

ALZHEIMER SOCIETY

LANGUAGE GUIDELINES

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 enflame 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 that words can have.

Language used to describe Alzheimer's and related diseases 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 and related diseases to a series of labels, symptoms or medical terms. The Alzheimer Society has developed these common language guidelines as a tool for anyone who lives with, supports or cares about a person living with Alzheimer's or a related disease. We are hopeful 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 and related diseases, in effect, making the disease one that people are more likely to acknowledge and discuss. The preferred terms are meant to maintain the dignity of individuals and the person.

How to use these Guidelines

These guidelines have been developed for use by all Alzheimer Society staff and volunteers. In order to promote person centred language, the sharing of these guidelines with organizational partners is encouraged. 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 commonlanguage@alzheimer.ca with your input.

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Principles and definitions

Person-centred language

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

To 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

To accept each person with unconditional positive regard; to accept behaviour as a form of communication which expresses unmet needs or emotions; and to assist the person to continue to enjoy basic personal freedoms.

IV. Relationships

To support and preserve present relationships; to support the person in the development of other positive relationships.

V. Recognition and Individuality

To recognize the individuality of each person with their own unique life experiences, personality, values, beliefs and opinions; to have these factors respected and incorporated in support planning.

VI. Relationships of Trust

To 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 is maintained; and the person will not be abandoned.

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Person Centred Language	Language Commonly Used	Problem with Current Language
<ul style="list-style-type: none"> Day Centre(s)/Programs Provincially specific term 	Adult Day Care Centre(s)/ Day Care	<ul style="list-style-type: none"> More appropriate for children's services than adults'
<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 	<p>Aggressive Behaviour</p> <p>Agitated</p> <p>Challenging Behaviour</p> <p>Difficult/ Problem Behaviour</p> <p>Hoarder/Hoarding</p>	<p>These terms are not specific and therefore do not support a person-centred response</p>
<ul style="list-style-type: none"> e.g. person with the disease seems to become agitated and restless at approximately 5-6 pm most days 	Sundowning/ Sundowner	<p>Implies that sundowning is part of the disease rather than acknowledging that the environment may be part of the cause</p>
<ul style="list-style-type: none"> Reference: For more information about wandering visit www.safelyhome.ca 	Wandering/ Wanderer	<p>Implies aimlessness. The person may be purposefully seeking something or someone</p>
<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. 	Burden of Caregiving/ Caregiver Burden	<ul style="list-style-type: none"> Implies that caregiving is always a burden. Interpretation of caregiving should be up to the caregiver
<ul style="list-style-type: none"> Ask caregiver what term they prefer on an individual basis Examples: Family member, caregiver, care partner, care team member, practitioners of care Healthcare professionals, name of actual professional Cite title or name of professional 	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 Lack of consistency in terms Families who provide care often feel their care is 'professional'

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<ul style="list-style-type: none"> • People with dementia/person with dementia, people we serve • Family member 	Cases	<ul style="list-style-type: none"> • People are not “cases”. This term depersonalizes
Refer to section entitled ‘Describe the behaviour’ on page 3	Challenging Behaviour	Refer to section entitled ‘Describe the behaviour’ on page 3
<ul style="list-style-type: none"> • Respond to • Understand • Assist with • Support with • Meet the needs of 	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	Difficult/ Problem Behaviour	Refer to section entitled ‘Describe the behaviour’ on page 3
A person who needs support to: <ul style="list-style-type: none"> • Eat • Drink 	Feeders (and similar terms for other needs)	<ul style="list-style-type: none"> • Labels person • Depersonalizes
Care for; see person centred language under ‘Deal with’	Handle (as in handle people with dementia)	<ul style="list-style-type: none"> • Sounds physical
<ul style="list-style-type: none"> • Home support workers • Provincially specific term 	Homemakers	<ul style="list-style-type: none"> • These individuals may do more than household tasks
<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 them to help you understand what they and their 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.” 	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"> • Person/people with dementia • Name the relationship, (mother, husband, etc) 	Loved One(s)	<ul style="list-style-type: none"> • Relationship between person 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

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<ul style="list-style-type: none"> Person/people with dementia (or the specific diagnosis, if known) 	Mentally Fragile	<ul style="list-style-type: none"> Sounds negative and does not provide useful information
<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. 	Non-Compliant	<ul style="list-style-type: none"> It is unreasonable to expect a person to comply with something they do not understand or that does not fit with their values
<ul style="list-style-type: none"> Provincially specific term 	Nursing Home	<ul style="list-style-type: none"> Medically oriented and historically has negative connotations
<ul style="list-style-type: none"> Person/people with dementia (or Alzheimer's disease) 	Patient	<ul style="list-style-type: none"> Medically oriented Should be used only within medical profession
<ul style="list-style-type: none"> Person with dementia or name the specific type 	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"
Refer to section entitled 'Describe the behaviour' on page 3	Sundowning/ Sundowner	Refer to section entitled 'Describe the behaviour' on page 3
<ul style="list-style-type: none"> Whoever helps the person Person's family/friends/ community 	Support Network	<ul style="list-style-type: none"> May be considered 'jargon'
<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 Group Leader	<ul style="list-style-type: none"> Sounds "expert" and disempowering of group
Refer to section entitled 'Describe the behaviour' on page 3	Wandering/ Wanderer	Refer to section entitled 'Describe the behaviour' on page 3