

## The Power of Words

*The following is excerpted from*

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Words are singularly the most powerful force available to humanity. We can choose to use this force constructively with words of encouragement, or destructively using words of despair. Words have energy and power with the ability to help, to heal, to hinder, to hurt, to harm, to humiliate and to humble.

Our words have the power to change destinies, both our own and that of others. Often, we throw around words in jest or perhaps in anger that harm and hurt and create long lasting damage. If we understood the seriousness of what we were saying, we might never say it. Words have power and they have energy that we put out there into the minds, and thoughts of our children, our friends, our mates and our peers. If we are in a position of leadership where our words create policies, we have to be sensitive and diligent. If we were handling a bomb which could go off at any minute as a result of our actions, we would mind ourselves and be delicate. Our words have the same power, yet we wield them around as though they were powerless and insignificant.

The key is awareness. Once we have the awareness that our words are what sets us apart from the animal kingdom, we might consider using them with greater consciousness and awareness. And if you don't think that words have power, ask a child who has been told that he is nothing all his life, or a population that is reminded by its leaders that they are victims.

As humans, we are given the gift of having moral compasses. If we think about it, we know the words that have a positive effect and the words that have the power of destruction. Let's use this navigation tool to share our thoughts so as to affect our societies positively.

Each and every one of us has the ability to transform our lives and the lives around us by choosing to utter the words of encouragement. Whether you consider yourselves neo-thinkers, sages, scholars, intellects, theorists, philosophers, paradigm shifters, or just ordinary citizens, help the world around you by empowering people to share courage with others. It is not enough to directly influence the people in your immediate circle. Voice your opinion. Empower those around you to empower those around them to challenge repression.

## Transforming the Worldview of Neurocognitive Disorders—with Words

To build a better and more inclusive world, NCDM avoids using the below stigma-laden words and offers these alternatives instead.

Unhelpful or Stigmatizing Term	Preferred Terms
Agitation	Use “visibly upset” or “distressed”
Alzheimer's	Use “dementia,” “cognitive impairment,” or “neurocognitive disorder” → The term Alzheimer’s disease should only be used when specifically referring to Alzheimer’s disease and not as a blanket term to refer to other forms of dementia.
Alzheimer’s disease and “related” dementias	Use “dementia” or “neurocognitive disorders” → The term “Alzheimer’s disease and other related dementia” is misleading and can incorrectly suggest that Alzheimer’s disease is the umbrella term, with the other dementias under that term.
Behavioral and Psychological Symptoms of Dementia or BPSD	Use “communication,” “need,” or “response” → <i>Behavioral and Psychological Symptoms of Dementia (BPSD)</i> is a term often used to label personal expression, nonverbal communication, or responses to stimuli. The use of this term makes it easy to interpret nonverbal communication—especially distress—as a result of brain change rather than as a personal expression or unmet need.
Behaviors	Use “nonverbal communication” or “personal expressions” → Persons living with dementia are frequently described as demonstrating “behaviors” that need to be managed, controlled, diverted, etc. However, all human behavior, including by persons living with dementia, is a form of nonverbal communication. Nonverbal communication often increases when the message is not being “heard” or understood.
Burden	Use “impact” or “cost” depending on the context → Say “cost” when referring to financial impacts, such as on the Medicare or Medicaid systems. → Say “impact on care partners” instead of “burden of caregiving.”
Care	Use “support” instead of “care” → “Care” is often perceived as “doing for” rather than “doing with.” The preferred term “support” promotes autonomy and independence.
Caregiver	Use “care partner” or “support partner” instead of “caregiver” → The term “caregiver” reflects a relationship where one person is the active giver and the other is a passive receiver. The term “care partner” or “support partner” reflects a reciprocal relationship between individuals.

Unhelpful or Stigmatizing Term	Preferred Terms
Decline	Use “progression” or “change” → As a person moves along the dementia continuum, change is expected. However, “decline” does not fully or accurately describe this experience. Abilities may fluctuate on any given day or at any given time.
For (as in “doing for”)	Use “with” → Avoid terms such as “doing for” and replace with “doing with.”
Memory loss	Use “cognitive change,” “brain change,” “dementia,” or “neurocognitive disorders,” depending on context → The term “memory loss” is often used interchangeably with terms such as dementia or Alzheimer’s disease. This is an oversimplification of the experience of living with dementia. Dementia is much more than memory loss.
Non-compliant	Use “making one’s own choice”
Patient	Use “person living with dementia” instead of “patient,” unless you are the individual’s healthcare provider. → Referring to the person living with dementia as a “patient” diminishes personhood and objectifies the person. We are people first. Our medical conditions do not define us.
Pre-senile dementia or Early onset	Use “young onset” or “younger onset” → Young onset dementia refers to persons who receive a diagnosis prior to the age of 65. Some refer to it as “early onset,” but the preferred language is “young onset.” The terms early onset and early stage are often used incorrectly or confused with one another.
Stage	Use “continuum” or “spectrum” → The use of the term “stage” is an inaccurate description of the experience of living with dementia. An individual’s abilities are not fixed. Abilities may fluctuate on any given day or time.
Suffering	Use “living with dementia” instead of “suffering from dementia” → Life with dementia includes both joys and challenges and is not defined by suffering.
Sundowning	Use “cognitive fatigue” → Sundowning is often used in a derogatory or dismissive way to label nonverbal communication that may be a result of cognitive fatigue, unmet needs, sensory overload, or even environmental factors such as low lighting, increased shadows, etc.
Them or Those	Avoid using terms such as “them” or “those.” → Exercise caution when using language that differentiates or creates a sense of “otherness” for persons living with dementia. It is not us versus them.

Unhelpful or Stigmatizing Term	Preferred Terms
Toilet, Feed, Change, etc.	<p>Use “Assist with” toileting, eating, changing clothes, etc., depending on the task at hand</p> <p>→ Using these terms alone as verbs reduces the person to a task. Saying “assist with” acknowledges personhood and denotes a supportive partnership, and promotes independence.</p>
Wander	<p>Use “walk” or “walking” instead of “wander”</p> <p>→ Wandering denotes traveling aimlessly from place to place. Humans walk for a reason or purpose. It may be for exercise or to get from one location to another. It may be to enjoy the outdoors or burn off nervous energy or anxiety. Persons living with dementia walk for the same reasons.</p> <p>→ Walking may also be a personal expression or form of nonverbal communication such as pain, boredom, restlessness, or curiosity. It may mean a person is seeking something or someone, or it may be to get away from an unpleasant environment or experience.</p> <p>→ Just because we haven’t figured out the purpose, doesn’t mean something is purposeless</p>
Wanderer, feeder	<p>Use “person” or “individual.”</p> <p>→ Terms like “wanderer” or “feeder” are “otherizing” labels that shape how we perceive and treat persons living with dementia. These terms strip a person’s identity and individuality.</p>

### Additional Information

In 2017, the topics of Alzheimer’s disease/Alzheimer’s disease and related disorders nomenclature terminology were elevated to the level of a National Alzheimer’s Project Act (NAPA) Council recommendation. The public members of the NAPA Advisory Council made a formal recommendation that “emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.”

The NAPA Council formed an outside committee and dementia nomenclature is now being pursued by the Dementia Nomenclature Initiative. For more information on this initiative, visit the National Institute on Aging’s website at

<https://www.nia.nih.gov/research/milestones/enabling-infrastructure/milestone-14-l>