

Changing Words, Touching Lives

Hurt can come in different forms; it doesn't have to be physical. Sometimes words can hurt, too. And when they do, it's more than just skin deep.

The appropriate language should be respectful, non-stigmatising, accurate, empowering, and inclusive. Adopting such words early is important, not just for the sake of persons living with dementia, but also to change the mindset of the community towards it.



Talking about Dementia

Dementia is an umbrella term used to describe symptoms of impairment in memory, communication and thinking. Many of the words to avoid are outdated and were used when it was thought that symptoms presented were simply a normal part of ageing, rather than caused by specific types of disorders of the brain.

PREFERRED WORDS

- Dementia
- Alzheimer's Disease and other forms of dementia
- A type of dementia

WORDS TO AVOID

- Dementing illness
- Demented
- Affliction

Talking about People with Dementia

Many of the words to avoid are demeaning and derogatory. Words such as 'demented', 'sufferer' and 'victim' are demeaning and derogatory, and contribute to the stigma associated with dementia and places the condition before the person. We should always remember to use words that maintain the dignity of the person, and that do not place judgements on the individual just because they have dementia.

PREFERRED WORDS

- Person/People with dementia
- Person/People living with dementia
- Person/People with a diagnosis of dementia

WORDS TO AVOID

- Sufferer
- Victim
- Demented person

Talking about People with Dementia Under 65

The term 'Young onset dementia' is preferred to prevent confusion when talking about people with dementia under 65, as 'Early onset' is sometimes also applied to the earlier stages of dementia when the first symptoms are observed and experienced.

PREFERRED WORDS

- Young onset dementia

WORDS TO AVOID

- Pre-senile dementia
- Early onset dementia



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Talking about Behavioural and Psychological Symptoms of Dementia

It is important to understand that behavioural changes are caused by changes to the brain and can also be affected by medication and the individual's social and physical environment. By avoiding the words that hurt, we ensure that we are not defining the person living with dementia by their symptoms. We should always remember that people with dementia are individuals like us and their medical diagnosis and symptoms should not be the defining aspect of their lives.

PREFERRED WORDS

- Changed behaviour(s)
- Expressions of unmet need(s)
- Responsive behaviours

WORDS TO AVOID

- Challenging behaviour
- Difficult behaviours
- Wanderer

Talking about Impact of Dementia

The impact of dementia on each person living with the condition varies from one person to another. They will also relate differently at different times of their diagnosis. While we need to be truthful and realistic about the impact of dementia, the words we use do not need to be negative, pessimistic or disempowering.

PREFERRED WORDS

- Disabling
- Challenging
- Life Changing

WORDS TO AVOID

- Hopeless
- Unbearable
- Impossible

Talking about Caring for People with Dementia

Only a person with dementia can truly understand what it is like to live with dementia. Similarly, only a caregiver knows what it is like to care for a loved one with dementia. Using words like 'burden' assumes that the caregiving role is entirely negative, or that caring for a person with dementia is difficult.

PREFERRED WORDS

- Impact of supporting (someone) with dementia
- Effect of supporting (someone) with dementia

WORDS TO AVOID

- Caregiver burden
- Burden of caring

Talking about Dementia in a Medical Context and Research

It is important to remember that even in research and in a medical context, the focus is on the person and the preferred words that maintain their dignity and individuality should be used.

PREFERRED WORDS

- Dementia as a condition
- Participant (if in a research trial)
- Medical condition

WORDS TO AVOID

- Illness
- Disease (unless speaking about a type of dementia such as Alzheimer's Disease)
- Subject



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