

Language Guidelines: Reframing for Respect

The Gayle Wells Foundation for Early Onset Alzheimer's & Care (GWF) believes appropriate terms and language must be used to respect those who have been diagnosed with early onset Alzheimer's disease and other forms of dementia. It is crucial to use language and terms that are accurate, respectful, inclusive, empowering, and non-stigmatizing. No one should be defined by their diagnosis. A diagnosis of early onset Alzheimer's disease does not erase someone's identity, nor does it become their identifying characteristic.

Below are common terms and phrases the GWF uses to ensure that respect and dignity are at the forefront of all communication.

Language to Avoid	Language of Respect	Reason
Adult Day Care	Dementia day program Support program	Day care is used to describe programs for children.
Behaviors	Unmet needs	Behaviors are thought of as "acting out," "misbehaving" or something that needs to be corrected. The person is communicating an unmet need. Defining, understanding, and addressing the unmet need will deepen relationships and provide for a better quality of life.
Bibs	Napkins	Bibs are for infants. A napkin is a cloth covering to protect clothing during meals.
Burden of caregiving Caregiver burden	Care partner stress Care partner challenges Effects of providing care State individual issues experienced by care partners	Implies that being a care partner is always a burden and a negative experience. The interpretation of being a care partner should be left to the person providing care. While the term can validate some care partner experiences, it should not be assumed nor used as a general statement.
Caregiver	Care partner	Reframes the relationship between the roles as a partnership. Each person is equally important and the ability to give and receive, as well as make new memories, still exists in the relationship.
Cases	People we serve Person with early onset Alzheimer's disease	The term "cases" depersonalizes the person living with the disease.
Dementia patient	First person language Use of the person's name	The person needs to be recognized as a person and not be defined by the disease.
Diapers Adult undergarments Pull-ups	Underwear or whatever term the person used to describe their underwear	Diapers is demeaning and defined as something that babies wear. Respect the dignity of the person.

Language to Avoid	Language of Respect	Reason
Difficult Non-compliant Refuses care Uncooperative	Use the person's name with a description of what is occurring	If a person is demonstrating unmet needs, then they are trying to communicate that something is wrong. They may be afraid and confused. They may not understand what is happening because no one is talking to them. Learning about the person and understanding their characteristics can help identify what may be happening.
Don't you remember? Remember when?	The time we went to	Asking the individual to remember events can be stressful. Begin the story and let the individual fill in any details they recall or let them enjoy listening to the memory.
In denial	Validate the person's feelings Ask the person to explain what they are experiencing and feeling	This phrase is judgmental. Denial implies a choice to refuse or reject reality. Denial may be part of the grieving process that needs to be addressed.
Patient Client / customer Resident Sufferer/victim Demented person Afflicted Empty shell Not all there Fading away	Person Individual Use of person's first name	Recognition of the person as a human being is essential. They need to be recognized for who they are and not defined by institutional and demeaning labels.
Word salad	Disorganized speech Fragmented speech Jumbled speech	The term "word salad" is used when the person with the disease has difficulty with verbal language and words are often jumbled, like a "tossed salad." In the midst of the disease, this term can be interpreted as insensitive.
Trigger Triggered (In the context of discussing an event that provokes an emotional response from a past trauma)	Activated Provoked Sensitive issue Pushed your buttons Painful association	The terms "trigger" and "triggered" are often politicized, minimized, and mocked in today's society. Additionally, the increase in gun violence throughout our country increases the sensitivity and trauma around the use of these words.