GLOBAL BRAIN HEALTH INSTITUTE

Words and Images to Use in Dementia and Caregiving

A Guide to Dementia-Friendly Language and Images

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"Language exerts hidden power, like the moon on the tides"

—Rita Mae Brown
American writer

The purpose of this guide is to promote the use of inclusive and non-stigmatizing language when talking or writing with or about people living with dementia. This is intended to benefit and support the Global Brain Health Institute (GBHI) community in creating a common language around dementia and caregiving to improve outcomes for everyone, keeping in mind that language and attitudes evolve and change in use and meaning.

LANGUAGE IS POWERFUL

The words we use can strongly influence how others treat or view people with dementia. For example, referring to people with dementia as "sufferers" or as "victims" implies that they are helpless. This not only strips people of their dignity and self-esteem, but it also reinforces inaccurate stereotypes (Dementia Friendly Language Position, Alzheimer's Australia, 2009; Swaffer, 2014).

"I am only a patient when I visit my general practitioner or a member of my medical team, or I am in hospital. When I am involved in advocacy work or research, I am a person with the disease, not a patient."

—Kevin Quaid
Advocate & person with Lewy body dementia

LANGUAGE SHAPES PERCEPTION

When talking about dementia, our words can have a strong impact on the person with dementia, their family, and friends. Our words can affect a person's mood and self-esteem. Language is essential in making a person feel valued, supported, and heard. Language can create mutual respect and foster engagement.

"My sister struggled with the stigmatization of the term 'dementia.' As a former executive director of a large social service organization with young-onset Lewy body dementia, she would tell people she had Parkinson's disease or, on occasion, Lewy body disease. The label 'dementia' disturbed her, and she spoke often of her fear that her legacy would be one of a 'demented or crazy person' who people would immediately disregard if they knew her diagnosis."

—Helen Medsger
Advocate & former caregiver

LANGUAGE IS USED IN CONTEXT

Words, terms, and phrases can differ between cultures, and what may be acceptable for one group, may not be for another. In addition, our choice of words can depend on the environment. For example, it is common to refer to research participants as "subjects" which can be perceived as impersonal yet protects privacy. Similarly, in public areas of a hospital where information can be overheard, a patient might be referred to by their room and bed number.

Be flexible and adapt where possible to accommodate the people affected by dementia and their families. Remember that you are engaging with people, not cases or diseases. Be hopeful, helpful, and kind.

> "When I was a nurse in the hospital, we often referred to our patients by their room and bed number. I know it was impersonal, but given the nature of the setting (a busy unit with lots of staff and visitors), it was a way to communicate efficiently ("I need help in 14A") while also protecting the privacy of our patients."
>
> —Jennifer Merrilees, RN, PhD
> *Clinical Nurse Specialist in Geriatrics*

A perspective on the language of "Dementia" in South Africa

Khanyo Ntokozo Ngcobo, MBChB, FcPsych, MMed, is an Atlantic Fellow for Equity in Brain Health and a Specialist Psychiatrist in South Africa.

There is very low awareness of dementia in South Africa. There are also many misconceptions, with some communities believing that the symptoms of dementia are due to witchcraft or bewitchment, which causes stigma for people living with dementia and leads to a lack of health and social service utilization. No word has been identified in the South African languages to mean "dementia." The term used in literature for dementia in IsiZulu, the most spoken first language in South Africa, is "ukuwohloka komqondo," which, when directly translated, means "breakdown of the mind."

However, this term is neither known nor understood by most of the isiZulu-speaking population.

Clinicians need to be aware that isiZulu words often have more than one meaning. So, it is critical to explore the meaning and context of words used during medical visits, especially when consultations use a non-professional translator. It is essential to probe the person with dementia and family's cultural understanding and acceptability of the symptoms experienced. Engagement with indigenous leaders and healers—to understand the indigenous beliefs about dementia and gain insights into providing culturally appropriate care—needs further investigation.

In our multi-ethnic society, using incorrect language can further reinforce myths and stereotypes about dementia. Therefore, we need to deliver culturally appropriate dementia education and services to improve dementia awareness and friendliness in our communities.

"I don't suffer with dementia. I struggle with dementia."
—*Helen Rochford Brennan, Advocate & person with early-onset dementia*

GENERAL GUIDELINES FOR LANGUAGE

1. Prioritize the person and not the condition.
2. Be sensitive of other people who have relationships with the person with dementia, such as family, friends, and caregivers.
3. Be aware of cultural differences.
4. Use the words or terms preferred by the person.
5. Choose words that appropriately target your audience (for example, medical terms might be appropriate for a medical audience but less appropriate in material meant for the public).
6. Use language that is as inclusive as possible that avoids "us" versus "them."
7. Use plain language that can be easily understood.
8. Choose language that is clear and meaningful.
9. Encourage the person to tell you about their experience in their own words.
10. Use terms that are appropriate to the person's age, gender identification, etc.
11. Avoid language that is aggressive and offensive.
12. Be conscious that the use of slang, abbreviations, acronyms and unfamiliar terms may be harder for some people to understand and to follow.
13. When in doubt, clarify the meaning of the words and phrases being used.
14. Gestures and facial expressions are also powerful ways we communicate and show our support.

"Finding the right words might not always be possible, and this is why non-verbal expressions of love and genuine compassion are needed. Love and compassion heal, lessen confusion and hurt, and unite people in good and bad times."

—Tatyana Mollayeva, MD, PhD
Scientist & Assistant Professor

SUGGESTIONS FOR DEMENTIA FRIENDLY LANGUAGE USE

Topic	Preferred Terms	Terms to Avoid
Dementia	Condition, disease or illness affecting the brain A form or type of dementia: If possible, refer to a specific type of dementia, e.g., Azheimer's disease (AD), frontotemporal dementia (FTD), Lewy body dementia (LBD) **Note:** Mild cognitive impairment (MCI) refers to a condition in which the person is experiencing cognitive difficulties (for example, trouble with memory) but not to the degree to warrant being referred to as "dementia."	Dementing illness Affliction Senile dementia Senility A touch of dementia
Person or people living with dementia	A person (or people) with dementia A person (or people) living with dementia A person (or people) with a diagnosis of dementia	Demented person Demented patient Sufferer Afflicted Victim Subject or case Derogatory or slang expressions such as: not all there, lost their mind, delightfully dotty, doolally, away with the fairies Terms that are ageist such as "cute" or "sweet"
People with dementia under 65 years of age	Young-onset dementia or younger age dementia Early-onset dementia Younger person with dementia	Pre-senile dementia

Topic	Preferred Terms	Terms to Avoid
The symptoms of dementia	Describe the symptom(s) with objectivity and without judgment. Examples include: memory loss, at risk for getting lost, incontinent, non-verbal or rarely speaks	The person is obstructive, an attention-seeker, being difficult, a problem
The impact of dementia on the person	Challenging Disabling Life changing Stressful Progressive Chronic	Hopeless Unbearable Impossible Painful Distressing Fading away or empty Empty shell Disappearing Being stolen away The longest goodbye Struggle, battle, fight or similar conflict-oriented words A death sentence Tragic
The impact of dementia on society	Impactful A critical challenge A health priority Has significant implications Innovative opportunities for education, psychosocial interventions, medicine and research	Tsunami Tidal wave/other catastrophic terms Disaster Pandemic Burden on society Waging a war and other warlike metaphors **Note:** Consider avoiding generic appeals to "do something" about dementia. Instead, offer concrete examples such as "Develop intergenerational community centers" or "lobby for increased Medicare funding"

Topic	Preferred Terms	Terms to Avoid
The person who is caring for or supporting a person living with dementia	Carer, caregiver, care partner, supporter, advocate Care-worker, care-professional **Notes:** • Carers are often categorized as being informal (family and unpaid) or formal (paid) • Consult with caregivers/supporters themselves on how they would like to be referred. If a son is caring for a parent with dementia, they might prefer "son" or "child" over "carer."	Affected by dementia The invisible patient Sitter Unfortunate, poor dear Dependent (or other similar terms that diminish a person — try to use terms that support what the person can do) **Notes:** • Assumptions or generalizations about relationships should be avoided. A value-loaded term like 'loved one' might not be appropriate for all family members. Again, when in doubt, consult with the caregiver or the person living with dementia. • Do not make assumptions on the impact of caring/supporting on an individual, or express judgments on their choices for themselves and their loved ones. Do not assume it is their responsibility or their duty. • Do not assume someone is a carer because they are a partner or family member of a person living with dementia. Many people, particularly in the early stages, do not need care, yet they may need support.
The act of providing care/support for a person with dementia	Caring for a person with dementia Supporting a person with dementia Facilitating a person with dementia to live a good life Supporting health and well-being	Sitting service Implying the person does nothing

Topic	Preferred Terms	Terms to Avoid
The experience of caring or supporting	Use the words of the caregiver(s) to describe the impact, effect, and/or the meaning of caregiving for them.	"Burden" is a term that often refers to economics and it is also not always the way a carer characterizes what they are doing on behalf of a person living with dementia. Duty of caring Misery Stressful
Death	End of life Terminal stage Died, passed away Died due to dementia **Notes:** • Reinforce openness to discuss death using terms preferred by the person.	If a person broaches a discussion about their death, don't respond by saying that it's better to focus on life. Avoid vague, ambiguous words that may not be clear and are not the preferred by the person.

Resources used in creating this language guide:

- Alzheimer's Association Inclusive Language Guide
- Alzheimer's Australia: Dementia Language Guidelines
- Alzheimer's Society of Canada: Person-centred language guidelines
- Alzheimer's Society UK: Positive language – An Alzheimer's Society guide to talking about dementia
- Swaffer, K. Dementia: Stigma, language, and dementia-friendly. *Dementia (London).* 2014;13:709–16. DOI: 10.1177/1471301214548143.
- The Alzheimer Society of Ireland: Dementia Friendly Language
- The Plain Language Action and Information Network (PLAIN): a working group of United States of America federal employees from different agencies who support the use of clear communication in government writing.

"I have Lewy body dementia, but my wife Helena lives with it."
—*Kevin Quaid, Advocate & person with Lewy body dementia*

"I was struggling and overwhelmed, there was no way to sugarcoat this."
—*A caregiver*

IMAGES ARE LANGUAGE TOO

USE REALISTIC IMAGES

Avoid unrealistically positive or negative scenes of people in later life and try to avoid using images that only focus on frailty and declining health (consider the camera angle—is the person at eye level or is the camera looking down at them). The situations shown should be true to life.

EMBRACE DIVERSITY

Include photos that reflect the variety of older adults and people with dementia in the community. Try to represent a multi-dimensional experience of aging alongside other aspects of identities (e.g., race/ethnicity, gender identity or expression, body type, religion).

"Please no more acronyms! If I am on a Dementia Advisory Committee, please name it that. I don't understand 'DC-RAP' and other abbreviations like this."

—Kevin Quaid
Advocate & person with Lewy body dementia

CONSIDER THE CONTEXT

When using images, consider the context and associated headlines. Don't use a person's likeness for stories on sensitive topics or to imply that the individual supports a certain belief or position. Be careful to not dehumanize or make insinuations with your choice of image to accompany the text.

CONSIDER HOW YOU PRESENT INFORMATION

When you give a talk or presentation, your handouts and slides should also consider the use of supportive language as well as the visual needs of your audience. Materials that are visually "busy" can make your points difficult to follow and comprehend.
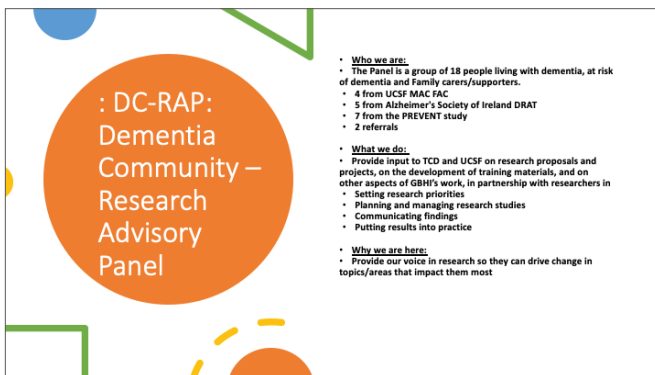
GENERAL GUIDELINES FOR SLIDE PRESENTATIONS

1. Avoid artwork that does not add to or clarify your message.
2. Put your key points on the slide and move supporting content to your notes so that you can refer to them during your talk.
3. Use background colors and type that is easy to read.
   - If you are presenting in a dark room, it is generally easier to read light or white text on a dark or black background.
   - If you are presenting in a well-lit room, it is generally easier to read dark text on a white or light background.
   - Limit text on the slide so that you can make it large enough for your audience to read.
   - Use standard typefaces that are designed for easy reading (Arial, Helvetica, Times New Roman, Garamond, Verdana, etc.) versus decorative typefaces designed for display (i.e., script or fonts made to look handwritten).

Below are two examples of slides: the first has artwork that can be visually challenging and contains lots of abbreviations and acronyms that can be difficult to follow. The second slide, while blander, is an example of a way to present information that can be easier for the audience to understand.
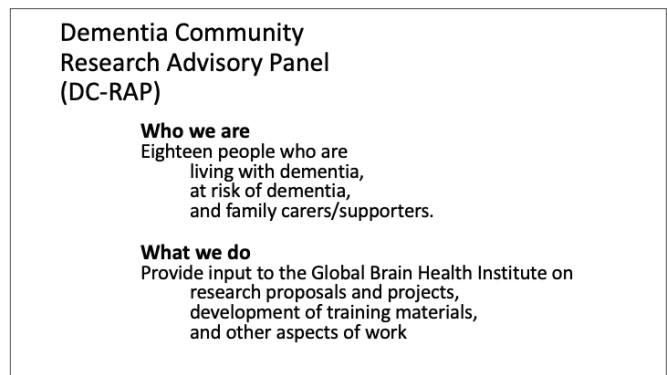
Example of a challenging slide

Example of a clearer slide

SPEAKER NOTES FOR THE PRESENTER

Who we are:
- 4 from the University of California, San Francisco, Memory and Aging Center Family Advisory Council
- 5 from The Alzheimer Society of Ireland Dementia Research Advisory Team
- 7 from the PREVENT study
- 2 referrals

What we do
- Setting research priorities
- Planning and managing research studies
- Communicating findings
- Putting results into practice

Why we are here
- Provide our voice in research so they can drive change in topics/areas that impact them most

Resources used in creating this image guide:

- Centre for Ageing Better: Age-positive images
- Changing the Narrative: Ending Ageism Together
- Citi and Getty images: Diversity, Equity, & Inclusion Imagery Toolkits