



Gofal Cymdeithasol **Cymru**
Social Care **Wales**

Using positive language about dementia

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The language we use to talk about dementia influences how people with the condition are seen and how they feel about themselves.

Why it's important to use positive language about dementia

[View transcript](#)

LIZ:

[00:00:00] [Laughing]

[00:00:09] Hello, I'm Liz, I'm fifty-two or sixty-two, or one of those but I don't know because numbers have gone.

[00:00:16] And I don't remember them telling me that they were leaving.

[00:00:20] I don't know what time they went because time has gone too, so I have my talking watch.

[00:00:25] [Recorded voice] The time is three zero two].

[00:00:28] Dates have gone and days have gone, birthdays have gone.

[00:00:33] I don't remember when my children's birthdays are and that really hurts.

[00:00:42] But they know, they know that I love them, I'm still here, I'm still happy and things could have been a lot worse.

[00:00:50] I'm a mum, I'm a nana and a greyhound walker.

[00:00:58] I'm a good friend, I hope, and a good laugh.

[00:01:03] I love a joke and I love to dance around the house and I love to sing, even though I'm a terrible singer.

[00:01:12] I can climb any tree you like [laughter].

[00:01:16] I don't cook anymore, how many grams, how many minutes, I think I'll have a sandwich, bar of chocolate.

[00:01:23] I have dementia, dementia doesn't have me.

[00:01:26] I'm not a condition, I'm not an illness, I'm not a disease, I'm not a symptom.

[00:01:32] my name is Liz, nice to meet you.

The language used in dementia care is often negative, for example 'elderly mentally infirm', 'sufferers', 'wanderers', people who are 'damaged'.

The language we use to talk about dementia influences how people with the condition are seen and how they feel about themselves.

Every word matters - we must use positive words that focuses on people's strengths not their limitations:

Not

A dementia sufferer

She was a wife, a mum

But

A person with dementia / a person living with dementia

She is a wife, a mum

Focus on people's strengths

It's important to recognise that while people with dementia may need support with some areas of their lives, particularly as their dementia progresses, they will retain abilities.

It's better to consider the new behaviours people with dementia may experience as change rather than loss.

As home care workers, the key is to recognise strengths, and work in an enabling way.

It is about working with people, not doing to people.

There is much truth in the idea of practising a craft to maintain ability.

When friends, family and carers take over, often with a kind intent, people who have dementia will become more dependent on others and start to lose their previous abilities.

The Pool Activity Level Instrument (PAL) for occupational profiling is highly regarded and recommended as a way of working with people with dementia by focusing on strengths and abilities they've retained.

PAL shows how an individual takes part in activities and how to create an environment for that person that makes the most of their abilities.

[Purchase the Pool Activity Instrument](#)

There is more to a person than dementia

There's a danger that when someone develops dementia, this becomes the main thing people see in them, not the person.

As a result, some might think that the person with dementia is 'no longer there'.

This is harmful to the person, who may be treated as an object and not as someone with a life history and current thoughts, feelings and desires.

What not to say to a person with dementia

Avoid negative terms than dehumanise people:

'An empty shell'

'Someone who has lost their marbles'

People with dementia prefer words and descriptions that are accurate, balanced and respectful.

The Dementia Engagement and Empowerment Project (DEEP) suggest avoiding terms like:

- Dementia sufferer
- Demented
- Senile or senile dementia
- Burden e.g. people are a burden or cause a burden
- Victim
- Describing dementia as 'a living death', an 'epidemic', a 'plague' or an 'enemy of humanity'

As well as 'people with dementia' / 'people living with dementia' / 'people living well with dementia', the term 'people affected by dementia' acknowledges that the condition impacts not only on the person, but those around them.

Many home care organisations will have their own term to describe the people they support, for example clients / service users / citizens/ customers.

Some people with dementia may not like these terms either, as they imply there's nothing more to them than that and that they're defined by their condition.

Remember that negative language reinforces the stigma of dementia and has a negative impact on how people with dementia view themselves.

Tom Kitwood (1997) suggests we should focus on seeing 'a **person** with dementia', not 'a person with **dementia**'.

Useful resources

[DEEP's guidelines for language about dementia](#)

[Dementia-friendly language in Australia](#) (this includes a detailed list of preferred and non-preferred terms and the reasons behind them)

Research links

Improve your practice by accessing the latest research findings:

["I don't think of it as an illness": Illness Representations in Mild to Moderate Dementia](#)

[Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health \(2016\)](#)

[Developing better ways to talk to people with Alzheimer's disease about their illness \(Alzheimer's Society\)](#)

We want your feedback

Help us to improve the Dementia resource for care professionals by telling us what you think about it in our short [four question survey](#).