

# Dementia Friendly Language



## Position Paper 4

UPDATED JUNE 2009 (Supersedes Position Paper 4: Dementia Terminology Framework)

### Alzheimer's Australia

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#### Introduction

Language is a powerful tool. 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, it reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia.

We have a responsibility to use language that is empowering and inclusive of the diverse experiences of dementia. It is important to convey that dementia is not necessarily a defining aspect of life and that life does not stop when dementia starts.

The purpose of this paper is to promote the consistent use of appropriate language across Alzheimer's Australia nationally and to guide the language used by others. It outlines a framework of preferred terminology related to dementia and offers a brief rationale for the preferred use of each term.

#### Background

As the national peak body for people living with dementia, their families and carers, Alzheimer's Australia's mission is to provide leadership in advocacy, policy, services and research. Our vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia. Integral to this is the need to communicate in ways that are positive, while remaining realistic about the nature of the condition.

Alzheimer's Australia has an important role to play in encouraging the use of positive language and setting a standard for other organisations, government, media and the general community, in their communications about dementia and with people with dementia. This paper will strengthen our capacity to fulfil this role by promoting consistency across the organisation and by providing a reference document for others to use.

People living with dementia or individual families and carers themselves will, of course, continue to describe the impact of dementia on their own life and the lives of others close to them in whatever terms they choose.

#### Feedback

Language is constantly changing and it is important to review terminology regularly. This paper will therefore be updated regularly. If you would like to comment on the paper or its contents, please contact Alzheimer's Australia:

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## The Condition

Preferred terms	Non-preferred terms	Rationale
<p><b>Dementia</b></p> <p><b>A form of dementia</b></p>	Dementing illness	<ul style="list-style-type: none"> <li>There is a need to reflect accurately that dementia is an umbrella term for a large group of illnesses that cause a progressive decline in a person's functioning.</li> </ul>
<p><b>Condition</b></p> <p><b>Illness</b></p>	Disease	<ul style="list-style-type: none"> <li>Dementia is more appropriately described as a condition or an illness. There are different forms of dementia and each has its own causes. Alzheimer's disease is most common, followed by vascular dementia, frontotemporal lobar degeneration (FTLD) and dementia with Lewy bodies.</li> </ul>
<p><b>Younger onset dementia</b></p> <p><b>Younger people (under 65) with dementia</b></p>	Early onset dementia	<ul style="list-style-type: none"> <li>'Younger onset dementia' describes any form of dementia diagnosed in people under the age of 65.</li> <li>Confusion with early stage dementia can be avoided by using the term 'younger onset' in preference to 'early onset'.</li> <li>Some features of dementia are commonly classified into three stages or phases, described as 'early', 'moderate' and 'advanced'. Not every person will go through every stage; however it remains a useful description of the general progression of dementia.</li> </ul>

## The People

Preferred terms	Non-preferred terms	Rationale
<p><b>Person/people with dementia</b></p> <p><b>People living with dementia</b> (inclusive of people with dementia, their families and carers)</p>	<p>Sufferer</p> <p>Victim</p> <p>Demented person</p>	<ul style="list-style-type: none"> <li>• Terms such as 'sufferer' and 'victim' contribute to the stigma surrounding dementia.</li> <li>• People with dementia experience changes in their abilities over time. While their need for support may increase as the condition progresses, it is important to avoid language that implies they are helpless.</li> <li>• Choose positive and inclusive terms that maintain the dignity of those affected and are free of value judgements.</li> <li>• 'Demented person' places the condition before the person. People with dementia are individuals first and the condition should not be regarded or referred to as the defining aspect of their life.</li> </ul>
<p><b>Families and carers</b></p> <p><b>Family carers or carers</b></p> <p><b>Wife, husband, partner, daughter, son, friend,</b> for example.</p> <p><b>Care partner</b></p>	<p>Care-giver</p>	<ul style="list-style-type: none"> <li>• A 'carer' is someone who provides unpaid care for a relative or friend with care or support needs.</li> <li>• 'Family carers' may be used to avoid confusion where 'carers' may mean 'service providers'.</li> <li>• In one-on-one discussions, use the terms people themselves use, e.g. husband, wife, daughter, friend.</li> <li>• 'Care partner' has been proposed by younger people with dementia to reflect the partnership arrangement they may have with partners or friends who are assisting them.</li> <li>• 'Care-giver' denotes a one-way relationship.</li> </ul>
<p><b>Older person/people</b></p>	<p>Aged person</p>	<ul style="list-style-type: none"> <li>• 'Aged' can be seen as a patronising term.</li> <li>• 'Older' is more inclusive of a wider range of ages.</li> </ul>
<p><b>Service providers</b></p> <p><b>Workers or support workers</b></p> <p><b>Care workers or care staff</b></p>	<p>Professional carers</p> <p>Aged care workers</p>	<ul style="list-style-type: none"> <li>• 'Professional carers' may be seen as implying that family members are not doing a good job in caring for the person with dementia.</li> <li>• 'Aged care workers' is not inclusive of people with younger onset dementia who may require a care worker.</li> </ul>

## The Impact

Preferred terms	Non-preferred terms	Rationale
<p>Words to describe the impact:</p> <p><b>Heart-breaking</b>  <b>Devastating</b>  <b>Terrible</b>  <b>Painful</b>  <b>Distressing</b>  <b>Debilitating</b>  <b>Challenging</b></p>	<p>Hopeless</p> <p>Unbearable</p> <p>Impossible</p> <p>Tragic</p>	<ul style="list-style-type: none"> <li>• Appropriate descriptive words should be chosen to suit the audience and the context.</li> <li>• Not everyone will experience every emotion. Each person will relate differently at different times and have an individual response</li> <li>• It is important to be realistic about dementia while not being overly pessimistic or frightening. In particular, it is necessary to assist people with early stage dementia to be positive in tackling the consequences of their diagnosis.</li> <li>• The words proposed here are appropriate to describe the intensity of the impact, especially as the condition progresses through to the moderate and advanced stages of dementia when the impact on the person's life and on those who love and care for them is more severe and keenly felt.</li> </ul>
<p><b>Impact/effect</b> of caring for a person with dementia</p>	<p>Carer burden</p> <p>Burden of caring</p>	<ul style="list-style-type: none"> <li>• It is important to use terms that are emotionally neutral and inclusive. Describing caring as a burden, or using 'burden' to describe people with dementia, is negative. While caring for a person with dementia can certainly be challenging, many carers also identify positive and rewarding aspects to their role.</li> <li>• Technical terms such as 'burden of disease' or 'disease burden' – used by epidemiologists to measure 'years of healthy life lost due to a condition' – are appropriate to use in this technical context. As is the term 'carer burden'.</li> </ul>
<p><b>Continence</b></p> <p><b>Bowel/bladder problems</b></p>	<p>Incontinence</p>	<ul style="list-style-type: none"> <li>• The preferred term avoids negativity by focusing on achieving and managing continence.</li> <li>• At times, it may be appropriate to use the term incontinence as the medically correct term for the condition.</li> <li>• Where 'continence' may not be well understood, terms such as 'bowel or bladder problems' may be used in explanation.</li> </ul>

## The Impact continued

<p><b>Changed behaviour(s)</b></p> <p><b>Behaviour(s) of concern</b></p> <p><b>Behavioural and psychological symptoms of dementia</b></p>	<p>Challenging or difficult behaviours</p>	<ul style="list-style-type: none"> <li>▪ Behavioural and psychological symptoms of dementia may include agitation, aggression, anxiety, wandering and disinhibition.</li> <li>▪ Behavioural and psychological symptoms of dementia vary by individual, the cause and/or stage of dementia.</li> <li>▪ Most people only experience behavioural and psychological symptoms of dementia for a limited period of time.</li> <li>▪ While behavioural changes can be enormously challenging, particularly for families and carers, it is important to understand that the behaviour is due to the condition and that strategies can be put in place that may prevent it.</li> <li>▪ Some behaviours are an expression of extreme frustration and unmet need. The feelings behind the behaviour, for the person with dementia, need to be acknowledged and every attempt made to understand them.</li> <li>▪ 'Challenging' or 'difficult' behaviours are negative terms that may be open to judgemental interpretation.</li> <li>▪ The preferred terms avoid implying that the person with dementia is responsible for their behaviour.</li> </ul>
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## Services

Preferred terms	Non-preferred terms	Rationale
<p><b>Residential (care) facility</b></p> <p><b>High care/low care/mixed care residential facility</b></p>	<p>Nursing home</p> <p>Hostel</p>	<ul style="list-style-type: none"> <li>• 'High/low/mixed may be used where information is needed to give a more technical description of the type of residential facility – but such terms can be misunderstood by people unfamiliar with the field eg. people can assume 'low care' means 'low quality care'.</li> </ul>
<p><b>Caring for a person in a residential facility</b></p> <p><b>Shared Care</b></p> <p><b>Partners in Care</b></p>	<p>Relinquishing care</p>	<ul style="list-style-type: none"> <li>• Many people remain actively involved in caring for a person with dementia after they have moved to a residential facility. To describe this as 'relinquishing care' is inaccurate and may offend.</li> </ul>
<p><b>Previously cared for ... his/her wife/husband, father/mother, etc or a person with dementia</b></p> <p><b>Past or former carer</b></p>	<p>Graduate carer (referring to a family member of a person now deceased)</p>	<ul style="list-style-type: none"> <li>• 'Graduate carer' implies an achievement and this is inappropriate when someone is deceased.</li> </ul>
<p><b>'Taking a break' (with respite care services)</b></p> <p><b>Respite</b></p>		<ul style="list-style-type: none"> <li>• Respite services should provide an enjoyable and worthwhile break for both the person with dementia and their family and carers.</li> <li>• There are various types of respite services to suit individual people and situations: in home respite; recreational respite; and residential respite.</li> <li>• There are different ways of organising respite, depending on the individual situation: urgent and short term respite or planned and ongoing respite.</li> <li>• When using the term 'respite,' broaden understanding by explaining the meaning of the term.</li> </ul>