

PERSON-CENTRED LANGUAGE

December 2012

Introduction: The power of words

Language is our unique human gift and our most powerful means of communication.

Words can inform and comfort us, excite and thrill us, warm our hearts and inflame our desires. Words can also slap and punch us, rattle our nerves, discourage our initiative and destroy our self-confidence. We react physically and emotionally to what is said to us and about us. How language is used can affect us as powerfully as physical actions. This is the power of words.

Language used to describe Alzheimer's disease and other dementias 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 promotion of perceptions, interpretations and approaches to care that focus on weakness rather than strength, illness rather than wellness and victims rather than whole persons.

Statement of purpose

By consciously using language in a more sensitive manner, we can avoid reducing individuals with Alzheimer's disease and other dementias to a series of labels, symptoms or medical terms. The Alzheimer Society has developed these language guidelines as a tool for anyone who lives with, supports or cares about a person living with Alzheimer's disease or another dementia. We hope that they will promote consistency in the use of respectful language throughout dementia support services.

Person-centred language helps tackle the fear and stigma surrounding Alzheimer's disease and other dementias, in effect, making the disease one that people are more likely to acknowledge and discuss. The preferred terms are meant to maintain dignity and respect for all individuals.

How to use these guidelines

These guidelines have been developed for use by all Alzheimer Society staff and volunteers. 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 and educational presentations. The terms are listed alphabetically under 'Language commonly used' for easy reference.

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 language@alzheimer.ca with your input. The purpose of language is to communicate. To be truly person-centred, language should be chosen that will meet that goal and be fulfilling for everyone involved in the conversation.

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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 opportunity for self-determination 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 help the person continue to enjoy basic personal freedoms.
- IV. **Relationships**
Support and preserve present relationships. Support the person in the development of other positive relationships.
- V. **Recognition and individuality**
Recognize the individuality of each person's unique life experiences, personality, values, beliefs and opinions. Respect and incorporate these factors in support planning.
- VI. **Relationships of trust**
Provide the conditions necessary to satisfy fundamental needs and create a climate for personal realization 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.

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Language commonly used	Problem with current language	Person-centred language
Adult Day Care Centre/Day Care	More appropriate for children's services than for adults.	<ul style="list-style-type: none"> • Adult Day Centre/Programs • Provincially-specific term
Acting out Aggressive behaviour Agitated Challenging behaviour Difficult/Problem behaviour Hoarder/Hoarding Violent Sundowning/Sundowner Wandering/Wanderer	<p>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>	<p><i>Describe the behaviour</i> 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 agitated and restless at approximately 5-6 pm most days • For "wandering," consider using: <ul style="list-style-type: none"> • Getting lost • Losing one's way • Getting separated <p>Reference: For more information about wandering visit www.safelyhome.ca.</p>
Bib	The term is reflective of products used in the care of children.	<ul style="list-style-type: none"> • Clothing protector • Apron

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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 • Meaningful caregiver experience
Informal caregiver Professional caregiver	<ul style="list-style-type: none"> • May offend people in the early stages who do not need 'caregivers' but rather people who will support them • 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 team member, practitioners of care • Health-care professionals, name of actual professional • Cite title or name of professional
Cases	People are not "cases." This term depersonalizes.	<ul style="list-style-type: none"> • People with dementia/person with dementia, people we serve • Family member
Challenging behaviour	Refer to section entitled 'Describe the behaviour' on page 3	Refer to section entitled 'Describe the behaviour' on page 3
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 'Describe the behaviour' on page 3

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Demented/Demented person	<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
Diapers	The term is reflective of products used in the care of children.	<ul style="list-style-type: none"> • Incontinence products • Incontinence briefs • Adult briefs
Difficult/Problem behaviour	Refer to section entitled 'Describe the behaviour' on page 3	Refer to section entitled 'Describe the behaviour' on page 3
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
Handle (as in handle people with dementia)	<ul style="list-style-type: none"> • Sounds physical and impersonal 	Care for; see person-centred language under 'Deal with'
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
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 her to help you understand what she and her family are going through e.g. "Mum's just been diagnosed with Alzheimer's disease but I think there is nothing wrong with her." <i>Respond to the feeling</i> – "It can be pretty scary to hear a term like Alzheimer's disease. Tell me what that's been like for you."

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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
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)
Non-compliant	<ul style="list-style-type: none"> It is unreasonable to expect a person to comply with something he does not understand or that does not fit with his values 	<ul style="list-style-type: none"> Description of response and potential reasons for response e.g. person with disease pushes medication away when offered. May not understand.
Nursing home	<ul style="list-style-type: none"> Medically-oriented and historically has negative connotations 	<ul style="list-style-type: none"> Provincially-specific term Long term care home
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 Alzheimer's disease)
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

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Sufferer, Victim	<ul style="list-style-type: none">• Sounds negative• Does not support the concept of “personhood”• Does not fit with a philosophy of “hope” and “wellness”	<ul style="list-style-type: none">• Person with dementia or name the specific type of dementia
Support group leader	Sounds “expert” and disempowering of group	<ul style="list-style-type: none">• Group facilitator¹ (e.g. person’s role is not to be an expert but rather to facilitate group discussion) <p>¹ 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.</p>
Support network	May be considered “jargon”	<ul style="list-style-type: none">• Whoever helps the person• Person’s family/friends/ community• Supports