

# Dementia words matter: Guidelines on language about dementia

## Key messages

- **This guidance is for journalists, organisations and communications departments.**
- **The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.**
- **People with dementia prefer words and descriptions that are accurate, balanced and respectful.**

Dementia is discussed more regularly now in the media - both on television and in newspapers and magazines. The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. People with dementia prefer words and descriptions that are accurate, balanced and respectful.

These recommendations are written by 20 people with dementia who came together for a day in Liverpool to discuss the words that are used about dementia.

## Words and descriptions to avoid

People have identified the words they believe should **never** be used to describe dementia or people with dementia. These are words that have been used in print media over the last couple of years.

These were considered to be 'curl up and die' words:

- words that make people physically flinch when they hear or read them!
- words that send out the message that a life with dementia is not worth living, that people are helpless and have nothing to contribute!
- words that are negatively attached to the person rather than the condition of dementia
- words that create stereotypes.

## Words to avoid

Dementia sufferer

Demented

Senile or senile dementia

Burden e.g. people are a burden or cause burden

Victim

Plague

Epidemic

Enemy of humanity

Living death e.g. dementia is a living death

## Alternative words about people with dementia

Person/people with dementia

Person/people living with dementia

Person/people living well with dementia

## The context of words and descriptions of dementia

People with dementia do recognise that particular words and descriptions are used to create a good story and catch the reader's attention. Words can raise awareness about the existence of dementia, create a sense of urgency about the need for research and treatment developments, and increase funding for dementia.

However, people with dementia make a distinction between a) extreme and 'sensationalist' language choices and b) language which is accurate in the information it seeks to share.

People with dementia urge you to be thoughtful about your choice of words when talking about what it is like to live with dementia. Any evocative words should be chosen with intent and careful consideration of the message that will actually be received – and the impact it may have on people with dementia themselves.

## The word 'dementia'

The word 'dementia' is often misrepresented in media reports. Dementia is an umbrella term and refers to lots of different types of conditions. Some of the more common types of dementia include Alzheimer's disease, vascular dementia, Lewy Body dementia, and fronto-temporal dementia e.g. Pick's disease. People will choose many different ways to identify themselves in the context of their dementia.

Some people will describe themselves as 'a person with dementia' (or with a dementia), whilst others might identify themselves as someone with Alzheimer's disease.

When describing 'real' people with dementia (for example, a personal story with a named person), it is helpful to find out how the person identifies themselves. Avoid using 'dementia sufferer' as the descriptor, including within story headlines e.g. "Steve - a dementia sufferer".

## Patient, service user or client

Many people with dementia dislike the terms 'dementia patient' or 'service user' or client when these are used generically to refer to all people with dementia. This is because they imply that they are nothing more than this. It is

preferable to use 'person with dementia' or 'person living with dementia' as a rule.

However these terms may be appropriate when used in a specific context - such as when talking about people in a hospital or actually using a care service.

## Accompanying images

Sometimes the images selected to illustrate articles can serve to undermine the actual story. Images should be used in context. For example, when talking about someone trying to live a positive life, use an image that reflects the whole person rather than a fading face or wrinkled hands.

This guide was created with help from 20 people with dementia who came together for a day in Liverpool

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email [rachael@myid.org.uk](mailto:rachael@myid.org.uk) or telephone 01392 420076.

October 2014

FUNDED BY



JOSEPH  
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