

DEMENTIA LANGUAGE GUIDELINES

The purpose of this paper is to promote the consistent use of appropriate, inclusive and non stigmatising language when talking about dementia and people with dementia.

What is appropriate language for talking about dementia and why do we need it?

The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community.

The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination.

Appropriate language must be:

- Accurate
- Respectful
- Inclusive
- Empowering, and
- Non stigmatising

Everyone deserves respect

Respectful language recognises that dementia is not the defining aspect in the life of someone with a diagnosis and does not reflect their capacity or level of understanding. It is important to respect others preferences about words used about them, regardless of whether the person being talked about is present or not.

Be mindful of not reinforcing stereotypes or myths about dementia

It is important to know the facts about dementia. For example, dementia is not a normal part of ageing, nor is memory loss the only symptom. Dementia can affect language, planning, problem solving, behaviour, mood and sensory perception.

Talking about dementia in a negative manner or by using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate the myths and misinformation about dementia.

Everyone with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people.

Don't be afraid to ask

Individuals and families will express their experiences of dementia in ways that has meaning and significance to them. Not everyone will wish to have their experiences with dementia described in the same way. Where possible, ask that person directly. We can respect the dignity of each individual by respecting that person's wishes regarding use or non-use of certain terms relating to dementia.

Empowering language

It is important to use language that focuses on the abilities (not deficits) of people with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

For a full copy of this guide, including background information on the preferred terms listed in the table go to: www.dementiafriendly.org.au

You can find more information about dementia at: www.fightdementia.org.au

The following are terms that people with dementia would prefer to be used when talking about dementia and people with dementia in different situations.

CONTEXT	PREFERRED TERMS	DO NOT USE
TALKING ABOUT DEMENTIA	Dementia Alzheimer's disease and other forms of dementia A form of dementia A type of dementia Symptoms of dementia	Dementing illness Demented Affliction Senile dementia Senility Going on a journey
TALKING ABOUT PEOPLE WITH DEMENTIA	A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia	Sufferer Victim Demented person Dementing illness Dements Afflicted Offenders, absconders or perpetrators Patient (when used outside the medical context) Subject Vacant dement He/she's fading away or disappearing Empty shell Not all there Losing him/her or someone who has lost their mind He/she's an attention seeker Inmates (referring to people with dementia in care facilities) An onion with the layers peeling away Slang expressions that are derogatory, for example, delightfully dotty, away with the fairies, got a kangaroo loose in the back paddock, a couple of cents short. 'They' (talking about all people with dementia rather than the individual)
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves)	Living alongside (someone/ a person/my partner/my mother etc) who has dementia Living with/caring for/supporting a person who has dementia Living with/caring for/supporting a person with a diagnosis of dementia Living with the impact of dementia	Person living with dementia
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else)	Family member(s) Person supporting someone living with dementia Wife/husband/partner Child/Son/Daughter Parent Friend Carer or care-giver – not everyone will like to be referred to as a carer. If possible ask what the person's preference is before using this term	

CONTEXT	PREFERRED TERMS	DO NOT USE
IMPACT OF CARING	Impact of supporting (someone/a person/my partner/my mother etc) with dementia Effect of supporting (someone/a person/my partner/my mother etc) with dementia	Carer burden Burden of caring
PEOPLE WITH DEMENTIA UNDER 65	Younger onset dementia	Pre-senile dementia Early onset dementia
THE IMPACTS OF DEMENTIA	Disabling Challenging Life changing Stressful	Hopeless Unbearable Impossible Tragic Devastating Painful
SYMPTOMS OF DEMENTIA	Describe the symptom itself e.g. reduced vision, hallucinations, difficulty communicating Describe the impact it is having e.g. difficulty communicating	
BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA	Changed behaviour(s) Expressions of unmet need Behavioural and psychological symptoms of dementia (in a clinical context)	When talking about the symptoms Behaviour(s) of concern Challenging behaviours Difficult behaviours When talking about the person Difficult Faded away, empty shell or not all there Disappearing Aggressor Wanderer Obstructive Wetter Poor feeder Vocaliser Sexual disinhibitor Nocturnal Screamer Violent offender
IN RESEARCH	Dementia as a condition A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia A participant (if in a research trial)	
MEDICAL	Condition	Illness Disease