

Dementia may be a common condition around the world, however there is still a lot of misunderstanding around it, and the way we talk and write about dementia can make a huge difference, affecting not only the people living with dementia, but their families, friends, and carers, as well as the public understanding of dementia. Casual misuse of words or using words with negative connotations has the potential to influence how others think about dementia.

Appropriate language must be:

- Truthful
- Respectful
- Inclusive
- Encouraging
- Non judgemental

## **The Basics**

There may be physical as well as psychological symptoms affecting a person's communication, organising ability, problem solving, behaviour, mood, and sensory awareness.

## **Don't Know What to Say! Ask!**

Each family or individual may express their experience with dementia in varying ways, as what is significant to one may be completely different to another. Age, background, culture, language, and life journeys can all impact dementia, and the way it is discussed.

## **Positive or Negative Language?**

Focussing on the negatives of dementia can be a disheartening experience, and thinking and being negative ignores the rest of the person's life and experiences. It can also be tempting to speak only positively to and about the person, and while that may sound a positive strategy, be careful not to deny the person their feelings. Discuss dementia with sensitivity and thoughtfulness (as you would with anyone) and try to be mindful of listening rather than constantly talking and instructing.

*When you're talking about dementia, these terms may be useful:*

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

*Some terms that are now seen to be negative include:*

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

*When you're talking about a person living with dementia, these terms may be useful:*

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

*Talking about and to families, friends and carers:*

Caring for a person living with dementia can be a difficult role, which needs to be respected.

- living alongside someone who is living with dementia.
- living with/caring for a person who is living with dementia.
- living with the impact of dementia.

*A person caring for a person living with dementia may choose to be called a carer, care partner or caregiver (some people like to be referred to as a carer, and some don't. Listen to how the person describe themselves, and if you're not sure, ask politely.)*

## **Talking About the Impacts of Dementia**

Depending on the cause of dementia and its current progress, people will be impacted differently. When you're talking about the impacts of dementia, these terms may be useful.:

- Life-changing
- Stressful.

Avoid negative terms like hopeless, unbearable, devastating, or painful.

*As a general guide when discussing symptoms these terms may be useful:*

- describe the symptom itself: confusion, forgetfulness, change in behaviour, inability to express appropriate words.
- describe its effect: trouble with communicating, disturbed sleep, poor appetite, restlessness in the afternoons.
- when talking about behavioural symptoms try terms such as: changed behaviour, unfeeling responses, inflexible to routines, unaware of the environment and describing the actual behaviour.