



# LIVING FULLY WITH DEMENTIA: WORDS MATTER

July 2015





The Dementia Action Alliance is a volunteer coalition engaged in changing understanding of and attitudes about dementia. We are committed to helping people live fully with dementia and supporting those who care about them. The Alliance is led by CCAL-Advancing Person-Centered Living, AMDA: The Society for Post-Acute and Long-Term Care Medicine, LeadingAge Georgia, Planetree, and The Eden Alternative.

We are thankful and appreciative to some powerful thought contributors to this paper – all individuals living with dementia or other form of cognitive impairment - Robert Bowles, Christine Bryden, Michael Ellenbogen, Sandy Halperin, Truthful Loving Kindness, Kate Swaffer, and Harry Urban.

We also thank Alzheimer’s Australia for their leadership in creating *Dementia Language Guidelines*, an excellent framework that addresses discriminatory language widely used in descriptions about dementia and the people living with the condition. Alzheimer’s Australia paved the way for us to advance information about this important topic, and we are extremely grateful for their pioneering efforts.



## **LIVING FULLY WITH DEMENTIA: WORDS MATTER**

*"Language shapes our behavior and each word we use is imbued with multitudes of personal meaning. The right words spoken in the right way can bring us love, money and respect, while the wrong words - or even the right words spoken in the wrong way- can lead a country to war. We must carefully orchestrate our speech if we want to achieve our goals and bring our dreams to fruition."*

Words Can Change Your Brain (Neuberg & Waldman, 2012)

If the wrong words can lead a country to conflict, consider the overwhelmingly positive effect the right words can have. The words currently used to describe people who are living with dementia, including Alzheimer's are often not positively oriented. Instead, the words are frequently derogatory and discriminatory. This presents significant barriers to being able to live life fully with dementia and perpetuates the stigmas and misperceptions about the condition. This paper is intended to heighten understanding of the impact words and phrases can have on the well-being and lived experience of people who have dementia, and to provide preferred words/phrases, including the rationale for their use, as determined by a consensus of a number of people who are living with early-stage dementia.

In the 1960's, it was hailed as progressive to use the term "mental retardation" rather than "idiot" and "moron". Times progress and in 2010 Rosa's Law was enacted to mandate use of the term "intellectual disability" instead of "mental retardation". Many of the words and terms used today about people who have dementia are the discriminatory equivalent of "moron" and "idiot" such as "demented," "victim," and "sufferer," and the condition as a "dementing illness" or an "affliction". This type of language can have tremendous impact on how people living with dementia feel about themselves and how they are treated and considered by others. They often face social isolation because negative perceptions can fuel misunderstanding, distrust, and add to the challenge of living with the condition.

*"How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued...Give us reassurances, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain our social networks." (Bryden, 2005)*

The disability community coined the phrase, "nothing about us without us" in order to be included in any discussions, policymaking, and research about them. Without their involvement, there was an inaccurate understanding of their condition(s). Similarly, there should be a "nothing about us without us" mindset for dementia as inaccurate understandings and perceptions are prevalent, impacting the ability to make progress as a nation in helping people to live fully with dementia.

## **IN THE WORDS OF PEOPLE LIVING WITH DEMENTIA**

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"Because dementia can be "invisible" to others and then often doubted, those with dementia and their care partners can feel invalidated and disheartened. This can exacerbate the stigma and therefore create major barriers to their joy of life... I am eager to see all those living with dementia and their care partners break through the barrier wall of stigma to live the most fulfilling and productive lives."

Sandy Halperin

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"Body language is often a much bigger deal for us than the words said. Touch a hand or shoulder, or simply sit companionably nearby... Extend the courtesy of talking to me directly, slowly, and pausing between phrases and sentences. Take the time to listen to what I have to say, allow me to interrupt before I forget what I wanted to say."

Truthful Loving Kindness

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“Look me in the eyes when you are talking to me. Make me feel like you want to talk to me. I can tell by your eyes if you really are comfortable talking to me or afraid to be around me. I sense your emotions and will copy them. If you are angry or frustrated, you will pass these emotions to me.”

Harry Urban

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“I read an article that women speak about 20,000 words a day and men speak about 7,000. Typically we speak at the rate of 100-150 words per minute. I cautiously showed this to my wife and suggested this might be the reason why I have so many emotional outbursts when she is talking. I asked her to imagine that she was talking to me for one minute and that during that time I had to process and remember 150 words. I would suggest that those without dementia consider having a better listening ear and decrease the number of words that are used in their communication with someone with dementia.”

Robert Bowles, Jr.

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“I do not like the term “patient” unless I am in a hospital or medical setting. If I hear this word used to refer to me in other settings, it weakens me and I worry I will start acting like a patient and need someone to do even more for me.”

Michael Ellenbogen

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## RECOMMENDED WORDS & RATIONALE

Borrowing from the excellent work developed by Alzheimer’s Australia’s “Dementia Language Guidelines” (<https://fightdementia.org.au/sites/default/files/language-guidelines.pdf>) as well as interviews and discussions with people living with dementia, the following is the Dementia Action Alliance’s list of recommended words and the rationale for using them.

| RECOMMENDED WORDS  | WORDS TO AVOID   | RATIONALE   |
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| <ul style="list-style-type: none"> <li>▪ Person living with dementia; or a specific condition (ex: person living with Lewy Body dementia)</li> <li>▪ Patient (only appropriate when used in the context of a medical event)</li> </ul> | <ul style="list-style-type: none"> <li>▪ Patient (inappropriate when used outside of a medical event)</li> <li>▪ Sufferer</li> <li>▪ Victim</li> <li>▪ Demented</li> <li>▪ Demented person</li> <li>▪ Dementing illness</li> <li>▪ Senile</li> <li>▪ Afflicted</li> <li>▪ Wanderer</li> <li>▪ Sundowner</li> <li>▪ Feeder</li> <li>▪ Empty shell</li> <li>▪ Losing his/her mind</li> <li>▪ Loss of self</li> <li>▪ Not all there</li> <li>▪ Behavior problem</li> <li>▪ PWD (researchers)</li> <li>▪ PLWD (researchers)</li> </ul> | <p>Webster’s dictionary defines “patient” as – <i>a person receiving medical treatment</i>. When the word “patient” is used in circumstances that are non-medical it infers the person’s life is an on-going medical treatment which is stigmatizing.</p> <p>The words listed under those to avoid are considered derogatory and offensive and should never be used.</p> <p><u>NOTE</u> -</p> <p>The use of acronyms in research work infers a lack of sensitivity and respect for the personhood of an individual or group of people. Spelling out the words is a sign of respect.</p> |

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| <ul style="list-style-type: none"> <li>▪ Dementia, including Alzheimer's; or</li> <li>▪ Dementia as the umbrella term for the many different forms of memory loss and other cognitive impairments</li> </ul>  | <ul style="list-style-type: none"> <li>▪ Alzheimer's unless used to refer specifically to that type of dementia</li> </ul>   | <p>Not everyone who has dementia has Alzheimer's disease. It is insensitive when the term is used ubiquitously. The term "dementia," however, is a general term and can be used inclusively.</p>   |
| <ul style="list-style-type: none"> <li>▪ Care partner</li> <li>▪ Spouse, wife/husband, daughter/son, family member, loved one, or friend</li> <li>▪ Carer</li> </ul> <p>*(It is best to ask the individual in the support role how he/she would like to be known as.)</p> | <ul style="list-style-type: none"> <li>▪ Caretaker</li> <li>▪ Caregiver</li> <li>▪ Custodian</li> <li>▪ Dutiful wife/husband, etc.</li> <li>▪ Person burdened with care</li> </ul> | <p>It is important to use words that recognize the reciprocity and caring relationship between the person living with dementia and their care partner. While the level of support varies based on the stage of the condition, words that support a positive relationship-based connection are preferred.</p> |
| <p><u>Providing</u> -</p> <ul style="list-style-type: none"> <li>▪ Support</li> <li>▪ Assistance</li> <li>▪ Care and support</li> </ul>   | <p><u>Providing</u> -</p> <ul style="list-style-type: none"> <li>▪ Caregiving</li> <li>▪ Care</li> </ul>   | <p>Words such as "caregiving" and "care" infer a one-way relationship.</p>   |
| <ul style="list-style-type: none"> <li>▪ Expressions of unmet need;</li> </ul>  | <ul style="list-style-type: none"> <li>▪ Behavior problem</li> <li>▪ Challenging</li> </ul>  | <p>Behavioral expressions are often expressions of unmet</p>   |

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| <ul style="list-style-type: none"> <li>▪ Behavior expressions;</li> <li>▪ Behaviors expressed by a person living with dementia</li> </ul>  | <p>behavior</p> <ul style="list-style-type: none"> <li>▪ Difficult behaviors</li> <li>▪ Behavioral and psychological symptoms of dementia (BPSD)</li> <li>▪ Vocalizer</li> <li>▪ Aggressor</li> </ul> | <p>needs, such as pain, hunger, thirst, boredom, loneliness or an underlying medical condition. Understanding behaviors from this broader perspective aids in uncovering the root cause of the behavior being expressed. (Love, K. p.26).</p>   |
| <ul style="list-style-type: none"> <li>▪ Individualized practice(s)</li> <li>▪ Personalized practice(s)</li> </ul>   | <ul style="list-style-type: none"> <li>▪ Non-pharmacological intervention(s)</li> <li>▪ Treatment</li> <li>▪ Intervention</li> </ul>  | <p>The consensus opinion of dementia experts from the <i>Dementia Initiative</i> recommend use of the term “personalized approach” instead of “non-pharmacologic”. Non-pharmacologic infers a medical focus rather than a holistic. Additionally, the term “individualized practice” reinforces a focus on the person rather than generic practices. (Love, K. p 28).</p> |
| <p><u>The condition is –</u></p> <ul style="list-style-type: none"> <li>▪ Challenging</li> <li>▪ Stressful</li> <li>▪ Life changing</li> </ul> <p><u>The condition can make one feel –</u></p> | <p><u>The condition is not -</u></p> <ul style="list-style-type: none"> <li>▪ Hopeless</li> <li>▪ Tragic</li> <li>▪ The long goodbye</li> <li>▪ Fading away</li> <li>▪ Burdensome</li> </ul>          | <p>Those of us living with dementia are alive. We can feel, we can laugh, we can cry no matter what stage we are in. There are so many things we can continue to do during the course of the condition</p>  |

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| <ul style="list-style-type: none"> <li>▪ Hopeless</li> <li>▪ Depressed</li> </ul>    |  | (Myriam Marquez, 7.8.15).  |
| Young-onset dementia to refer to someone under the age of 65 diagnosed with dementia | Early-onset dementia to refer to someone under the age of 65 diagnosed with dementia | Early onset is sometimes used to describe dementia symptoms that occur before the age of 65, but can also be used for the first cognitive impairment symptoms experienced at any age. To avoid confusion, the term young-onset dementia is seen as preferable as it specifically refers to any form of dementia where symptoms appear in people under the age of 65. |

**ADDITIONAL CONSIDERATIONS**

- "Victim" - Dementia does not victimize a person. Poor levels of care, abuse, and disrespect victimizes a person. I have avoided a "victim mentality". There is no alternate language for "victim", please don't use it.
- "I often forget where things are too." – invalidates us.
- "I can't find my words either ... but we are just getting older." – also invalidating.
- "You don't (look/sound/write) like you have dementia." My reading comprehension is down to fourth grade level, yet my writing is mostly intact. Instead say, "You are looking well today."
- "Please leave your name, phone number, date of birth, brief description for your call, along with the best time to call ... after the beep". I likely will leave my name but with all the other directions, I will probably forget to leave any other information.

- *"Just take this home and read it".* Will I understand it? Will I remember what to do with the information?
- *"But this was important so, of course, you remember \_\_\_."* Just because something is/was important doesn't mean that I am more likely to retain memory of it.
- *"Can you introduce your friend?"* I may not remember their name. It is best for them to introduce his/her self.

Truthful Loving Kindness

- *Don't blame the person for the changes in behavior or personality.*
- *Don't assume I can't answer for myself.*
- *Don't talk about me to someone else, in front of me.*
- *Don't assume we can't communicate even if we can't speak.*
- *Don't assume we don't understand just because we are silent.*
- *Don't assume because we can't tell you, your words or actions don't hurt our feelings.*

Kate Swaffer

Words are powerful. The use of appropriate words can dramatically help to reshape attitudes, actions, and thoughts about people who are living with dementia. Rather than disrespecting and diminishing any person, all words used should be supportive, respectful, and life-affirming.

**PLEASE CHOOSE THE WORDS YOU USE CAREFULLY  
SO AS NOT TO DIMINISH OR DEVALUE ANY PERSON  
WHO IS LIVING WITH DEMENTIA.**

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