

Dementia Language Guidelines

Contents

What is appropriate language for talking about dementia and why do we need it?	3
Everyone deserves respect	3
Don't be afraid to ask	4
Empowering language	4
Cultural awareness	4
When talking about dementia	5
When talking about people with dementia	6
When talking about a carer, family member or friend of a person with dementia	7
When talking about people with dementia under 65	9
When talking about the impacts of dementia on the person living with dementia	9
When talking about the symptoms of dementia	10
When talking about the behavioural and psychological symptoms	11
When talking about dementia in research or in a medical context	12

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

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

The words used to talk or write about dementia can have a significant impact on how people living 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
- 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's experience of living with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people. You can find more information about dementia at dementia.org.au

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 living with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

Cultural awareness

Using the term dementia and related words in English may not always be appropriate when talking to people from culturally and linguistically diverse communities or in translation as it may be seen as offensive or disrespectful. Although the understanding of dementia is growing in the Anglo Australian community, there is still a lack of awareness of dementia in many diverse communities. In some cases dementia may be regarded as a mental illness or as a normal part of ageing. Words and phrases that are appropriate in one community may be offensive or of no meaning in another community. It is important to be aware of the cultural background of the person, family or community so that you can use the most appropriate language. It is always advisable to seek guidance from culturally and linguistically diverse communities on appropriate terminology where possible.

When talking about dementia

It is important to know that dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia may affect thinking, communication, memory and in some instances behaviour, and/or the ability to perform everyday tasks and in time it will impact on the person's family, social and working life.

The following terms/phrases are preferred when talking about dementia:

- dementia
- Alzheimer's disease and other forms of dementia
- a form of dementia
- a type of dementia
- symptoms of dementia.

The following terms/phrases should not be used:

- dementing illness
- demented
- affliction
- senile dementia
- senility
- going on a journey.

Why?

It is important to accurately reflect that dementia is an umbrella for the symptoms and that there are many different forms of dementia, each with its own cause. Senile dementia is an outdated term that used to be used when it was thought that memory loss or other cognitive impairment was a normal part of ageing, rather than being caused by specific types of disorders of the brain.

When talking about people with dementia

People with dementia are individuals first and their diagnosis should not be regarded or referred to as the defining aspect of their life.

The following terms/phrases are preferred when talking about a person with dementia:

- a person/people with dementia
- a person/people living with dementia
- a person/people with a diagnosis of dementia.

The following terms/phrases should not be used:

- 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).

Why?

Many of the terms listed are demeaning and derogatory. Terms such as ‘sufferer’ and ‘victim’ contribute to the stigma surrounding dementia and ‘demented person’ places the condition before the person. Using the terms person/people with dementia or person/people living with dementia maintains the dignity of the person, emphasises that they are a person first and does not place judgements on the individual because they have dementia.

Often people with dementia are referred to in a group as ‘they’ which loses sight of the individual and focuses on the condition, using the preferred terms avoids this situation.

When talking about a carer, family member or friend of a person with dementia

People with dementia would prefer the term person/people living with dementia to be used by or to refer to a person diagnosed with dementia rather than used to refer to family, carers and friends.

It is preferred that carers, family and friends are referred to as:

- 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.

When describing someone who is caring for a person with dementia the preferred terms/phrases are:

- 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.

In this context the terms apply to someone that is providing unpaid care to a person with dementia, which is different to a professional or paid carer.

When describing the impact of the caring role on someone providing care for a person with dementia the preferred terms are:

- 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.

The following terms should not be used when describing the impact of the caring role on someone providing care for a person with dementia:

- carer burden
- burden of caring.

Why?

Only a person with dementia can truly understand what it is like to live with dementia. Similarly, only a carer knows what it is like to care for a person with dementia.

It is important when referring to someone else in a caring role that you use terms that are emotionally neutral. Everyone has a different experience as a carer and using terms such as ‘burden’ assumes the role is entirely negative, or that caring for the person with dementia is difficult. Emotionally neutral terms do not make assumptions that the role of the carer is either negative or positive. Of course it is acceptable for a carer to talk about the difficulties they may experience as a result of providing care.

When talking about people with dementia under 65

Approximately 7 per cent of all people with dementia are under the age of 65.

The preferred term/phrase when talking about a person with dementia under 65 is:

- younger onset dementia.

The following terms/phrases should not be used when talking about a person with dementia under 65:

- pre-senile dementia
- early onset dementia.

Why?

Senile dementia is an outdated term that was used when it was thought that memory loss or other cognitive impairment was a normal part of ageing, rather than being caused by disorders of the brain.

Early onset is sometimes used to describe dementia symptoms that occur before the age of 65, but is sometimes also applied to the first symptoms experienced with dementia at any age. To avoid confusion, the term younger onset dementia is seen as preferable to early onset as it specifically refers to any form of dementia where symptoms appear in people under the age of 65.

When talking about the impacts of dementia on the person living with dementia

The symptoms of dementia will be different for each individual, depending on the cause of the dementia and the progression of the disease. It will therefore impact upon people's lives in different ways, of which not all may be negative.

The preferred terms when talking about the impacts of dementia are:

- disabling
- challenging
- life-changing
- stressful.

The following terms should not be used:

- hopeless
- unbearable
- impossible
- tragic
- devastating
- painful.

Why?

Each person will relate differently at different times to their diagnosis and how dementia impacts their life will vary from one person to another. While it is important to be truthful and realistic about the impact of dementia, the words used do not need to be negative, disempowering, pessimistic or frightening.

When talking about the symptoms of dementia

It is important to remember that while there are some symptoms of dementia that will be experienced by most people to some degree, the nature and severity of symptoms can also be very different for each person, and symptoms are likely to change over time.

The following are preferred when talking about the symptoms of dementia:

- Describe the symptom itself. For example memory loss, change in mood or behavior, word finding problems.
- Describe the impact it is having. For example difficulty communicating.

When talking about the behavioural and psychological symptoms

Dementia affects people in different ways and changes in the behaviour or emotional state of a person with dementia are common. However in most cases, behavioural and psychological changes are an expression of some need or sensation that the person with dementia is experiencing (for example, frustration, pain, boredom, loneliness, confusion) that they are not able to communicate verbally.

The following expressions and terms are preferred when talking about the behavioural and psychological symptoms of dementia:

- changed behaviour(s)
- expressions of unmet need
- behavioural and psychological symptoms of dementia (in a clinical context).

The following terms/phrases should not be used when talking about the behavioural symptoms of dementia:

- behaviour(s) of concern
- challenging behaviours
- difficult behaviours.

The following terms/phrases should not be used when talking about the person with behavioural symptoms of dementia:

- difficult
- faded away, empty shell or not all there
- disappearing
- aggressor
- wanderer
- obstructive
- wetter
- poor feeder
- vocaliser

- sexual disinhibitor
- nocturnal
- screamer
- violent offender.

Why?

It is important to understand that behavioural changes are caused by changes to the brain and can also be affected by an individual's environment (social and physical), health and medication.

Describing the symptom or change suggests that we are defining the person by their symptoms. Regardless of the symptoms the person is experiencing at the time they are always a person first.

When talking about dementia in research or in a medical context

The following expressions and terms are preferred when talking about dementia in research or in a medical context:

- 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).

The following terms should not be used when talking about dementia in research or in medical terms:

- illness
- disease (unless speaking about a type of dementia such as Alzheimer's disease)
- subject
- case
- PWD (as an abbreviation for a person with dementia)
- PWYOD (as an abbreviation for a person with younger onset dementia).

Why?

In a medical sense dementia is more appropriately described as a condition or set of symptoms unless talking about a specific subtype of dementia such as Alzheimer’s disease.

In regards to research it is important to remember you are still referring to a person and the preferred terms should be used.

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	<ul style="list-style-type: none"> • dementia • Alzheimer’s disease and other forms of dementia • a form of dementia • a type of dementia • symptoms of dementia. 	<ul style="list-style-type: none"> • dementing illness • demented • affliction • senile dementia • senility • going on a journey.

Context	Preferred terms	Do not use
Talking about people with dementia	<ul style="list-style-type: none"> • a person/people with dementia • a person/people living with dementia • a person/people with a diagnosis of dementia. 	<ul style="list-style-type: none"> • 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).

Context	Preferred terms	Do not use
A carer, family member or friend of a person with dementia (About themselves)	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • person living with dementia.
A carer, family member or friend of a person with dementia (About someone else)	<ul style="list-style-type: none"> • 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. 	
Impact of caring	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • carer burden • burden of caring.

Context	Preferred terms	Do not use
People with dementia under 65	<ul style="list-style-type: none"> • younger onset dementia. 	<ul style="list-style-type: none"> • pre-senile dementia • early onset dementia.
the impacts of dementia	<ul style="list-style-type: none"> • disabling • challenging • life changing • stressful. 	<ul style="list-style-type: none"> • hopeless • unbearable • impossible • tragic • devastating • painful.
symptoms of dementia	<ul style="list-style-type: none"> • describe the symptom itself. For example reduced vision, hallucinations, difficulty communicating • describe the impact it is having. For example difficulty communicating. 	

Context	Preferred terms	Do not use
Behavioural and psychological symptoms of dementia	<ul style="list-style-type: none"> • changed behaviour(s) • expressions of unmet need • behavioural and psychological symptoms of dementia (in a clinical context). 	<p>When talking about the symptoms</p> <ul style="list-style-type: none"> • behaviour(s) of concern • challenging behaviours • difficult behaviours. <p>When talking about the person</p> <ul style="list-style-type: none"> • difficult • faded away, empty shell or not all there • disappearing • aggressor • wanderer • obstructive • wetter • poor feeder • vocaliser • sexual disinhibitor • nocturnal • screamer • violent offender.

Context	Preferred terms	Do not use
In research	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • condition. 	<ul style="list-style-type: none"> • illness • disease.

Contact Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia has a range of support services available.

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**