Positive language guide

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Alzheimer's Society
United Against Dementia

What is positive language and why is it important?

There are currently 850,000 people living with dementia in the UK, each with their own unique personalities and life stories. They have the right to be treated with respect, and not stigmatised or treated differently to others because of their dementia.

The way we talk about dementia has a direct effect on how people living with the condition feel. It can also have a profound effect on society. After all, the words we use affect the way we think, and the way we think affects how we behave. The language we all use has the power to impact the lives of millions of people around the country.

For those living with dementia, using words or phrases that label, belittle or depersonalise people can have a big impact on them and their family and friends. It changes the way they feel about themselves, shaping their mood, self-esteem, and feelings of happiness or depression. It can also change the way other people think about dementia, and increase the likelihood of a person with dementia experiencing stigma or discrimination.

On the other hand, using positive language – words and phrases that empower people, treat them with dignity, and respect them as individuals – can change how society views and treats people with dementia. It can make people feel valued and included, and contribute to changing the landscape of dementia.

This is our guide to using positive language. It has been informed by what we have been told by people with dementia, their carers and all those affected by the condition. By following these guidelines you can help improve people's ability to live well with dementia, and bring about lasting social change.

This guide includes how we should talk about:

- ✓ dementia
- ✓ people living with dementia
- ✓ the effects of dementia
- ✓ people caring for a person with dementia
- ✓ other illnesses and disabilities
- ✓ black, Asian and ethnic minority (BAME) groups
- ✓ sex, gender and sexual orientation.

Contents

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The main rules and principles

There are some important basic principles to follow when writing about dementia.

✓ Always use language that recognises dementia is not the defining aspect of a person's life. **See the person, not the dementia.**

✓ **Always think about how a person with dementia would feel** about your choice of words. Respect people's wishes about how they want to be talked about, whether they are present or not and whether you think they can understand or not. If you are unsure of what words to use, or how to talk about someone, ask them what they prefer.

✓ When you are telling someone's story, **use their own words as much as possible**, as long as it is appropriate. Dementia affects everyone differently, and everyone will express their experiences of dementia in their own way. If you can, ask the person directly.

✓ Use language that **focuses on what people can do, rather than what they can't**, or that shows someone that you are with them but not doing something for them. This can help people stay positive and retain feelings of self-worth. For example, use phrases like 'supporting a person to eat', rather than 'feeding'.

✗ **Avoid labelling people**, or using terms that place the emphasis on the condition or behaviour, rather than the person. For example, don't label someone by their condition or behaviour – a person may have dementia, but they are not a 'dementia sufferer'; they may be experiencing changes in behaviour, but they are not 'a shouter'.

✗ **Don't reinforce stereotypes or myths about dementia.** It is important to know the facts and avoid assumptions. For example, it is not a normal part of ageing, nor is memory loss the only symptom or always present in the early stages.

✗ **Do not use abbreviations to describe people**. For example, do not use 'PWD' (person/people with dementia) or 'YPWD' (younger person/people with dementia).

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How to talk about dementia

Dementia is not a disease. It is a condition that is caused by diseases:

- Dementia is the name for a group of symptoms that may include memory loss and difficulties with thinking, problem-solving or language, as well as changes in perception, mood or behaviour.
- Dementia is caused by diseases that affect the brain. The most common of these is Alzheimer's disease. However, there are many causes of dementia and they affect people differently.
- Dementia is not just about memory loss, and many people with dementia will not have memory loss. While some people may prefer to speak of their 'memory problems' rather than their dementia, we should not use the two synonymously as this can exclude people with other types of dementia, or who have different symptoms.

Young-onset dementia

If someone develops dementia before the age of 65, they have young-onset dementia. This is sometimes referred to as working age dementia or early-onset dementia. (Note that this doesn't mean the early stages of dementia). Never use senile or pre-senile dementia.

✓

Use the following ways of describing dementia:

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

✗

Don't use the following:

- dementing
- demented
- affliction
- senile dementia
- senility.

Senile dementia is an outdated term that was used when it was thought that symptoms associated with dementia, such as memory loss or difficulties with thinking, were just a normal part of ageing, rather than being caused by diseases that affect the brain.

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How to talk about people with dementia

People with dementia are individuals with a history, personality, relationships and desires. Their diagnosis is not the defining aspect of their life, nor does it mean that their life is over. We should use language that reflects this.

Use the following when talking about a person with dementia:

- A person (or people) with dementia
- A person (or people) living with dementia
- A person (or people) with a diagnosis of dementia (if appropriate – remember not all people with dementia get a diagnosis).

Using these terms helps to maintain the person's dignity. They put the person first and don't make assumptions or pass judgment on people because of their dementia.

However, try to avoid using 'person with dementia' or 'person living with dementia' too often, as it can become almost another label. Vary the language used – for example, 'someone who has dementia', or, 'Mrs Jones, who has Alzheimer's disease'.

Some carers may describe themselves as 'living with dementia', because they feel like they live with the condition by living with a person with it. However, for clarity reserve this term for people who have dementia. For more about how to talk about people who care for a person with dementia, see page 15.

Never use the following:

- sufferer, suffer from, afflicted, victim or any other words that disempower people with dementia by making them seem passive, childlike, or worthy of pity
- senile, pre-senile or demented
- slang expressions that are derogatory – for example, 'not all there', 'delightfully dotty', 'away with the fairies', 'doolally', 'a few cups short of a tea set', 'a few pennies short of a pound'
- patient – don't describe someone as a 'dementia patient'. The term 'patient' should only be used specifically if a person is in hospital, or in relation to seeing their GP or other healthcare professional.

Younger people with dementia

There are currently more than 42,000 people in the UK under 65 who have dementia. You should describe someone with dementia who is under 65 as a younger person with dementia, or a person with young-onset dementia.

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How to talk about the effects of dementia

Symptoms

Dementia affects every person differently. This depends partly on the type of dementia the person has, but also on their personality and experiences, and how other people respond to them. The nature and severity of symptoms are likely to change over time.

When talking about symptoms, describe the change itself – for example, ‘memory loss’, or ‘problems finding the right word’. Never label someone as a result of their symptoms. For example, if someone is experiencing changes in behaviour that cause them to walk about or shout out, they are not a ‘wanderer’ or a ‘shouter’. Labels such as these dehumanise the person and place the focus on the behaviour rather than what the person may be trying to achieve or express. This can also make it more difficult to identify what is behind a person’s behaviour, which makes it harder to address it.

Do not use the term ‘wandering’ if a person walks about. This implies movement without purpose. The person may have a clear purpose or motivation – they may be looking for somebody or something, or walking as a way of calming down – but they may not be able to express it easily. Use ‘walking’ or ‘walking about’ instead.

Challenging behaviours

Changes in a person’s behaviour or emotional state are common in dementia. However this will often be a sign of a person’s physical or emotional need or a feeling that they are not able to communicate. This could be for a number of reasons, for example anxiety, frustration, pain, boredom, loneliness or confusion.

The terms ‘challenging behaviours’ and ‘behaviours that challenge’ are used to refer to a specific subset of changes in behaviour. These include aggression, agitation, shouting or walking about. This is because they are a challenge for the person experiencing them, as well as someone caring for them.

They are often the result of needs or desires that are not being met or cannot be communicated. There is a reason the person is behaving that way – they are not simply ‘being difficult’. For example, if a person is shouting or is agitated, it may be because they are in pain but cannot communicate it. A third ‘challenge’ is to work out what is causing the person to behave this way.

As with all phrases, be careful not to repeat ‘challenging behaviours’ or ‘behaviours that challenge’ too often. Try using variants such as ‘behaviours that the person might find difficult’, or ‘distressed behaviours’. Be careful not to use ‘difficult behaviours’ as this can imply that the person experiencing the behaviour is being difficult.

Think carefully before using ‘behavioural and psychological symptoms of dementia’. It is very medicalised and is used to refer to a broad range of things, from apathy, depression and anxiety to psychoses (hallucinations, delusions) and behaviours that challenge (such as agitation or aggression). Not all of these, however, are inevitable symptoms of dementia. There may be a variety of other reasons for them.

Use the following terms to describe changes in a person’s behaviour or emotional state:

- changes in behaviour
- challenging behaviour
- behaviours that challenge
- distressed behaviours
- symptoms of distress
- behaviour that is out of character
- expressions of needs or desires that are not being met
- behavioural and psychological symptoms of dementia (in a clinical context).

Don’t use the following:

- difficult behaviours
- ‘being difficult’.

The impact of dementia

Because every person's experience of dementia is different, its impact on people's lives will be varied and not always negative. Use language that reflects this. While it is important to be truthful and realistic about the impact of dementia, we don't need to use words that are negative, disempowering, pessimistic or frightening.

✓

Use the following when describing the impact of dementia:

- challenging
- life-changing
- stressful.

✗

Don't use the following:

- hopeless
- unbearable
- impossible
- tragic.

It is OK to use these words if this is how someone has described their own personal experience of dementia, though you should always make it clear when you're quoting someone directly. However, we shouldn't assume these things or put words in someone else's mouth.

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How to talk about people caring for a person with dementia

Note that we use ‘carer’ to refer to someone who is providing unpaid care to a person with dementia. It is different to a professional or paid carer, where we should use ‘care worker’ or ‘care professional’.

Not everyone will like to be referred to, or even see themselves as a carer, although this language is widely used in the health and social care system (for example, a carer’s assessment, Carer’s allowance). If possible, ask the person how they feel about this term. It may change over time.

You should also think before assuming that someone is a carer just because they are the partner of a person with dementia. Many people, particularly in the early stages of dementia, don’t need any care yet. They may find it patronising and presumptuous if their partner is automatically referred to as their carer.

‘Living with’ and ‘affected by’ dementia

Most people with dementia say that they prefer the term ‘living with dementia’ to be used for a person who has dementia. Although family, carers and friends are all affected, it is usually not helpful to say that they are also ‘living with dementia’.

The term ‘affected by dementia’ is a much more broad term. This doesn’t just apply to people living with the condition, but to their carers, friends, family, or anyone else who is close to them or provides support. Only use this when talking about this broad group. For example, ‘Alzheimer’s Society is here to support anyone affected by dementia’ – because this includes carers, friends and family as well as people living with dementia.

While you may hear people use these terms in other ways, for clarity and consistency this is how we should be using them.

Use the following when talking about those caring for a person with dementia:

- supporting a person with dementia
- caring for a person with dementia.

Don’t use the following:

- **Burden –** this can be used in different ways, and context is key:
    - Everyone has a different experience as a carer, and using terms such as ‘burden’ in relation to a person’s caring role assumes that role is entirely negative or always difficult. Of course, a carer may talk about the difficulties they experience as a result of providing care, and they may use this word themselves, but we should not make assumptions. Avoid ‘burden’ unless a carer uses the word themselves - use ‘impact’ or ‘effect’ instead.
    - We should never refer to a person themselves as being a burden. This dehumanises someone, and makes them out to be nothing more than a drain on time and resources rather than a human being.
    - In the broader context of health and social care policy, we may talk about ‘the burden of unpaid care’ – this refers to the cost (in terms of time, money and effort) that unpaid carers are having to shoulder on behalf of society. In this broad context, when we aren’t referring to specific people but to issues of policy, the term ‘burden’ is acceptable.
- **Sitting service or sitter –** this implies that the person with dementia is a passive recipient of care, and also has connotations of babysitting.
- **Feeding, dressing or toileting –** again, these terms imply that the person is passive and does not participate in the activities described. When talking about specific tasks, use phrases like ‘supporting (or helping) the person to eat’.

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How to talk about other conditions or disabilities

'Disability' is the recognised term for people with conditions or impairments that have an adverse effect on their ability carry out daily activities. However, many people who would be considered 'disabled' do not identify with that label due to its negative connotations.

Whilst 'disability' is a recognised term, some people may prefer:

- differently-abled
- accessibility needs
- living with impairments.

When talking about impairments or disabilities it's important not to define the person by these impairments, or make assumptions about their abilities.

- Use the terms 'wheelchair user' or 'person who uses a wheelchair', not 'wheelchair bound' or 'in a wheelchair'.
- Use the term terms listed above, not 'invalid', 'handicapped person' or 'disabled person'.
- Use the term 'person with a learning disability' not 'mentally handicapped', 'backward', 'slow' or 'retarded'.
- Do not use the words 'sufferer', 'victim' or 'afflicted by' when referring to people with disabilities.
- Do not use a condition as an adjective. Use the phrase 'person with diabetes' rather than 'diabetic' or 'person with depression' rather than 'depressive'.

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How to talk about race, ethnicity and culture

We wouldn't make assumptions about people because they have dementia. Nor should we make assumptions about people because of their community, ethnicity or race. Not everyone will have the same experience because they are from the same background.

- 'BAME' stands for 'black, Asian and minority ethnic' and refers to anyone of a minority ethnic group. Use the phrase 'black, Asian and minority ethnic' (BAME) followed by either 'people', 'communities' or 'groups'.
    - Bear in mind that, because this is a group made up of separate ethnicities, many people will not identify themselves as 'being BAME', so it may not be appropriate for external materials.
    - Also bear in mind that everyone's sense of identity is different, and a person's ethnicity might not be as important to them as other things, such as their nationality. So for instance, referring to someone as 'Asian' rather than 'British' could feel alienating to some people.
- 'African-Caribbean' refers to Caribbean people and those of Caribbean ancestry who are of African descent. Don't use 'Afro-Caribbean'.
- 'South Asian' refers to people from India, Pakistan, Sri Lanka and Bangladesh.
- The word 'black' (lower case) refers to people of African and African-Caribbean ancestry.
- 'Black' (upper case) can have a meaning as a political identity, beyond skin colour. Non-white people who are not of African or African-Caribbean ancestry may identify as politically Black, particularly in the context of anti-racism movements.
- 'People (persons) of colour' (often shortened to 'PoC') is an Americanism, and refers to anyone who is not white. It is usually used in the context of power dynamics, privilege and common experiences of racism, so please do not use it outside of this context. If you are unsure, avoid using it.
    - This term is distinct from coloured, which is a term of abuse.
    - Also note it is different to BAME, which includes white ethnic groups, such as the Gypsy, Roma and Traveller communities.
    - You may see variants of this, such as 'women of colour', 'writers of colour', etc.
- 'Gypsy', 'Roma' and 'Traveller' all refer to distinct groups. The collective term 'Gypsy, Roma and Traveller' is acceptable to most members of this group. English Gypsies prefer the term 'Gypsy', though Irish travellers find it offensive.
- Avoid the phrase 'ethnic minority people'.
- Do not refer to a person as 'ethnic'.

For more information, the Institute of Race Relations has a helpful glossary available at: www.irr.org.uk/research/statistics/definitions/

Cultural awareness and dementia

The word 'dementia' may mean other things to people from different cultural backgrounds or who speak other languages. It can be seen as offensive or disrespectful. Although the understanding of dementia is generally growing, and the stigma around it generally reducing, be aware and sensitive to the fact that this change is happening differently in each community.

In some languages there is no equivalent word for dementia, and the closest word sometimes has implications of 'madness'. In some cultures dementia is associated with mental illness, or seen as a natural part of aging. Words and phrases that are appropriate in one community may be offensive, ambiguous or meaningless in another. It is important to be aware of the cultural background of the person, family or community so that you can use the most appropriate language. Ask for guidance from the relevant community where possible.

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How to talk about sex, gender and sexual orientation

Everyone has a sex, a gender identity and a sexual orientation, but these terms are sometimes confused, or used wrongly or inappropriately.

Sex

This refers to the biological condition ascribed at birth. A person might be:

- **Male**
- **Female**
- **Intersex –** a term used to describe a person who may have the biological attributes of both sexes or whose biological attributes do not fit with societal assumptions about what constitutes male or female. Intersex people may identify as male, female or non-binary **(see page 23)**.

Gender

This refers to a person's sexual identity in relation to culture and society. For trans people, their gender identity is different from the sex ascribed at birth and how others may perceive them. A person may be:

- **Cisgender –** a person whose gender identity is the same as that assigned to them at birth.
- **Trans –** this is the preferred and more inclusive term, rather than 'transgender' (felt sometimes to be a more restrictive description). It refers to someone whose gender identity is different to that assigned to them at birth, or who sees themselves as between, beyond or outside of the standard categories of male and female. A trans man or trans woman may or may not have undergone gender reassignment. A trans woman is a woman who was identified previously as male and a trans man previously female.
- **Non-binary –** an umbrella term for a person who does not identify as only male or only female, or who may identify as both.
- **Questioning –** the process of exploring your own gender identity and/or sexual orientation.

Sexual orientation

This describes who a person has an emotional, romantic or sexual orientation towards. A person could describe their sexual orientation in a number of different ways, including:

- **heterosexual –** this refers to a man who has an emotional, romantic or sexual orientation towards women, or a woman who has an emotional, romantic or sexual orientation towards men
- **lesbian –** a woman who has an emotional, romantic or sexual orientation towards women
- **gay –** a man who has an emotional, romantic or sexual orientation towards men
- **bisexual –** a person who has an emotional, romantic or sexual orientation towards men and women.

Do not make assumptions about someone's sexual orientation based on their gender identity. A trans person may be heterosexual, lesbian, gay or bisexual.

LGBT+

This is a term that refers collectively to lesbian, gay, bisexual, and trans people, as well as people of other gender and sexual identities (such as intersex, non-binary or asexual) that are outside of the traditional cisgender/heterosexual categories. LGBT+ is our preferred collective term, but you may hear others such as LGB, LGBT and LGBTQI.

This can be a useful term, but be careful not to lump all these different groups together unless you need to. Some people may not identify as being LGBT+, and some may not like the term or feel like they don't have much in common with other members of the grouping.

Also be careful to think about the context and who you are writing for. If you are writing information for the LGBT+ community but haven't included information for trans, intersex or non-binary people, then 'LGB' might be a more accurate term.

Queer

This has been used as a derogatory term in the past. It has now been reclaimed by many LGBT+ people to include others who don't identify with traditional categories around gender identity and sexual orientation. However, be careful when using this term for an older audience as it is still considered derogatory by some, particularly older LGBT+ people.

- Use these words as adjectives, not nouns, to describe a person. For example, a person is bisexual, they are not 'a bisexual'; or talk about gay people, rather than 'gays'.
- Use the pronoun (for example, 'he', 'she') that the person you are referring to prefers.
- Use 'they' when the sex of a person is unknown or when this is their preference.
- Use neutral terms such as 'actor', 'author', 'waiter', to refer to both men and women, and use 'chair' not 'chairperson' for both men and women.
- Avoid gendered terms – think of alternatives, for example 'capacity' rather than 'manpower' or 'humankind' instead of 'mankind'.

For more information, Stonewall has a helpful glossary of terms available at:
www.stonewall.org.uk/help-advice/glossary-terms

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Glossary of preferred terms

The following is a list of DOs and DON'Ts – however this list is for guidance only. It is not exhaustive and does not cover everything. Also, some of these words are OK if you are reporting how someone affected by dementia describes their own experience of the condition.

ℹ Topic	✓ Preferred terms	✗ Do not use
Dementia	dementia (a condition) Alzheimer's disease and other types of dementia a form of dementia a type of dementia symptoms of dementia young-onset dementia	dementia (a disease) dementing illness demented affliction senile dementia senility
People living with dementia	a person (or people) with dementia a person (or people) living with dementia a person (or people) with a diagnosis of dementia	sufferer suffer from afflicted victim demented patient (when used outside the medical context) not all there lost their mind derogatory slang expressions – for example, delightfully dotty, doolally, away with the fairies
People with dementia under 65	young-onset dementia (preferred) working age dementia early-onset dementia	pre-senile dementia

ⓘ **Topic**	✓ **Preferred terms**	✗ **Do not use**
The symptoms of dementia	Describe the symptom itself – for example: memory loss difficulty communicating changes in behaviour expressions of unmet need challenging behaviour behaviours that challenge behavioural and psychological symptoms (in a clinical context)	wanderer shouter wandering difficult behaviours being difficult
The impact of dementia	challenging disabling life changing stressful	hopeless unbearable impossible tragic
People caring for a person with dementia	caring for a person with dementia supporting a person with dementia	living with dementia
The act of providing care to a person with dementia	caring supporting/helping the person to eat/dress/go to the toilet	sitting service sitter feeding dressing toileting burden (for an individual)

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Other useful resources and acknowledgements

Writing for Alzheimer's Society: A guide to our tone of voice (Alzheimer's Society, 2017).

Our house style 2017 (Alzheimer's Society, 2017).

Dementia words matter: Guidelines on language about dementia (The Dementia Engagement and Empowerment Project [DEEP], 2014). Available at:
http://dementiavoices.org.uk/2014/10/dementia-words-matter/

Stonewall glossary of terms (Stonewall). Available at:
www.stonewall.org.uk/help-advice/glossary-terms

Equality, diversity and inclusion (ED&I) is an integral part of our work. See more of our ED&I resources **here.**

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