



# Guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia

**for the media, researchers, journalists, policy makers and anyone responsible for the portrayal of or communication about dementia**

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# Introduction

Communication involves sharing or exchanging information including, for example, news, ideas and feelings. Portrayal means how somebody or something is shown or described in a picture, play, book, speech, report or other means of communication. The two are closely related and undeniably of great importance to people with dementia. How we represent dementia in words and images can influence how we think about and treat people with dementia. It has implications for the lives of millions of people worldwide, for their rights (i.e. to full and equal participation in society, and access to healthcare and treatment) and for relationships and emotional wellbeing. It can also significantly influence decisions about research priorities, service development and policy.

The European Working Group of People with Dementia (EWGPWD) has been working on this issue throughout 2022 and has developed guidelines for the media, researchers, journalists, policy makers, and indeed anyone who communicates about or portrays dementia and people with dementia in the public domain. The following guidelines are aimed at provoking greater reflection and increasing awareness about these issues. It is not our intention to act as the “word police” and our guidance goes beyond the choice of individual words. As we explain in the guidelines, preferences and objections to certain words, whilst important, vary greatly. Rather, we would like to offer constructive and friendly guidance to help raise awareness of the need to communicate in an ethical and inclusive manner. This means paying attention to messages and images that we communicate and use, and trying to ensure that they convey respect for people with dementia, that they are not harmful (e.g. stigmatising, insulting or degrading) and that they both reflect and promote the inclusion of people with dementia from all walks of life, including those from marginalised groups, in society.

This guidance concerns information and images in the public domain or targeted at specific groups but not one-to-one interactions. It is the end product of work carried out by people with dementia for people who do not have dementia. People with dementia use language, sometimes including metaphors, to convey their personal experience of dementia at a particular moment in time, whereas words and images communicated by others tend to be understood as representing or summing up the experience of all people with dementia, often reducing people with dementia as a group to sufferers or patients or portraying every aspect of dementia as a devastating natural catastrophe.

We therefore seek your support in helping us to ensure a balanced and positive communication and portrayal of dementia and people with dementia, and in contributing towards a more inclusive and respectful society for us and for our partners, friends, relatives and fellow citizens who may develop dementia at some point.

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# Guidelines

1. Use terms and words which are not offensive or stigmatising and are respectful and inclusive when referring to people with dementia and/or people providing support or care to people with dementia.

When writing or presenting information about people with dementia and people providing care or support to them, avoid using terms that some people with dementia may feel uncomfortable with. For example, in many countries the term “demented” has very negative connotations and many people with dementia from different countries have publicly stated that this is a word they find offensive. Use terms which have more positive connotations, that capture a sense of agency and reflect that people with dementia are valued members of society. This includes, for example, using the term “participant” instead of “subject” when referring to people who have participated in a research study and to be mindful of whether, and if so when, to use the term “patient”. In the same way, bear in mind that not everyone providing informal support or care to a person with dementia is a relative and that at some stages, the word “supporter” may reflect better the type of relationship that someone has with the person with dementia than the term “carer”.

There are several national guidelines which include terms to avoid and preferred terms. However, these should not be seen as check lists or recipes for respectful communication as there are many regional differences, as well as differences between language use in different cultural groups, and also as language is constantly evolving.

Terms may not have the same connotations in every country and community. The term “dementia”, for example, is considered very negative in some countries or solely used to refer to people at a very advanced stage (e.g. in Finland where the term “memory disorder” is preferred), whilst in others, it is the preferred or standard term. The context where terms are used may also influence their perceived appropriateness. The term “patient”, for example, may be considered acceptable in the context of healthcare provision, but not when used in a generic way to refer to people with dementia going about their daily lives.

2. Be mindful of the terms and concepts that you use when communicating and how these may be interpreted by the general public, use them in a precise and clear way and when necessary include some background information or explanation to ensure that people can understand what you are communicating.

The conceptualisation of Alzheimer’s disease (AD) has changed over the last few decades. Nowadays, the term “Alzheimer’s disease” is used to refer to a continuum which includes the preclinical, prodromal and dementia stages.<sup>1</sup> This term is used in this way extensively in the research or clinical care context but many lay people and people with dementia still think of the term Alzheimer’s disease as meaning a type of dementia. This means that many people do not understand that the term can also be used to refer to pre-dementia stages. Examples of other complex terms are “risk” and “prevention” of dementia. What professional and researchers mean may be quite different to what lay people, including people with dementia, understand.

There are frequently misleading or deliberately ambiguous reports and headlines in the media such as “Miracle drug halts process of Alzheimer’s disease” or “A handful of blueberries a day could keep dementia away”. Such headlines certainly attract attention but are unethical in that they are misleading and inaccurate, and falsely raise the hopes of people with dementia and their families and friends. Even if the reports go on to explain the limitations of a particular study, such claims are potentially damaging to many people’s wellbeing. They may also undermine trust in research and in the medical profession.

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<sup>1</sup> Please see Alzheimer Europe’s report on changing terminology surrounding AD.  
<https://www.alzheimer-europe.org/resources/publications/2016-discussion-paper-ethical-issues-linked-changing-definitions/use-terms>

### 3. Consider the audience you are presenting to and the purpose and make sure the contents, terms and format are appropriate to them.

With the exception of internal communications between colleagues and fellow researchers, audiences (e.g. for newspapers, research materials, television, magazines and films) can be fairly broad. This should be taken into account, with the aim of ensuring that people who are least informed about the topic, who are not familiar with jargon and abbreviations and who may have various impairments (e.g. linked to dementia) can understand and relate the information to their own lives and situation if relevant.

### 4. Reflect on ways to capture the dignity, personhood, individuality and citizenship of the people you are portraying.

When writing about or portraying individuals with dementia remember that dementia is not a person's whole identity. It is important to look beyond the dementia to the person. John, for example, is not just a man with dementia; he is a retired builder, father of three and Manchester United football fan. Mercedes is not just a woman with dementia but a university lecturer, a member of the local town council and an accomplished pianist.

- “My name is Kevin, not Lewy.” (Kevin)
- “I may have dementia but I am Real. I am first and foremost a person.” (Real)
- “Please don't reduce me to my diagnosis. That is an aspect of my identity that is of least relevance or importance to me.” (Shelagh)
- “I often experience our society as stigmatising and marginalising in everyday life. Despite all the challenges caused by my illness, there are many things that I can still do very well, especially in my usual areas of life. And sometimes I need help, so I ask for support.” (Lilo)

### 5. Strive for a balanced/nuanced portrayal of dementia.

Avoid generalising about the experience and impact of dementia as it affects different people in different ways. Focus on terms and positive images such as people with dementia enjoying life, interacting with others or involving themselves in community, social and political life (rather than solely focusing on wrinkled hands, people looking lost or staring into space). Try to show how some people may be able to continue to carry out their daily activities as they did before and have a sense of meaning in their lives despite the challenges of the condition. Of course, it is not helpful to portray dementia in an overly positive way either. Dementia is a change that affects all areas of life. People and their experiences of dementia are more complex than that. Don't hide aspects of dementia that people might find disturbing but put those aspects into perspective and context.

### 6. Avoid portraying dementia in a way that is deliberately alarmist, frightening or based on negative stereotypes, clichés and inappropriate metaphors.

Think about whether your portrayal of dementia reflects or perpetuates negative stereotypes or clichés that you have read or heard about. Conjuring up images of battles and fighting, which used to be common in the field of cancer, suggests courage and strength. It also suggests that there are not only winners but also losers. This also implies being unsuccessful or not having tried hard enough, potentially resulting in pity, and people with dementia feeling guilty and powerless. Referring to natural disasters such as plagues and tsunami may help capture the extent or scale of dementia within society but also focuses on the negative, implying that dementia is catastrophic and uncontrollable. References to time bombs, explosions and economic burden suggest that people with dementia are dangerous, a threat to society and using up valuable financial resources that could perhaps be better used elsewhere. This kind of terminology and related images are quite common in the press because they capture people's attention. It makes people sit up and take notice, but they come at a price as they are overly negative and lose sight of the individual.

## 7. Question your own assumptions about dementia.

Not everyone has encountered or experienced dementia. Those who have may have very different experiences of it. Perhaps when they were a child, they visited a grandparent with dementia in a nursing home or they currently have a partner or friend with dementia. Some young dementia researchers have never met someone with dementia. However, most of us have heard about dementia on television or in magazines and books. We therefore have images, ideas, beliefs and even fears and concerns that lead to assumptions that may be reflected in what we write and how we portray dementia. It is important to think about this and consider whether, and if so how, you might be unwittingly communicating such assumptions (e.g. people with dementia all being old, in the later stages, passive and their main challenges being just linked to memory).

- “I was sitting with my partner waiting for the meeting to begin and chatting away to the other people. He was a bit tired and wasn’t really joining in the conversation. The organisers eventually turned up and immediately assumed that I was the carer and that he had dementia (because he was sitting there quietly) .” (Marguerite)
- “I showed slides at a meeting last week of two groups of people at a conference. I asked which people had dementia. They responded, “The ones on that slide”. Everyone in that group was over 70. I told them none of the people in either group had dementia, except the younger man at the front (my cousin). They had all assumed that the older people had dementia.” (Nélida, Idalina’s daughter)

## 8. Avoid portraying people with dementia as “other”, fundamentally different or inhuman.

Avoid thinking in terms of “us” and “them”. People with and without dementia are all part of the same society that we live in. You and people you know may at some stage develop dementia. You may have a friend or relative who has or had dementia. Although a diagnosis of dementia can be life changing, people do not change overnight and become a different person or in some way less human. It may be important to specifically mention that people have dementia but try to avoid implying that this makes people fundamentally different than people who don’t have dementia, making negative stereotypes (e.g. people who have dementia are, by definition, X, Y or Z) as this can be dehumanising, threaten their status as valued individuals and fuel stigmatisation.

## 9. Avoid reducing people to numbers, objects, medical cases and problems.

Facts and figures about dementia are useful in showing politicians, researchers and service providers that there is a need for services and support for people with dementia and their carers/supporters, and for more research about dementia (e.g. about care and support, but also about prevention and treatment). It is important, however, to avoid reducing people to mere numbers and transforming them into objects (e.g. medical cases or “problems” that need to be addressed). Behind every fact or figure there is a real person with a unique experience and with individual needs, wishes, hopes, fears and relationships with other people.

## 10. Portray people with dementia from a wide range of sub-groups within society and from all walks of life.

Bear in mind the diversity of people with dementia. Dementia affects people from all ethnic groups. It is not limited to “very old” people or to people who are either straight or from LGBTQ+ communities. It is not affected by a person’s wealth, social position or to where they live. Some groups of people are at higher risk than others but literally anyone can develop dementia. Often, images of people with dementia in Europe show fairly old, White people, surrounded by children and grandchildren and looking fairly well off. This excludes so many people who have dementia and cannot relate to such images and may contribute towards their specific needs being overlooked when planning services or conducting research.

### 11. Seek feedback from people with dementia about issues you intend to portray or report.

When writing about or commenting on the experience of dementia (e.g. in a newspaper article or a script for a character with dementia in a television series) try to obtain some feedback from an Alzheimer association and, if possible, someone with dementia. If the article is about a specific person, it is essential that they see what you have written and give their approval before it is printed. This also applies to any photos or images you wish to use as they can put a whole different slant on the issue and convey a powerful message that contradicts the content of the article (e.g. an article about something extraordinary or important that a person with dementia has achieved being accompanied by a photo of a forlorn-looking individual, staring into space, symbolising pity, passivity and perhaps a life not worth living). The issue here is not just about accuracy but also about respect, dignity and trust.

### 12. Know your facts and figures, and put them into perspective.

It is your responsibility to do your homework and ensure that everything you write is correct. If unsure, check with an expert or leave it out. Facts and figures are often included as background information and as a context for the message being communicated. They are not, however, totally neutral because there are usually other facts or figures that could also have been presented but weren't, and for a good reason (e.g. because they do not capture attention in the same way or they show another side of the story that the authors are less interested in showing). Many people do not fully understand statistics and can easily draw false conclusions such as having a high risk of getting dementia even though their risk is actually very low. For this reason, when presenting statistics about specific risk factors (e.g. of smoking or obesity) provide information about both the relative risk and the absolute risk. When providing facts and figures, put them into context or perspective so that people can make sense of them and see how they relate to them and their lives.

Alzheimer's dementia is the most common form of dementia but there are hundreds of different types and not all of them have memory problems as the main symptom. It is therefore important to use the term dementia when referring to dementia in general, to use the term Alzheimer's dementia when referring to that specific type of dementia and to use other terms (such as vascular dementia or fronto-temporal dementia) when referring to other specific types of dementia.

### 13. Be prepared to challenge the way dementia is portrayed if you feel that it is inaccurate, disrespectful or misleading.

You may come across documents produced by colleagues or others in your field of work that portray dementia or people with dementia inaccurately, are disrespectful or are misleading. Have the courage to point this out.

### 14. Provide details of an Alzheimer Association or other organisation where people can obtain support.

Even if you portray or communicate about dementia and people with dementia accurately and in a respectful, balanced and unambiguous manner, some people may be disturbed by what they read. Your article might, for example, trigger concerns about their own health or that of a loved one, or it might awaken a painful memory of the death of someone they loved. Try therefore to include the contact details or a link to an organisation where people can seek support at the end of your article.

# Authors

This report was developed by the members of the EWGPWD in collaboration with Alzheimer Europe (Dianne Gove, Ana Diaz and Jean Georges), building on earlier work carried out by previous members of the EWGPWD and Alzheimer Europe's ethics working group on perceptions and the portrayal of dementia. Special thanks to all supporters and carers of members of the EWGPWD and to Soraya Moradi-Bachiller and Daphné Lamirel for their support for this work.

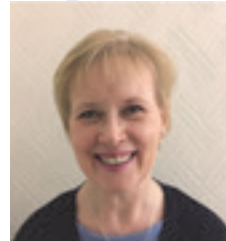
## European Working Group of People with Dementia in 2022



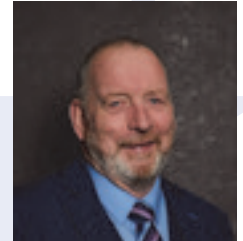
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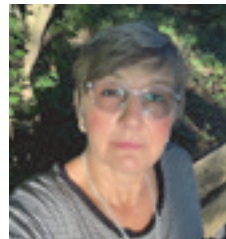
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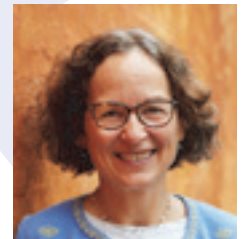
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