



How to talk about dementia A media guide



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

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Introduction

Dementia is the UK's biggest killer. One in three people born in the UK today will develop dementia in their lifetime. Yet it isn't the priority it should be. There are around a million people in the UK with dementia. Many are undiagnosed and do not receive the support they need and deserve.

Alzheimer's Society is the UK's leading dementia charity and the only one to tackle all aspects of dementia by giving help and hope to people living with dementia today and in the future. We give vital support to people facing the most frightening times of their lives, while also funding groundbreaking research and campaigning to make dementia the priority it should be.

This guide is designed to help professionals working in media and communications to understand how best to work with people affected by dementia, and write, talk about and portray dementia in their work.

For more statistics on dementia please see our [Facts for the Media](https://www.alzheimers.org.uk) webpage on [alzheimers.org.uk](https://www.alzheimers.org.uk).

Why use this guide?

For the public, the media can be one of the most important sources of information and advice about health, treatments and support. Equally the public look to the media for authentic representations of people living with dementia. Small changes to language and tone can make a real difference and can deepen your audiences' understanding of dementia.

It is therefore important that when talking about dementia in the media that the language used is factual, not sensationalist and could not be considered discriminatory. This guide helps to support you to do this effectively.



The Alzheimer's Society Media Guide is a vital resource for anyone who is engaging with people like me who are living with dementia. Its practical, no-nonsense advice provides a wealth of useful guidance and information that will help your work to shine.



Pete, Alzheimer's Society volunteer
and living with dementia

What is dementia?

Dementia is a group of symptoms. It's caused by diseases that damage the brain. Its symptoms get worse over time and can include memory loss, confusion, needing help with daily tasks, problems with language and understanding, and changes in mood and behaviour. Some people also experience changes in perception, such as hallucinations, delusions and difficulty making sense of what they are seeing. The symptoms will vary for each person and will depend on what type of dementia they have and at what stage it is at. For some people, their early symptoms may not involve increasing forgetfulness.

All types of dementia are progressive, meaning that symptoms are relatively mild at first, but get worse with time.

As dementia progresses, a person will need increasingly more help and, in the later stages, will eventually need full-time care and support with daily living and personal care.

However, the speed at which dementia progresses varies a lot from person to person and there is typically no way to know in advance how quickly a person's dementia will progress.

Dementia is not a normal part of ageing. It's the result of different diseases that damage the brain. There are many types of dementia, but Alzheimer's disease is the most common, affecting around two out of three people with dementia. The next most common is vascular dementia.

Dementia also impacts younger people. Over 70,000 people living with dementia in the UK developed symptoms before the age of 65.

Dementia is also more common among women than men.



Alzheimer's Society has produced a free [symptoms checklist](#), endorsed by the Royal College of GPs, to support people to get a vital diagnosis.

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It's not just about a bad memory, it's a deconstruction of a person's entire life and personality. I expected to lose my husband, but I didn't expect to lose myself.”

Madeleine, a former carer

Top tips for portraying dementia

Things to remember



We understand the demands of working in the media and communications, and that reporting on and representing dementia can be challenging. We would ask that you read the advice shared throughout this document, but these are some of the top tips we would offer:

- Consider the language you are using to describe people living with a dementia diagnosis. Many feel that the term ‘dementia sufferer’ is unhelpful and stigmatising as it defines a person by their condition. Likewise, please do not describe someone as a ‘dementia patient’ unless they are in hospital or interacting with healthcare services – and even then, it would be better to refer to them as a ‘patient with dementia’ (full guide on appropriate language below).
- When reporting or representing people with dementia, where possible, try to portray the whole person, or at least enough of the person so they are not solely defined by having dementia. This includes focusing on their personality, likes and dislikes, identity, life history, relationships, lifestyle, and culture.
- Recognise that dementia can affect people of any gender, ethnicity, class or sexual orientation. It also does not just affect older people.
- Think about the wider impact of dementia on not only the person with the diagnosis but also their families and friends. It will likely be life changing for them as well, potentially giving up work or social activities to provide care. It will also have an impact on them emotionally and psychologically, and possibly on their general health. It can also have an impact on personal finances.
- Avoid using imagery that promotes stereotypes or perpetuates stigma (for example, using photos of the hands of an older person).
- Consider the needs of a person living with a dementia diagnosis and their families and carers when you work with them (see advice on working with people with dementia below). Do not make assumptions about how dementia affects them, every experience is unique.
- Ensure you have the consent of the person living with dementia or their representatives to share their story and image.
- Don’t over-simplify dementia causes or risk factors, as this could be misleading.
- Avoid making unsubstantiated links or speculating between incidents and an individual potentially having dementia unless it is confirmed by them or relevant to the story.
- Where possible give people with lived experience who have been interviewed the chance to review their story, in whatever format works best for them for example, a readback or emailed the copy.
- Include information on how to access support, for example
If you are worried about your memory please call Alzheimer’s Society’s Dementia Support Line on **0333 150 3456** or visit **[alzheimers.org.uk](https://www.alzheimers.org.uk)**

Working with Alzheimer's Society

Our experts are regularly quoted and interviewed for national and regional media, and we support people with lived experience of dementia to share their stories.

Alzheimer's Society media team send out press releases and comments on various topics from research to policy change. Please contact us to be added to our distribution lists.

Alzheimer's Society can help with:

- Background information about symptoms of dementia, progression, treatment, support and therapies.
- Provision of expert opinion through our spokespeople or ambassadors (you can find a list of our ambassadors on Alzheimer's Society's website.)
- Interviews and comments from our celebrity and high-profile supporters.
- Finding storytellers who can provide a unique and authentic insight into life with dementia.
- Key statistics, facts and figures on dementia.
- Advice for news stories and documentaries including fact-checking.
- Help to shape scripts and storylines for accurate and sensitive portrayals of dementia.
- Information on support and services Alzheimer's Society offer, such as our Dementia Support Line, which is staffed by expert Dementia Advisers, and our online Dementia Support Forum.





Working with people affected by dementia in the media

Media work can present very specific challenges for people living with a dementia diagnosis and their families.

When you have met one person with dementia you have done just that. Each individual will have different needs and may be open to different opportunities, so it is important to offer options and be flexible.

It is also important to be sensitive to the stage of dementia the person with dementia, or the person they are caring for, is at.

Being misquoted or having their words taken out of context is one of the concerns people with dementia have told us they have about working with the media, so it is useful to offer reassurances about how their words will be used.

People with dementia and their family and friends can also have other health conditions or issues that may have an impact on how you work with them, so ensuring you have a full picture of their needs is important.

Here are some key points to consider:



Process – Being flexible when it comes to timings and locations can be essential. Giving choice over the format of an interview can be helpful when circumstances allow, for example some people may prefer being interviewed over video (for example, over Zoom) to being interviewed over the phone. For people with dementia, pre-recording an interview is often a preferred option so it is important to ask what they might prefer.



Timing – We appreciate you may be working in a fast-paced sector, but the more time given to prepare, the better. Last minute requests can often be very challenging to accommodate, though not always impossible. There may be specific times of day when supporting media work is harder, such as afternoons and evenings. Some people may need to arrange support or a companion for a loved one. Please be patient with people with dementia and allow plenty of time in case they need a break or they need questions or conversations to be repeated.



Communication – Be clear and succinct in your communication, to ensure everyone understands what is being asked of them and how any information shared will be used. We know things can change but communicating them in a timely manner can help us to support people through any changes, and any disappointment that they naturally might feel if things do not go ahead as planned. Please also see our helpsheet [Communicating with a person with dementia](#).



Respect – Some people affected by dementia are often keen to share stories with the media as it helps them to feel heard and that it might help others in a similar situation. Many have struggled to get a diagnosis, support and wider acknowledgement of their experiences. They may go 'off topic' from what you ask specifically and may need to be brought back to the subject sensitively. It is important that people feel they are being listened to, even if sections are not used in the final edit.



Logistics and equipment – Be aware if you are bringing equipment into someone's home or bringing someone into a studio, that the bright lights, noise and number of people can have an overwhelming effect on them. Ask in advance about what you can do to make them feel more comfortable.

Interviewing people with dementia

Before an interview

- Consider what consent you have or need to do the interview, and the appropriate processes you may need to follow. For more information see [gov.uk/government/publications/mental-capacity-act-code-of-practice](https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice)
- Ask the person when and where they would like to be interviewed and find a suitable place. If somewhere is too busy or too noisy it may be distracting and negatively impact the interview. Consider options outside of the studio setting.
- Do some background research on the type of dementia the person has (alzheimers.org.uk has this), but go in with an open mind to understand their individual experience.
- Ask the person if they would like someone with them when they are interviewed. Give them a list of questions before the interview to help them prepare.
- Check in beforehand to ensure it is in their diary and they are feeling up to it. Loop in family members or carers to check they are happy and can support.

During the interview

- If the person is struggling with your questions, change how you ask them or break them down into simpler ideas.
- Ask one question at a time and give time for the person to process and formulate an answer.
- Non-verbal communication, including open body language and friendly facial expressions, are important. Being present and focused on their answers will help them.
- If you haven't understood what the person has said – rephrase what you have understood and check if you are right.
- Don't provide an 'on air' diagnosis or encourage 'experts' to do so.
- For longer filming, get to know the person's needs and try to schedule shorter filming sessions if necessary, allowing time and space for people affected to speak. Dementia can make it harder to maintain focus and may mean the person gets tired.
- For interviews being recorded for broadcasting, try to use an alternative to the typical sound level checking question of "What did you have for breakfast?" as for people with dementia this could cause anxiety if they are experiencing memory problems. "How are you feeling at the moment?" is a much better alternative.

Reporting on risks, research and treatments

Alzheimer's Society has funded dementia research for over 30 years and has played a key role in some of the biggest breakthroughs in the field.

The media team regularly work with the Research team to issue press releases and comments on breaking media stories based on our organisational priorities.

We advise that when you are reporting on dementia you don't over-simplify causes or risk factors; this can be misleading and does not reflect accurately the complexity and causes of the different types of dementia. Avoid suggesting risk factors where there is no proven link to dementia and avoid making assumptions about the causes of dementia.

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We are all in the same storm, but in different boats. Being a carer is often overlooked and they can feel unappreciated and not valued and they should be listened to as they are the expert when it comes to their loved one.”

Carla, a working carer



Guidance when portraying dementia in soaps, theatre and drama

Our experts and people with lived experience of dementia have been consulted on major creative and mainstream projects like *The Father* (starring Sir Anthony Hopkins), *Hollyoaks*, *The Restaurant That Makes Mistakes* and *Made in Chelsea*. This includes speaking with actors, script writers and producers at an early stage of developing the character and storyline, and we can help co-ordinate this for your work.

Accurate portrayals based on what it is like to live with dementia can positively inform viewers about dementia and how it affects people. Seeing a well-known character on screen helps to improve understanding of dementia, change opinions about it, inspire people to start a conversation about the storyline, talk about the issue on social media, and seek professional help or call our Dementia Support Line.

Here are our top tips for writing realistically for characters with dementia:

- **Authenticity is key:** make sure your character's situation and experience is authentic and plausible by researching the type of dementia, different symptoms, diagnosis pathway, treatment options, care planning and relevant services available.
- **Speak to people living with dementia:** to make the storyline as plausible and accurate as possible. These real-life experiences can help inspire storylines, scenes and fictional portrayals. Alzheimer's Society can facilitate these conversations.
- **Think about body language, gestures and facial expressions:** non-verbal communication is really important for people with dementia. If you're portraying someone in the later stages it will be one of the main ways the person communicates.
- **Clothing plays a part:** the stage of dementia someone is experiencing can affect their clothes and grooming. Having dementia does not necessarily mean someone will be unkempt or not well dressed. Confusion could be expressed through mismatched shoes. Those in middle-to-later stages of the condition may wear more comfortable or accessible clothing like jumpers and t-shirts or Velcro slippers that are easier for a carer to dress them in if they become unable to dress themselves.

- **Show the ups and downs:** like most people, characters with dementia will experience good and bad days, depending on what is going on around them. As with any storyline there is room for appropriate humour. You can address dementia with warmth and compassion.
- **Give the storylines time to develop:** the symptoms of most types of dementia often manifest over a period of time and the process for getting a diagnosis can take months or years. Some types of dementia can however progress rapidly. Think about how other characters might react or cope with this uncertainty.
- **Medication is not a miracle cure:** There is currently no cure for dementia. However, there are treatments for dementia, including medication, that can help with a person's symptoms. It does not work for everybody.
- **They're still the same person:** Just because your character has dementia, it does not necessarily mean their personality will change completely. It's better to represent them as the same person they've always been, who has dementia, with good and bad days.
- **Life goes on:** a character is more than their dementia. People have many facets to their life that do not just stop when they get a diagnosis.
- **It's not always obvious:** people often try to hide their dementia for a range of reasons including not knowing they have it, denial or embarrassment. Subtle indications such as loss of memory, repetition or small mistakes (for example having trouble carrying out common tasks like making a cup of tea) can provide the audience with clues.
- **Show the wider impact:** it is not just a person with a dementia diagnosis who is affected, but also their family and friends. Relationships change, for example someone going from being a husband to a carer.
- **Consider the cultural context:** Some cultures do not have a word for, or understanding of dementia. There may be a lot of stereotypes and stigma in some communities. It's important to think about this when developing the character. Research this properly and think about how the character can address some of these issues. Bear in mind there will be differences between people in the same community too – not everybody will think or act in the same way as each other. Some communities are disadvantaged more than others for example waiting longer for diagnosis and access to support.
- **Consider the time period:** Understanding and treatment of dementia has changed considerably over the decades. Ensure that depictions reflect the understanding of dementia at that time.

The importance of language

We know how important it is that dementia and its impact are represented accurately in the media and creative industries to prevent stigma and avoid sensationalising of the condition, which can cause distress.

It is important to think about how a person with dementia and those who love and care for them would feel about your choice of words if you're not quoting them directly. Understandably, no one wants to be defined by an illness when they are so much more.

Using positive language helps – words and phrases that empower people and respect them as individuals who are more than their diagnosis can change how society views and treats people with dementia.

Please review the following language guide, informed by people with dementia:

<p>Use the following ways to describe dementia:</p> <p>dementia Alzheimer's disease and other types of dementia a form of dementia a type of dementia a condition symptoms of dementia.</p>	<p>Don't use the following ways to describe dementia:</p> <p>dementing demented affliction senile, senile dementia or senility.</p>	<p>Always use language that recognises dementia is not the defining aspect of a person's life. See the person, not their condition.</p>
<p>Use the following when talking about a person with dementia:</p> <p>A person (or people) with dementia A person (or people) living with a dementia diagnosis A person (or people) with a diagnosis of dementia (if appropriate – remember not all people with dementia get a diagnosis) Use 'impact' or 'effect' but avoid 'burden' – unless a family member or carer uses the word themselves.</p>	<p>Don't use the following when talking about a person with dementia:</p> <p>sufferer suffer from afflicted burden victim or any other words that disempower people by making them seem passive, childlike, or worthy of pity. 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.</p>	<p>Using these recommended 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. Some family members or carers may describe themselves as 'living with dementia', because they feel like they live with the condition by living with a person with it. We should never refer to a person themselves as being a burden as this is dehumanising.</p>

The use of 'sufferer' to generically describe someone living with dementia is a common grievance of people living with the condition. For this reason, we advise against using the term 'sufferer' and to avoid defaulting to this term to describe anyone with dementia, unless you have their express permission to do so. Of course, a person with dementia may identify themselves in conversation as a sufferer or suffering from the disease, and that is their right as an individual.

<p>Use the following when describing the symptom itself:</p> <ul style="list-style-type: none">memory lossdifficulty communicatingchanges in behaviourexpressions of unmet needbehaviours that challenge behavioural and psychological symptoms (only in a clinical context, although even then this is used less frequently than it was)	<p>Don't use the following when describing the symptom itself:</p> <ul style="list-style-type: none">wanderershouterdifficult behaviourbeing difficult.	<p>Avoid labelling people, or using terms that place the emphasis on the condition or behaviour, rather than the person. 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. When talking about symptoms, describe the change itself – for example, 'memory loss', or 'problems finding the right word'. There is a reason the person is behaving that way – they are not simply 'being difficult'. For example, if a person is shouting or agitated, it may be because they are in pain but cannot communicate it.</p>
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Key Links

Facts for the media on dementia (Alzheimer's Society)
alzheimers.org.uk/about-us/news-and-media/facts-media

Symptoms checklist (Alzheimer's Society)
alzheimers.org.uk/checklist

Other language resources
alzheimers.org.uk/get-support/publications-factsheets-accessible-resources/information-in-your-language

Dementia Support Services
alzheimers.org.uk/get-support

Social Media
twitter.com/alzheimerssoc

facebook.com/alzheimerssocietyuk

instagram.com/alzheimerssoc/

youtube.com/user/AlzheimersSociety

www.linkedin.com/company/alzheimer's-society

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There's no one size fits all for how different communities deal with dementia. There are still some who really struggle with it and don't acknowledge it.”

Trevor, Alzheimer's Society volunteer and carer

“

The needs of the person and their carer are around dignity, self-esteem and being cared for.”

Ron, former carer

Quotes from our Ambassadors and supporters



“I know only too well the devastating effect dementia can have and just how challenging it is. Alzheimer’s Society continues to expertly raise the profile of dementia, keeping it in the public eye, so more can be done to stop the devastation it causes. I encourage anyone working in the media and arts to read these guidelines and collaborate with Alzheimer’s Society, if they are going to write about or portray dementia.”

Dame Judi Dench

Alzheimer’s Society Patron and actor



“Alzheimer’s Society has for decades been at the forefront of research into the care and cure of dementia. If you want to talk about dementia in an honest, accurate and respectful way, this guide will help you do just that. As someone who has seen the effects of dementia, I am so glad they are publishing this guide. It is so important to portray those living with dementia with absolute respect and compassion.”

John Suchet OBE

Alzheimer’s Society Ambassador,
journalist, broadcaster and author



“Insight from Alzheimer’s Society helped me understand the realities of dementia and its impact on, not only the person living with the condition but also their friends and families. Hearing from experts in the field and those with a dementia diagnosis, is an invaluable tool. The information shared in this guide will help you accurately and authentically portray dementia.”

Lucrezia Millarini

news journalist and television presenter



“Each person with dementia and those who love them, have their own unique story. It is vital that the realities of dementia are accurately reflected in the media and arts. The words and language used to talk about dementia undoubtedly impact how dementia is viewed. This practical guide highlights the real difference those working in the media and arts can make in increasing understanding, tackling discrimination and amplifying the voices of those living with dementia.”

Marverine Cole

journalist and broadcaster

This guide was created with the input of a number of people living with and affected by dementia. We would like to thank them for their invaluable help and insight.

Key contacts

To contact the national media team please email press@alzheimers.org.uk (please also use this email address to contact national and regional media teams outside of working hours)

To contact the regional media team please email regionalpress@alzheimers.org.uk

To contact either team by phone please call **0207 423 3595**.



Alzheimer's Society operates in England, Wales, Isle of Man and Northern Ireland.
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**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia