

# Guidelines for the Ethical and Inclusive Communication About/Portrayal of Dementia and People with Dementia

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## Dianne Gove

Dr Dianne Gove joined Alzheimer Europe in 1996 and is currently Director for Projects. After her Degree in Psychology, she obtained MAs in Education and Psychoanalysis and trained as an analytical Gestalt therapist, before being awarded a PhD from the University of Bradford in 2013 for her research into GPs' perceptions of dementia and how these relate to stigma. Her work is mainly focused on ethics and Public Involvement activities with people with dementia in various research projects.



## Ana Diaz

Dr Ana Diaz-Ponce has worked in the field of dementia for over 25 years and has an interest in social work, qualitative research and Public Involvement. In 2014, she completed her PhD in Trinity College Dublin on the topic of quality of life and anti-dementia drugs. Since then, she has worked at Alzheimer Europe as Project Officer. As part of her work, she supports the coordination of the European Working Group of People with Dementia and the Public Involvement work of the organisation.

## Keywords

Alzheimer's disease, dementia

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The *Guidelines for the ethical and inclusive communication about portrayal of dementia and people with dementia* were published by Alzheimer Europe and the European Working Group of People with Dementia (EWGPWD).<sup>1,2</sup> The document provides guidance on how to communicate about dementia and people living with dementia ethically and inclusively. The guidelines emphasize the importance of respecting the rights and dignity of individuals with dementia and of avoiding stigmatizing or negative portrayals of the condition. The document includes a set of recommendations for journalists, policymakers and other media professionals to help them ensure that their coverage of dementia and people with the condition is respectful, accurate and inclusive. The guidelines also provide advice for people with dementia and their families on how to participate in the media and advocate for themselves in a positive and empowering way. Overall, the guidelines aim to promote a more accurate and inclusive portrayal of dementia and people living with the condition in the media and in society.

In this expert interview, Dr Dianne Gove (Director for Projects, Alzheimer Europe, Luxembourg) and Dr Ana Diaz (Policy Officer, Alzheimer Europe, Luxembourg) discuss the current challenges in ethical and inclusive communication about and portrayal of dementia and people with dementia, the defining aims and goals of the guide, and the key take-home messages.

## Q. What are the current challenges in ethical and inclusive communication about and portrayal of dementia and people with dementia?

A key challenge with regard to ethical and inclusive communication about dementia and people with dementia is that stereotypes and stigma of the disease are still highly prevalent in society. Stereotypes of dementia emphasise deficits, focus on symptoms that are most common in very advanced dementia, overlook the experience of younger people with dementia and reduce people with dementia, who, like other members of society, have multiple intersecting identities, to sufferers, patients and vulnerable people with no quality of life. This, in turn, contributes to and reinforces the stigma of dementia, which is characterized by an "us" and "them" mentality, devaluation, fear, pity and discrimination.<sup>1</sup>

### Q. What are the defining aims and goals of the guide, and to whom is it targeted?

Lack of understanding about dementia, uncertainty about how to communicate respectfully to and about people with dementia, some degree of fear of people with dementia, and constant exposure to negative images, metaphors, and sensationalism in the media all hinder ethical and inclusive communication about and portrayal of dementia. This guide is targeted mainly at the media, researchers, journalists and policymakers but should also be of interest to anyone who communicates about or portrays dementia or people with dementia. We are keen to emphasize that communication concerning dementia is complex, influenced by agreed norms but also personal preferences and reactions to certain terms and forms of communication. There are cultural differences between different countries ethnic groups, but also within countries, ethnic groups and different communities. The members of the EWGPWD, who developed these guidelines, emphasized that they did not want to act as the 'word police' but rather to promote reflection, share their experiences and perspectives, and offer constructive and friendly guidance so as to ensure that whatever terms and images are used convey respect, are not harmful and are inclusive of people with dementia from all walks of life.<sup>2</sup>

### Q. How were the guidelines developed?

The EWGPWD was set up by Alzheimer Europe in 2012.<sup>2</sup> The group is composed of people with dementia from different European countries.

They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people living with dementia.<sup>2</sup> In 2022, members of the EWGPWD worked on the topic of ethical and inclusive communication about and portrayal of dementia and people with dementia. They discussed this topic at different meetings, online and face to face throughout the year. They also revised some existing guidelines on the portrayal of dementia that had been developed by Alzheimer Europe in 2013.<sup>3</sup>

### Q. What are the key take-home messages from this guide?

How people communicate about and portray dementia and people with dementia has implications for the lives and wellbeing of millions of people worldwide, their rights (i.e. to full and equal participation in society and access to healthcare, treatment and, support), and their relationships and emotional wellbeing. It can also have an impact on decisions about research priorities, service development, the funding of treatment and care and various policies. Paying attention to the communication and portrayal of dementia will hopefully contribute towards a more inclusive and respectful society not only for people with dementia but also for their partners, friends, relatives and fellow citizens who may develop dementia one day. □

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