meaningful caregiver experience
<ul style="list-style-type: none"> • Informal caregiver • Professional caregiver 	<p>May offend people in the early stages who do not need 'caregivers' but rather people who will support them</p> <ul style="list-style-type: none"> • Caregivers may not identify themselves in this way (e.g. "I am his wife, not his caregiver") • Lack of consistency in terms • Families who provide care often feel their care is "professional" 	<ul style="list-style-type: none"> • Ask caregivers what terms they prefer on an individual basis. • Examples: Family member, caregiver, care partner, care provider, care team member, practitioners of care • Health-care professionals, name of actual professional • Cite title or name of professional

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<ul style="list-style-type: none"> • Cases 	<ul style="list-style-type: none"> • People are not “cases.” This term depersonalizes. 	<ul style="list-style-type: none"> • People with dementia/person with dementia, people we serve • Family member
<ul style="list-style-type: none"> • Challenging behaviour 	Refer to section entitled ‘Language and behaviour’ on page 4 and ‘Describe the behaviour’ on page 5	Refer to section entitled ‘Language and behaviour’ on page 4 and ‘Describe the behaviour’ on page 5
<ul style="list-style-type: none"> • Deal with (as in deal with difficult behaviours) 	<ul style="list-style-type: none"> • Sounds negative and punishment oriented • Implies to exert control over another 	Refer to section entitled ‘Language and behaviour’ on page 4 and ‘Describe the behaviour’ on page 5
<ul style="list-style-type: none"> • Demented • Demented person • Senile dementia 	<ul style="list-style-type: none"> • Term connotes that the person is completely incapable 	<ul style="list-style-type: none"> • Person with dementia • Person living with dementia • The person; the individual
<ul style="list-style-type: none"> • Diapers 	<ul style="list-style-type: none"> • The term is reflective of products used in the care of children. 	<ul style="list-style-type: none"> • Incontinence products • Incontinence briefs • Adult briefs
<ul style="list-style-type: none"> • Difficult/Problem behaviour 	Refer to section entitled ‘Language and behaviour’ on page 4 and ‘Describe the behaviour’ on page 5	Refer to section entitled ‘Language and behaviour’ on page 4 and ‘Describe the behaviour’ on page 5
<ul style="list-style-type: none"> • Early onset dementia • Pre-senile dementia 	<ul style="list-style-type: none"> • This term can be confused with the early stages of dementia 	<ul style="list-style-type: none"> • Young onset dementia
<ul style="list-style-type: none"> • Feeders (and similar terms for other needs) 	<ul style="list-style-type: none"> • Labels person • Depersonalizes 	A person who needs support to: <ul style="list-style-type: none"> • Eat • Drink
<ul style="list-style-type: none"> • Handle (as in handle people with dementia) 	<ul style="list-style-type: none"> • Sounds physical and impersonal 	<ul style="list-style-type: none"> • Care for • Respond to the needs of the person with dementia • see person-centred language under ‘Deal with’
<ul style="list-style-type: none"> • Homemakers 	<ul style="list-style-type: none"> • These individuals may do more than household tasks 	<ul style="list-style-type: none"> • Home support workers • Provincially-specific term
<ul style="list-style-type: none"> • Illness • Disease 	<ul style="list-style-type: none"> • Dementia is described as a set of symptoms, unless talking about a specific dementia such as Alzheimer’s disease 	<ul style="list-style-type: none"> • Dementia as a condition • A person with a diagnosis of dementia • A person living with dementia

Language to be avoided	Why should you avoid it?	Person-centered language
<ul style="list-style-type: none"> • In denial 	<ul style="list-style-type: none"> • Judgmental; often used to indicate that a person is not coping as well as one would expect • Denial implies a conscious choice to reject or refuse to accept reality • Denial may be a part of the grieving process that needs to be addressed 	<ul style="list-style-type: none"> • The listener's role is to validate the person's feelings • Reflect back what you have heard, then ask the person to help you understand what them and their family are going through <p>e.g. "Mum's just been diagnosed with Alzheimer's disease but I think there is nothing wrong with her." Respond to the feeling – "It can be pretty scary to hear a term like Alzheimer's disease. Tell me what that's been like for you."</p>
<ul style="list-style-type: none"> • Loved one(s) 	<ul style="list-style-type: none"> • Relationship between people and their family/friends may have been problematic • Relationship doesn't have to be problematic for some people to be uncomfortable with the expression • Funereal in tone 	<ul style="list-style-type: none"> • Person/people with dementia • Name the relationship, (mother, husband, etc) • Family member • Friend
<ul style="list-style-type: none"> • Mentally fragile 	<ul style="list-style-type: none"> • Sounds negative and does not provide useful information 	<ul style="list-style-type: none"> • Person/people with dementia (or the specific diagnosis, if known)
<ul style="list-style-type: none"> • Non-compliant • Difficult • Refuses care • Uncooperative 	<ul style="list-style-type: none"> • It is unreasonable to expect a person to comply with something they don't understand or that does not fit with their values • The person may be afraid and confused (e.g. someone trying to take their clothes off for a shower) 	<ul style="list-style-type: none"> • Description of response and potential reasons for response e.g. person pushes medication away when offered.
<ul style="list-style-type: none"> • Nursing home • Facility • Unit/Wing • Institution 	<ul style="list-style-type: none"> • Medically-oriented and historically has negative connotations • Acute-care focused; not "home-like" 	<ul style="list-style-type: none"> • Provincially-specific term • Long term care home
<ul style="list-style-type: none"> • Patient 	<ul style="list-style-type: none"> • Medically-oriented • Should be used only within medical profession 	<ul style="list-style-type: none"> • Person/people with dementia (or name specific type of dementia) • Person with lived experience

Language to be avoided	Why should you avoid it?	Person-centered language
<ul style="list-style-type: none"> • Placement (Nursing home placement) • Placement planning • Place/put 	<ul style="list-style-type: none"> • One places or puts objects, not people 	<ul style="list-style-type: none"> • Moving to a long-term care home • Transition to a new home • Future care planning • Relocating to a long term care home
<ul style="list-style-type: none"> • Sufferer • Victim • Burden 	<ul style="list-style-type: none"> • Terms such as 'victim' and 'sufferer' add to the stigma and stereotypes surrounding dementia. Terms to avoid also send the message that a life with dementia is not worth living, and that people with dementia have nothing to contribute. Using the preferred terms maintains the person's dignity and focus on the person not on their condition. 	<ul style="list-style-type: none"> • Person with dementia or name the specific type of dementia
<ul style="list-style-type: none"> • Support group leader 	<ul style="list-style-type: none"> • Sounds "expert" and disempowering of group 	<ul style="list-style-type: none"> • Group facilitator (e.g. person's role is not to be an expert but rather to facilitate group discussion) • A good facilitator is neither a content expert nor a lecturer. A facilitator guides a process that will help participants to reach their stated goals and objectives within the time allotted.

Useful Resources

Alzheimer's Australia. Dementia Language Guidelines. Available at <https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf>

The Alzheimer Society of Ireland. Dementia Friendly Language. Available at https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/Dementia-Friendly-Language-Final-for-Web-Aug-15_2.pdf

Young Dementia UK. Guide for Journalists. A guide for language used to talk about people with young onset dementia. Available at <https://www.youngdementiauk.org/guide-journalists>

Pioneer Network. The Power of Language to Create Culture. Available at <https://www.pioneernetwork.net/wp-content/uploads/2016/10/The-Power-of-Language-to-Create-Culture.pdf>