PERSON CENTRED LANGUAGE





The power of words

How we talk about dementia can make a difference in the life of people living with dementia and their families. The language that we use can either make people with dementia and their families feel accepted and equal or it can add stigma and discrimination. The words we choose to use can impact other people as much as how we choose to behave.

Human rights

The language that we use when talking about dementia should reflect the following human rights principles:

- Respect for dignity, autonomy, freedom to make choices and 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

All behaviour has meaning. The way we behave is often a way of communicating distress, pain, frustration, loneliness, boredom and unmet needs, like hunger. Responsive behaviours and reactive behaviours are terms commonly used to refer to behaviours exhibited by a person with dementia as a way of responding to something negative, frustrating or confusing in their environment. The words we choose to use to describe a person's behaviour should be person centred and should help us understand what the person needs. See examples on the next page.



Cultural awareness

Using the term "dementia" may not be appropriate when talking with people from other cultures. If possible, learn about appropriate terms to use from people with the same cultural background as the person with whom you are working.



Alzheimer Society

Alzheimer Society

Here are some examples of person centred language.

To read our full person-centred language guidelines please visit www.alzheimer.ca/powerofwords

| | Preferred Terms | Non-Preferred Terms | Rationale |
|--|---|--|---|
| Behaviours | Describe the behaviour. Be as specific as possible, giving examples: e.g. person strikes out when asked to undress "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 getting lost or losing one's way | Acting out / Aggressive behaviour Agitation Challenging behaviour Difficult/Problem behaviour Hoarder/Hoarding Violent Screamer Sundowning/ Sundowner Wandering/Wanderer | 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. |
| Talking about the person with dementia | Person with dementia Person living with dementia The person; the individual Dementia as a condition A person with a diagnosis of dementia A person living with dementia Young onset dementia Person with dementia or the name of the specific type of dementia | Demented Demented person Senile dementia Illness Disease Early onset dementia Pre-senile dementia Sufferer Victim Burden | These terms suggest that the person is completely incapable. Dementia is described as a set of symptoms, unless talking about a specific dementia such as Alzheimer's disease Early onset and pre-senile dementia can be confused with the early stages of dementia These terms add to the stigma and stereotypes surrounding dementia. They 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 focuses on the person not on their condition. |
| Caregivers | Effects of caregiving Effects of providing care Caregiver stress Caregiver challenges Meaningful caregiver experience | Burden of caregiving Caregiver burden | These terms imply that caregiving is always a burden. The individual interpretation of caregiving should be up to the caregiver. |

Alzheimer Society of Canada

20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8 Tel: 416-488-8772 1-800-616-8816 Fax: 416-322-6656 E-mail: info@alzheimer.ca Website: www.alzheimer.ca Facebook: www.facebook.com/AlzheimerCanada Twitter: www.twitter.com/AlzCanada