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**Dementia Inclusive  
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# Speaking about dementia

How to talk and write about dementia in a way which is positive and inclusive of people living with the condition.

**Created by the Dementia Inclusive Singing Network with the  
Age Scotland Dementia Training Team**

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## Language, stigma and living well

The way we talk about dementia influences the way people living with the condition are seen and thought about – and also how people with dementia think about themselves.

There has been a tendency for the condition to be spoken and written about in a way which implies that life with dementia is not worth living and that people with dementia are helpless and have nothing to contribute.

**“Now really, do any of us look like we are suffering or that we are victims? It looks more to me like we are meaningfully engaged, in the real world, and having fun!”**

Kate Swaffer, author and activist, speaking at the Alzheimer’s Disease International Conference, Puerto Rico

This creates a lot of stigma around the condition and can have many negative consequences, such as:

- People with dementia not being included in discussions and decisions affecting them – or in the normal activities of daily life.
- People being reluctant to accept that they have dementia, to seek or access the support available.
- People with a diagnosis of dementia – and those close to them - feeling that life is over and living in a fulfilling and meaningful way is no longer possible



Words and phrases which contribute to this include:

- Sufferer / victim
- Demented / senile
- Plague / epidemic
- Enemy of humanity
- Misery / living death

People living with dementia urge us to be thoughtful about our choice of words when talking or writing about what it is like to live with the condition. While recognising that there is a need to raise awareness of dementia and the many challenges it poses, people living with the condition tell us that they prefer language which is accurate and informative rather than emotive and sensationalist.



## Positive, informative and inclusive language

Campaign groups such as the Dementia Engagement and Empowerment Project ([www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)) tell us that people living with dementia would rather be referred to in the following ways:

- Person/people with dementia
- Person/people living with dementia
- Person/people living well with dementia

“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. While research shows that most people are comfortable being referred to by the three phrases above, some people may prefer to use the name of their specific illness e.g. “someone with Alzheimer’s Disease.

If you are writing or speaking about someone with dementia, it is always better to check how the person wants to be identified.

## Living well with dementia

Increasingly, people with dementia are talking about their lives in positive ways. A recent survey by the [Scottish Centre for Social Research](#) found that almost 70% of people with dementia said they were living well. It is important that in speaking about dementia, in addition to raising awareness of the many challenges involved, we also reflect the fulfilment, contribution, participation, empowerment and enjoyment that people living with dementia experience as part of their everyday lives. Images used in telling stories about dementia that show whole people living positive lives are also powerful in challenging stigma and negative stereotypes.

**“We are just changing in ways the rest of you aren’t, we have increasing disabilities and the sooner it is looked at that way instead of the stigmas, misunderstandings and complete lies the better for all of us living with dementia. We desperately need others to enable us, not further disable us!”**

The infographic is titled "Living well with dementia" and features two individuals: Terry Pratchett and Kate Swaffer. Terry Pratchett is shown with a portrait and a quote: "It is possible to live well with dementia and write best-sellers - like wot I do." Below his name is a list of his qualifications: 2016 PhD Candidate, University of Wollongong; 2014 Masters of Science in Dementia Care (Distinction), University of Wollongong; 2010 Bachelor of Psychology, University of South Australia; 2009 Bachelor of Arts, Writing and Creative Communication, University of South Australia; 2005 Certificate of Small Business Management, Business South Australia; 1989 Graduate Diploma in Grief Counselling, University of Ballarat; 1987 Chef certificate "Australian Cuisine", Australian Cuisine, Regerency Park TAFE. Kate Swaffer is shown with a portrait and identified as an "Activist and author". To her right is a book cover titled "WHAT THE HELL HAPPENED TO MY BRAIN?" by Kate Swaffer. The infographic also includes the logo for "ageScotland" with the tagline "Love later life".

John Sandblom, Co-founder, Alzheimer Australia

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