



Dementia-friendly media and broadcast guide

A guide to representing dementia in
the arts, culture and popular discourse



Document purpose

This is a practical guide for media, broadcast and creative sectors representing or reporting on dementia. A supporting evidence review can be found in Appendix 2 showing key themes from our workshops with people affected by dementia¹, as well as common statistics and guidance applicable across the sector. This toolkit also includes, dementia statistics and industry standards for groups and individuals to support them in their specific roles when portraying dementia. It demonstrates that small changes to language and tone can make a real difference in supporting people affected by dementia to live well in their communities.

Title

A practical guide representing dementia in the arts, culture and popular discourse

Publication date

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Target audience

Individuals and outlets in the profession who contribute to the representation of dementia in the media and wider popular discourse. This includes:

- journalists and editors for online or print media either regionally, nationally or trade;
- commissioners for TV and radio, including documentaries, soaps, dramas;
- actors, playwrights, directors, scriptwriters, programme makers;
- individuals from the wider sector such as universities, regulatory bodies, associations and membership bodies

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Publisher

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¹This report uses the term 'people affected by dementia' to include people with dementia and those important to them, which may include friends or family members (including family carers).



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Foreword from Jeremy Hughes CBE, Alzheimer's Society

Dementia is now the UK's biggest killer. Someone develops dementia in the UK every three minutes and there is currently no cure. Dementia affects people from all parts of society, and will impact all of us. This is why we urgently need to unite against it.

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 use, particularly in the media, has the power to impact the lives of millions of people around the country.

The power of the media to influence change has been demonstrated through campaigns including Jamie's School Dinners and the focus on the

Dementia Tax during the 2017 general election. We are beginning to see some good examples of a changed approach.

Programmes such as "The Trouble with Dad", where David Baddiel spoke candidly about the impact of Pick's disease on his father and wider family have helped to move the conversation about dementia forward. This documentary showed, in David's words, that there is more to dementia than "the fictionalised ideas – a man or women in a wheelchair with a blanket looking at the wall." In other portrayals on television, ITV featured a dementia storyline in Emmerdale that pushed boundaries by, taking the storyline out of standard continuing drama territory. They used flashback and flash forward scenes to show the bewildering nature of the condition. In the recent film from Pixar, Coco, the title character's memory loss is portrayed seriously, sensitively and thoughtfully. The film accurately represented a person with dementia approaching the end of their life with dignity, surrounded by love and respect.

Last year, Alzheimer's Society partnered with ITV and Channel 4 to launch Alzheimer's Society United Against Dementia campaign. This guide is to support everyone in the media industry to play their part in changing attitudes to dementia.



Jeremy Hughes
CEO, Alzheimer's Society



Foreword from Julian Fellowes, Lord Fellowes of West Stafford

Through personal experience I have watched the impact of dementia from a close range. I have seen a mother of young children affected by younger onset dementia in her forties; I have witnessed older family members having to live with the condition.

From all this, I know that the stereotypes, misconceptions and inaccuracies portrayed about dementia in popular culture are neither true nor reflective of this complex condition.

Somehow, we need an emphasis and a step change to show that getting dementia is not the end of everything, that people with the condition are living full lives in their communities. I have seen that the language usually associated with the portrayal of dementia in drama causes fear, which stops people getting a diagnosis, and reinforces the stigma linked to dementia. From the 'misery' of dementia, to people 'suffering from it' not living with it, to those impacted being talked about in the past tense, all this is familiar to us.

We have heard in everyday conversations, people joking if they lose their keys that they 'must have dementia'.

Other health conditions, like mental health or cancer, are not reflected in this way, but I remember we were here with cancer only decades ago. When I was a child, to be diagnosed with cancer was a shameful thing. It wasn't spoken about and it was seen as a death sentence, but with more people surviving, the conversation has changed and it is out in the open. We need that change of public attitudes for dementia. The media, from news to dramas and documentaries, have a critical role in driving that cultural shift. I call on the sector to lead the way, to embed and use this guide, supporting the Alzheimer's Society, to work towards a world without dementia.

Photo credit: Nick Briggs



Fellowes of West Stafford

Julian Fellowes
Lord Fellowes of West Stafford

Foreword from Dan Brooke, Channel 4

Knowing our community and responding to their diverse needs is at the heart of effective public service delivery. From ‘Desmond’s’, the first black sitcom by Channel 4 in 1989, to our coverage of the World Para Athletics Championships in 2017, Channel 4 has brought previously neglected experiences and perspectives into the mainstream. Today, the story continues and we want to ensure all stories especially those from people affected by dementia, are brought to the forefront.

Our 360° Diversity Charter puts commitment to diversity at the heart of all activities at Channel 4, encompassing all under-represented groups including disabled people and people living with or affected by dementia. We have set ourselves challenging targets, not just because it’s the right thing to do, but because it makes us more innovative and more commercially successful. Becoming dementia-friendly is more than just raising awareness, for us it is about taking action and leading the way. But there remains more we must do.

We have tried not to shy away from the complexities around dementia, from David Baddiel’s *The Trouble with Dad* – showing that

dementia can be a lot more than just memory loss and how humour can be used as a mechanism to cope – to challenging the social care system for why some people with dementia have to pay for care while other conditions get NHS funding, through to Channel 4 Dispatches *How to avoid the Dementia Tax*.

We want to champion the unheard issues and challenges that all people affected by dementia face, but also the depth and range of inspirational stories which need to be heard. From featuring the innovative animal support schemes of the Dementia Dog project on Crufts, to highlighting unique support services of the UK’s first dementia café for the LGBT community, to the critically acclaimed social experiment *Old people’s Home for Four Year Olds*. This shows that dementia can and should be part of mainstream programming.



Dan Brooke
Chief Marketing and Communications
Officer and Channel 4 Diversity Champion

Introduction

Dementia is the greatest health and social care challenge facing society today. The growing movement for change has seen public interest and the appetite for stories about dementia increase dramatically. We have seen a number of sensitive portrayals of dementia in recent years, but there are sections of the media that continue to trivialise and sensationalise this condition.

This discourse has a huge impact, both positively and negatively, on different groups' individuals. It is essential that journalists are responsible when reporting about dementia to ensure accuracy and fair representation of the condition.

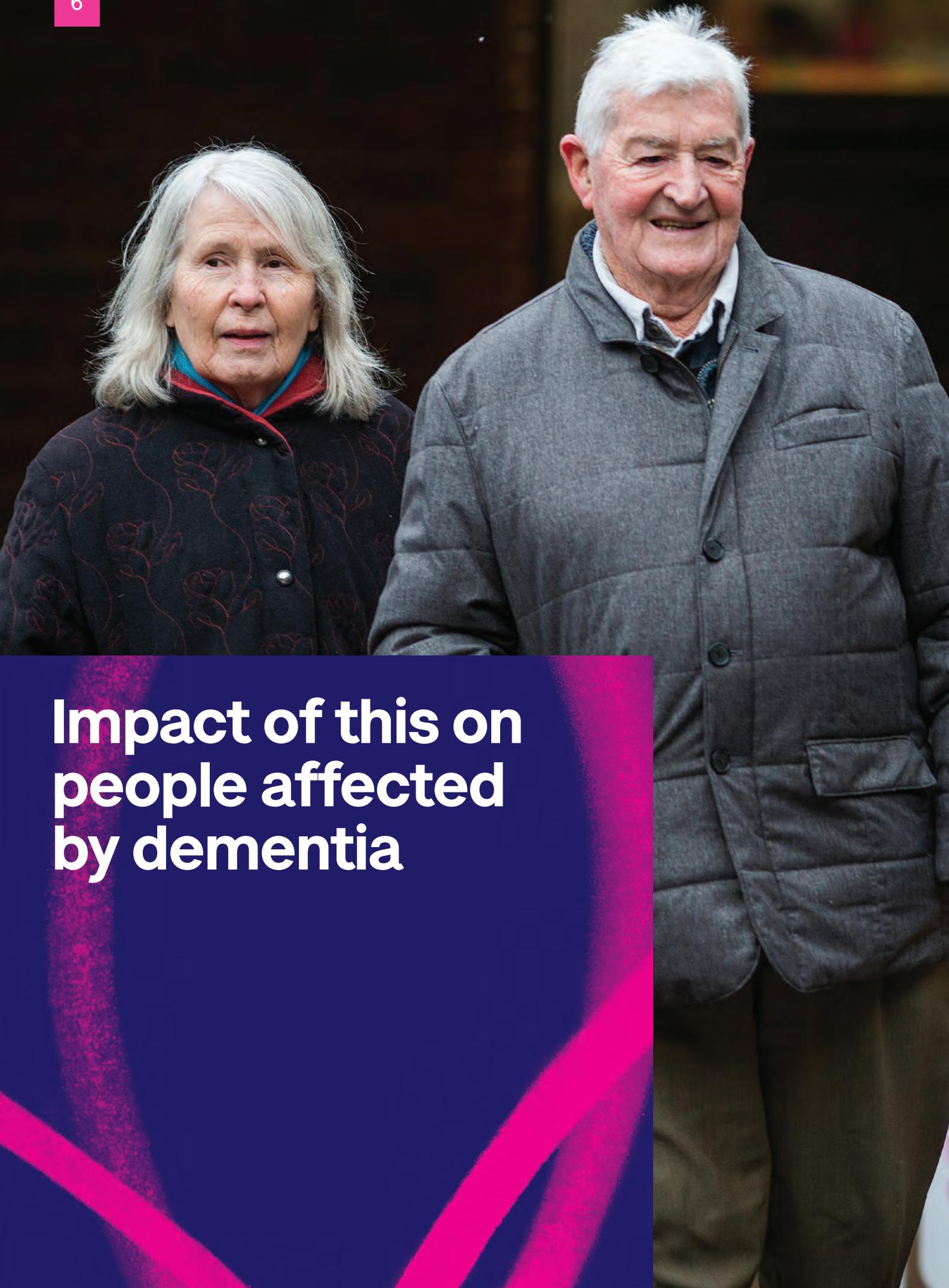
For the public, the media is one of the most important sources of information about health and medicine. This includes understanding of different conditions and diseases. Articles, stories and programmes are a vital part of the dementia movement in raising awareness, challenging misconceptions and signposting to further support. They can provide people affected by dementia with a platform and voice, to share experiences and expertise, and offer

audiences an insight into issues they know little or nothing about.

Personal stories, including those from celebrities, can also highlight other issues such as stigma and challenges associated with dementia. It is essential that we use public discourse to tackle stereotypes, to ensure that there is a fair and reflective portrayal of dementia in broadcast, print, drama, theatre, comedy and film.

In gathering evidence for this guide, the industry has come together to examine the discourse, narrative and portrayal of dementia and focus on the change needed. This work must continue to embed lasting change in all aspects of society.





**Impact of this on
people affected
by dementia**

From speaking to people with dementia, their families and carers, we found that current media portrayals:

- Support incorrect presumptions about dementia
- Increase stigma and fear of the condition
- Reinforce negative perceptions about dementia
- Increase isolation, by potentially stopping people from getting help or coming to terms with their diagnosis
- leave people with dementia open to inaccurate, intrusive and discriminatory press reporting.

“

‘The reaction I get at the end after saying, “Thanks for becoming a Dementia Friend, I was diagnosed with vascular dementia”, ...everyone is gobsmacked. I’ve shattered the myth – talked about it being possible to live with dementia throughout and then showing them you can!’

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‘It’s where cancer was 20 years ago. It was always called “the big C.”’

‘Stereotyping can actually disempower people with dementia – you put the kettle on for them. Then they don’t believe they can, it becomes negative for them.’

‘They don’t think about how their stories impact on us, as a person with dementia, or the upset they can cause to our families.’

‘The media need to listen to us. They need to sit down with us and talk to us about how their stories affect us – it’s the only way they’ll listen.’

‘When you think of [the] word dementia, 99% of the comments are negative. I agree it can be challenging but people’s views [are] entirely negative.’



The role of the media in the dementia movement

The media and popular culture can strongly influence attitudes, beliefs and actions. The voices of people affected and their families must inform the public debate, shape policies and strategies, and help design the services and support they want and need. People affected by dementia and the third sector need to work with the media to encourage realistic and sensitive portrayals of what it means to live with dementia. Ultimately, the media can help to hold organisations, care providers, governments and society to account.

We know that dementia is misunderstood by the public and the stereotypes often used to illustrate dementia can be damaging. The positive effects of portraying dementia in an accurate, compassionate and sensitive way, can improve understanding and make a significant difference by:

- raising awareness around dementia and challenge the stigma, stereotypes and misconceptions of dementia
- increase understanding and raise awareness of the reality of living with dementia
- promoting proven risk reduction messages
- encouraging people to seek or accept help through signposted support and specialist helplines because they recognise the signs and symptoms of dementia
- raising awareness of support services and information to enable people living with dementia, their families and carers to seek help when they need it
- calling for better treatment and further investment into research
- stimulating wider discussions that call on industry, government and wider society to tackle dementia
- promoting the understanding that you can live well with dementia.

We therefore encourage all those who work in media, arts and popular culture to:

- provide accurate information about dementia
- remember there are 850,000 people living with dementia in the UK, so they are not 'someone else'. It could be you, a friend, colleague or relative. A large majority of your audience will be affected in some way.



“

‘They don’t think about how their stories impact on us, as a person with dementia, or the upset they can cause to our families.’

‘The media need to listen to us. They need to sit down with us and talk to us about how their stories affect us – it’s the only way they’ll listen.’

‘When you think of word dementia 99% of the comments are negative. I agree it can be challenging, but people’s view is entirely negative.’



What is dementia?

Dementia is a complex condition that affects every individual differently. The information in this section provides an introduction to dementia.



The word 'dementia' describes a group of symptoms that may include memory loss, difficulties with thinking, problem solving or language, and often changes in mood, perception or behaviour. These changes are usually small to start with, but for someone with dementia they have become bad enough to affect daily life.

Dementia isn't a natural part of ageing. It occurs when the brain is affected by a disease. There are more than 100 known types of dementia. The most common are Alzheimer's disease and vascular dementia. Dementia is one of the main causes of disability in later life, ahead of cancer, cardiovascular disease and stroke.

A person with dementia might have problems with:

- **day-to-day memory** – for example, difficulty recalling events that happened recently;
- **concentrating, planning or organising** – for example, difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal);
- **language** – for example, difficulties following a conversation or finding the right word for something;
- **visuospatial skills** – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions;
- **orientation** – for example, losing track of the day or date, or becoming confused about where they are.

A person with dementia will also experience changes in their mood. For example, they may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).

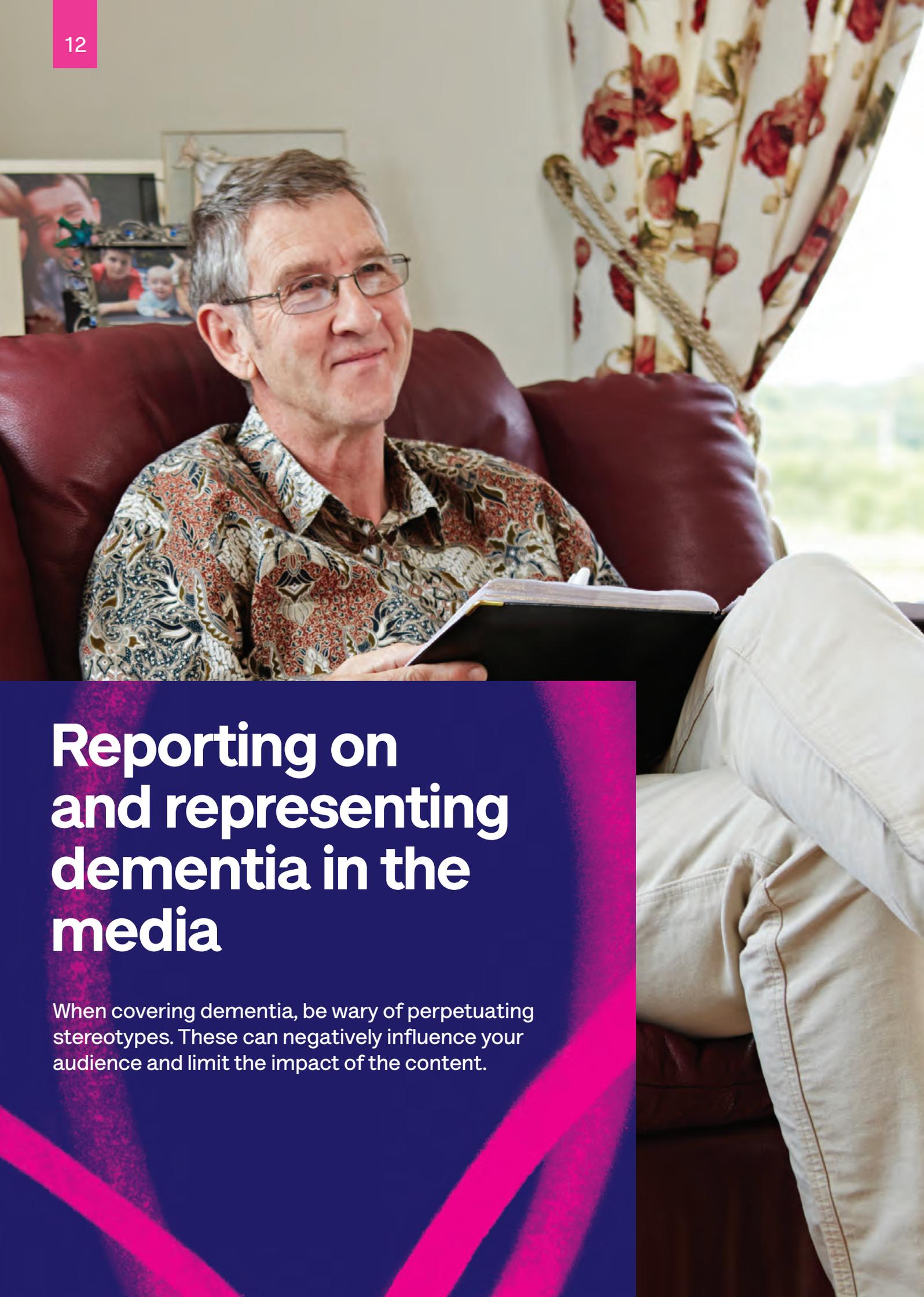


Living well with dementia

A diagnosis of dementia does not mean it is not possible to live well. Many people with dementia continue to drive and socialise. Even as dementia progresses, people can lead active, healthy lives, carry on with their hobbies and enjoy loving friendships and relationships. Someone with dementia may forget an appointment or tell you the same joke twice, but their condition does not stop them doing the things that matter the most.



For more information including a wide range of resources about dementia and how to live well with it see alzheimers.org.uk/get-support

A middle-aged man with short grey hair and glasses is sitting on a dark red leather sofa. He is wearing a patterned, batik-style shirt and light-colored trousers. He is holding a black notebook and a pen, looking off to the side with a thoughtful expression. In the background, there are floral curtains and a framed picture on the wall.

Reporting on and representing dementia in the media

When covering dementia, be wary of perpetuating stereotypes. These can negatively influence your audience and limit the impact of the content.

As a starting point, consider the following points:

- Is the person's dementia relevant to the story?
- Don't speculate about the relevance of the person's dementia.
- Is it appropriate for the person's dementia to be mentioned in the headline or lead?
- Don't ask questions of the person or make assumptions based on second-hand accounts.
- Would it help to add facts about the condition, prevalence and its impact?
- Consider consulting people with dementia as part of your research or reach out to a dementia charity who may be able to provide a spokesperson.

What people with dementia have told us:



'Headlines can be damaging – people have to relate and show empathy' [towards a] person with dementia.'

'These headlines disable.'

'When first diagnosed sometimes you don't remember you have dementia, imagine then how [it] feels seeing negative stories about how awful it is, that's all you see, all you look forward to. This is what you are reflecting back to people with dementia, no wonder so many people live in denial and there is such a stigma.'

Headlines

When writing headlines, think carefully about the potential impact and, consider whether it makes the story especially dramatic or misleading. Avoid using negative terms such as 'misery' or 'epidemic' (see page 14 for more details). Using language like this might have a damaging effect on people living with dementia and those affected by it.

Reporting on people living with dementia

Where possible, sensitively focus on the whole person and not just their dementia in relation to the topic. Avoid making unsubstantiated links or speculating between incidents and an individual potentially having dementia, unless it is confirmed or relevant to the story. Stick to the facts and consider contextualising these statistics against the wider demographic of people affected with dementia and the issues they face .

Reports about people with dementia often focus on aspects of their behaviour. It's important to focus on the context of any behaviour including the environment and any other factors that may influence the situation. For example, if the report is about someone who has gone missing, they may have become confused or lost, or they may have wanted something from the shop and gone out to meet this need.

Consider the impact on the individual and their family. Be mindful, considerate and respectful when reporting on anyone living with dementia.

What people with dementia have told us:



'Some of the stories make it sound like dementia is worse than it is. We can still do things, like drive or walk by ourselves.'

Reporting scientific research

There is often a lot of misinformation about reducing the risk or preventing dementia. It's important that claims are made based on the evidence available. Overall, the best kind of evidence for identifying risk factors come from clinical trials. These look at what happens over time when some people in the trial are given a medicine (eg to lower blood pressure) or adopt different behaviours (eg various diets). Generally, trials need to run for many years and involve hundreds or thousands of people to demonstrate effect.

Think about how what is being reported may impact people, especially if there is limited or no evidence for it. It can raise expectations and may negatively impact people affected by dementia, when the claims are found to be false or misleading.

Reporting on risk factors

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
- where there is no evidence or only evidence of an association or link, avoid making assumptions about the causes of dementia

It is important not to whitewash the complex realities of dementia and its impact on individuals living with condition, their friends and family.

What people with dementia have told us:



'People diagnosed feel at fault'

'People get it wrong and think we've caught it somehow.'

Reporting on treatments

Always include information on support groups and specialist charities where people can find help for themselves or a loved one. This really does make a difference and can provide hope when people need it most.

Representation in the media

Understandably, given the many myths and misunderstandings that surround dementia, there can be a tendency in news, drama, soaps and film to focus on the most vulnerable and negative aspects of dementia. The person with dementia is often characterised in the later stages of dementia – very elderly and frail, confined to their home or in a care home, very confused and reliant on others. This needs to change. We should also be covering early and mid-stages – for example, first person pieces on inspirational people with dementia travelling, working or campaigning and younger onset dementia and its impact. Showing people at earlier stages would help inform wider communities on how they can best help people with dementia, when they are out and about, enabling them to remain independent for longer.

What people with dementia have told us:



'The media needs to be better at expressing both sides of the story. They never really delve deeply into what's really going on – like research. It's not always clear.'



What people with dementia have told us:

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‘You don’t hear those stories in-between, the journey [is] not reflected.’



Visit Alzheimer’s Society Blog to find out more about recent projects, developments and schemes underway across the nations.



The importance of positive language

When representing dementia, the media can use language that can cause offence and be inaccurate. The use of specific words and tone can perpetuate stigma, sensationalise the condition and cause distress for people living with dementia, their families and friends.

In many different areas, terms that were once thought acceptable are no longer so, from medical terminology to slang about communities. We want to see change in the way language is used around dementia.

Impact on people affected by dementia

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.

People with dementia are individuals with a history, personality, relationships and desires. A person is not just a condition or symptoms they experience. Dementia is not necessarily a defining aspect of life, nor does it mean that their life is over. Use language that reflects this. Always think about how a person with dementia would feel about your

choice of words, if you're not quoting them directly. 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.

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. Because every person's experience of dementia is different, its impact on people's lives will be varied and not always negative. Being truthful and realistic about the impact of dementia doesn't mean being negative, disempowering, pessimistic or frightening. This includes avoiding messages such as a life with dementia is not worth living, or those that are negatively attached to the person rather than the condition or create or reinforce stereotypes. Using positive terms can make people feel valued and included, and contribute to changing the landscape of dementia.



The use of 'sufferer' to describe someone living with dementia is a common grievance for people. Of course, a person with dementia may identify themselves as a sufferer or suffering with the disease, and that is their right to do so. The issue comes as many people with dementia find the term derogatory and unnecessary and therefore using the term in media and the arts to describe all people with dementia is not ideal. We need to move away from defaulting to using the term to describe anyone with dementia.

What people with dementia have told us:

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'They called me a dementia patient, it didn't occur to them that this wasn't right I am a person who lives with dementia. It suggests you are in a hospital bed or a doctor with me every day which isn't true.'

'Think just memory loss and don't realise full implications of it.'

Here are the most common terms that people with dementia find offensive, some alternative suggestions and the views of people with dementia.

Do use the following	Don't use the following	Views of people with dementia
<p>Use the following ways to describe dementia:</p> <ul style="list-style-type: none"> ■ dementia ■ Alzheimer's disease and other types of dementia ■ a form of dementia ■ a type of dementia ■ a condition ■ symptoms of dementia. 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ dementing ■ demented ■ affliction ■ senile, senile dementia or senility. 	<p>Always use language that recognises dementia is not the defining aspect of a person's life. See the person, not the dementia.</p>
<p>Use the following when talking about a person with dementia:</p> <ul style="list-style-type: none"> ■ 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) ■ Avoid 'burden' unless a carer uses the word themselves – use 'impact' or 'effect' instead. 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ sufferer ■ suffer from ■ afflicted ■ burden ■ 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', 'lost their mind', 'lost their marbles', '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. 	<p>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.</p> <p>However, try to avoid using 'person with dementia' or 'person living with dementia' too often, as it can become almost another label.</p> <p>Vary the language used – for example, 'someone who has dementia', or, 'Mrs Jones, who has Alzheimer's disease'.</p> <p>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.</p> <p>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.</p>

Do use the following	Don't use the following	Views of people with dementia
<p>Use the following when talking about those caring for a person with dementia:</p> <ul style="list-style-type: none"> ■ supporting a person with dementia ■ caring for a person with dementia ■ use different words for professional or paid carers, such as 'care worker' or 'care professional'. 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ 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. 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. 	<ul style="list-style-type: none"> ■ The term 'carer' generally refers to people who provide unpaid care, such as a partner, family member or friend.
<p>Use the following when describing the symptom itself:</p> <ul style="list-style-type: none"> ■ memory loss ■ difficulty communicating ■ changes in behaviour ■ expressions of unmet need ■ challenging behaviour ■ behaviours that challenge ■ behavioural and psychological symptoms (in a clinical context) 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ wanderer ■ shouter ■ difficult behaviours ■ being 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.</p> <p>For example, don't label someone – 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' or 'a wanderer'.</p> <p>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 is agitated, it may be because they are in pain but cannot communicate it.</p>

Do use the following	Don't use the following	Views of people with dementia
<p>Use the following when describing any behaviours:</p> <ul style="list-style-type: none"> ■ 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. ■ 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'. 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ absconding ■ 'difficult behaviours' which 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. 	<p>Don't reinforce stereotypes or myths about dementia. A lot of people dislike the term 'wandering' if a person walks about because it 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. 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.</p>
<p>Use the following when describing the impact of dementia:</p> <ul style="list-style-type: none"> ■ challenging ■ disabling ■ life changing ■ stressful 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ hopeless ■ unbearable ■ impossible ■ misery ■ tragic ■ plague ■ epidemic ■ living death 	<p>It is important to be realistic about dementia while not being overly pessimistic or frightening. The words proposed here are appropriate to describe the intensity of the impact, without sensationalising or causing upset.</p>
<p>Use the following when talking about specific tasks:</p> <ul style="list-style-type: none"> ■ use phrases like 'supporting (or helping) the person to eat'. 	<p>Don't use the following:</p> <ul style="list-style-type: none"> ■ Feeding, dressing or toileting – again, these terms imply that the person is passive and does not participate in the activities described. ■ Sitting service or sitter – this implies that the person with dementia is a passive recipient of care, and also has connotations of babysitting. 	<p>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.</p>





Involving people affected by dementia

Interviewing a person, either living with or affected by dementia, can sometimes require sensitivity and discretion.



Telling someone's story requires sensitivity and discretion. If you are a programme maker or production company looking to contact people affected by dementia, contact Alzheimer's Society as a first step. We can also provide further support through the following process:

Interviews

- Is it relevant to the story that the featured person has dementia?
- Don't speculate about someone's diagnosis being a factor in the story unless you know this to be 100% true.
- Is it appropriate for the person's dementia to be mentioned in the headline or lead?
- Who are your sources? Can you rely on eyewitnesses or neighbours to provide facts or has an assumption been made about someone's health?
- Think about including contextualising facts about the condition, prevalence and its impact.
- Consider consulting people with dementia as part of your research or reach out to a dementia charity who may be able to provide a spokesperson

Before the interview

- Do you have their consent, or if they do not have the mental capacity to give consent, have you gone through appropriate processes?

(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.
- Ask the person if they would like someone with them when they are interviewed.
- Don't identify the person by name or using photos or moving footage, unless they have given permission.
- Explain to someone when you interview them how you intend to use their story and any personal information they give you. Seek agreement beforehand on the use of photos and video, and whether the person will be identified. You may want to give a written record of this for them to refer back to.
- Give them a list of questions before the interview to help them prepare.
- If you are interviewing different people be aware they are likely to have different opinions about their experience. Try to make sure you represent all sides.
- Think about how you will communicate with the person.
- 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.

What people with dementia have told us:



'I was scared when interviewing that they would be grilling me, but it was fine they were just asking my story. They came to the house and they were so patient when I was tired, giving me a break and reassuring me. It was exhausting, but it was so helpful for them and for me.'

During the interview

- Give the person plenty of time and try not to rush – it may take them longer to process the questions you ask and their thoughts.
- If the person is struggling with your questions, change how you ask them or break them down into simpler ideas.
- Speak clearly and calmly and use short easy to understand sentences.
- Ask one question at a time.
- Non-verbal communication is really important.
- If you haven't understood what the person has said – rephrase what you have understood and check if you are right.
- Try not to suggest that you understand the person's situation because you have known someone else with dementia – or even have personal experience of the condition – everyone's dementia is different and impacts individuals in very different ways.
- Don't provide an 'on air' diagnosis or encourage 'experts' to do so.
- People living with dementia or their families affected can sometimes feel embarrassed about their dementia. Be sensitive to this.
- 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 today?" is a much better alternative.

- Offer to stop the interview if a person does become very visibly upset, but accept that they may wish to continue despite their distress.
- Wherever possible, use the person's own words to represent their experiences.
- If you are speaking to a bereaved or affected family member, bear in mind that while it can be helpful to talk about grief – people may need to take their time, or to collect themselves if they become very upset.

Post interview or pre-publication/ broadcast

- Let the person know how the interview will be used including editing processes and whether other material will be used alongside it. If you intend to emphasise a particular angle, tell the person.
- If material is likely to be shared with other media outlets, make sure this is covered in the consent agreement and let the interviewees know, so they are not taken by surprise when their story appears in other contexts.
- Check the material you intend to use with the person and give the person copy approval.
- Help your readers or listeners who may be worried or concerned by headlines or coverage to seek help by adding information about available support, including helpline numbers, local services and websites.

If you are writing about dementia it is best to always include the voice of somebody either living with or affected by the condition, anonymously if needs be. A common problem in society is for people, including the medical profession, to talk to a person with dementia's partner, carer or friend rather than to the person themselves, which is very disempowering. Consider including people with dementia as expert contributors, not just as case studies or soundbites.



What people with dementia have told us:

“

‘Had an interview on the radio they didn’t call to give me warning, they called me live on air. I needed to explain I lose my words. They kept referring to previous story. They didn’t take me seriously, I was anxious when I spoke about dementia and how it affects me. He didn’t get it, I felt up against the ropes.’

‘Got to the studio early and was taken on a tour around introducing me to people. Then got to meet the presenter first and explained about my dementia and that I needed water. I explained to him what I was anxious about and they put my mind at rest. He treated me as a normal human, he was mindful I needed a little bit of time to think of an answer whilst live. They were kind but not patronising.’



Signposting and providing information on how to contact local and national specialist support can encourage people who are worried about themselves or someone else, to seek help. This can truly change lives and provide help when members of the public might need it most.

Contact your local Alzheimer’s Society to find out about any local campaigns, initiatives and the stories of people living with dementia in your area.

Guidance when making a documentary or filming with people with dementia

If you are a programme maker or production company who has an idea to be commissioned, get in touch even prior to getting the green light. We can then support you in developing the idea. Films about dementia can raise awareness amongst the wider public and targeted groups, can challenge common misconceptions, show the value of people with dementia to society and what they can do, and voice a particular issue or concern. Details about contributors getting support or going through a process, like getting a diagnosis, can help a viewer going through similar challenges. A balance is needed between the opportunity to increase understanding and the need to provide entertainment.

- **Prepare and research:** Read papers by clinicians and get in touch with specialist organisations, groups and charities for support. Alzheimer's Society can support in supplying information and having an initial discussion about the project.
- **Training and awareness:** Ensure that the crew have an understanding of dementia through free awareness-raising sessions like Dementia Friends. Discuss with them how they can support people affected throughout the process.
- **Speak to people living with and affected by dementia:** Meet people face to face to gain first-hand knowledge, talking to as many people affected as possible. Invite a group to a workshop or discussion to talk about the programme or series. Meeting a group can put people at ease and can be less pressure than a one to one interview. Alzheimer's Society can advertise opportunities to get involved on our website, services and communication channels, as well as putting you in touch with groups or service users.
- **Get to know your contributors:** Build a relationship slowly you don't need to know everything immediately. Sharing any personal experience of dementia can help put the individual at ease and break down barriers, showing that you understand dementia. Try to have one consistent point of contact with a member of the team throughout the filming to build and maintain a relationship and trust.

- **Spend time talking about their role with them, as well as family, friends or carers:** They will want to hear about the project, who you are, why you are making the show, what messages it will have, their role, how their contribution will be featured, where and when it will be shown, what support is available throughout, how people with dementia will be portrayed and the impact of transmission. Explain safeguarding and duty of care procedures. Their family, carer or loved ones might also have questions. Be clear from the beginning and consider leaving a written copy of this information so they can refer to this at a later date if they need too. Advise people they can leave the process at any point they wish and make sure people do not feel pressured to be involved.
- **Consult legal, guidelines and ensure safeguarding is in place:** Consult your legal department, Editorial Policy or Guidelines. Ensure parameters are in place for filming which outline how contributors will take part, what is expected and when. If there is no detailed requirements use common sense or seek guidance. Seek the appropriate level of professional advice and support for that participant.



Training and Consultancy

Alzheimer's Society Training and Consultancy team develop and deliver high-quality training and consultancy services to individuals and organisations. For more information see alzheimers.org.uk/dementia-professionals/training-consultancy

- **Amend and alter filming processes and procedures:** Be flexible and get to know the person's needs; don't rush filming. Be prepared to change your plans and filming schedule if necessary. Try to schedule shorter filming sessions at first, allowing time and space for people affected to speak. Dementia can make it harder to maintain focus and may mean the person gets tired. Check in with your contributors and consider that on the day they might not feel up to it. Inform camera operators of this before, so they are aware of the need to be flexible.
- **Interviewing:** Plan interviews together with the person, their family members or loved ones. Provide questions and topics to be discussed prior to the filming to give them time to prepare, especially if certain topics might be difficult subject areas to discuss. Reduce noise, distractions and potential interruptions.
- **Portraying non-visible conditions like dementia:** Consider how to illustrate someone's story in a visual way showing the challenges they face, that the viewer may not be able to see. Interviews with contributors talking to the camera, or reflective voiceovers to allow the individual to communicate what they were encountering at that time, can help interpret the complexities of dementia for viewers.
- **Editing:** Offer contributor's the opportunity to view their footage prior to transmission. Give them control through the whole process to ensure their engagement throughout. Consider the impact on a contributor if they are dropped or cut from the programme and ensure they are informed of all decisions on how their contribution is to be used. Throughout filming and editing show contributor's the footage so they can get used to seeing and hearing themselves on film and help contextualise what they are doing.
- **Consent:** The person with dementia must have the mental capacity to consent to take part and this should be assessed before the person is involved and checked as needed during the filming process. If someone cannot or does not provide informed consent then they cannot take part. Be aware that someone can remove their consent at any time and this must be respected. It's important to refer to your organisational consent policy as needed.
- **Aftercare:** Schedule and provide communication with participants up until after broadcast. This could be signposting to professional or clinical support, staying in touch with regular catch-ups, to small gestures including texts or calls on the day of broadcast, to check how the person is and that their contribution is valued. Being part of shows and projects can be hugely enjoyable for participants providing support, companionship and purpose.

What people with dementia have told us:

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‘People told us how they went and got a diagnosis because of the show. It gave permission to come out and live.’

Chris and Jayne Roberts

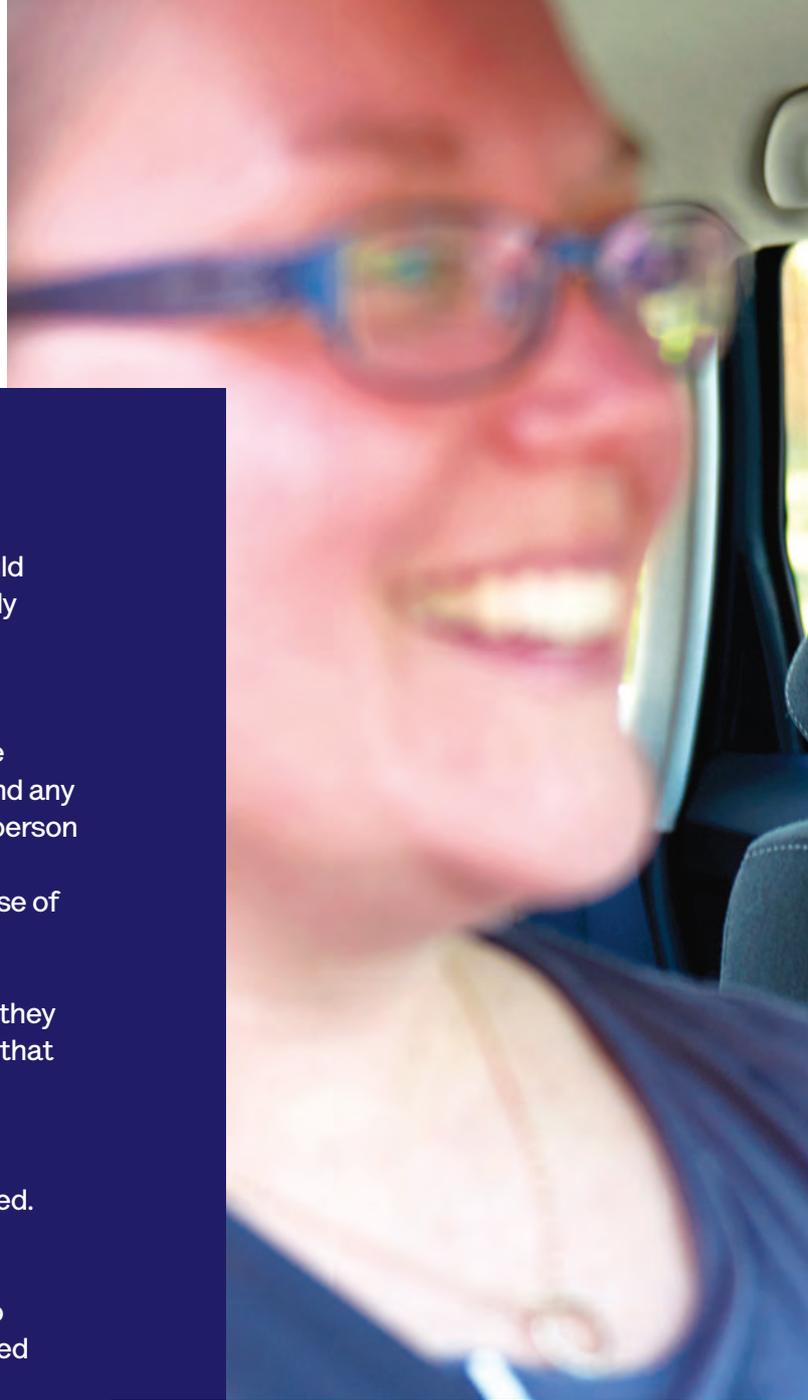
Getting consent

Getting consent from people living with dementia should be a continuous process. Consult your legal team, family members, carers and loved one of those contributing. Make sure you consider the following:

- ✓ When getting consent take as much time as the person needs to talk through the programme and any issues or questions they may have. Ensure the person and, where appropriate, others involved such as family, friends and carers understand the purpose of the film and how it will be made and used.
- ✓ When getting the person's consent ensure that they understand that this will be a public declaration that they have dementia.
- ✓ Be aware of the person's behaviour when being filmed and if they say anything about being filmed. If you get the impression they are not happy or don't understand what is going on, stop filming and check with the person whether they wish to continue, and ensure that you have their informed consent to proceed.
- ✓ Mental capacity and a person's ability to provide informed consent can vary from day to day, a person might understand something one day but then struggle to understand it the next. Therefore, it is crucial to recheck capacity and consent as appropriate and even during filming. Do note that anyone can change their mind about being filmed and this must be respected.
- ✓ When getting consent ensure that a potential contributor understands that once in the public domain and distributed there may be little control over how clips will be used, and if available over the internet film or clips may be shown in years' time.



If you are looking for inspiration on stories, ideas or participants take a look at our Blog to get an overview on the range of topics. You can also get in touch with our Stories team to find out more about working with case studies affected by dementia.







Use of images

Images can be powerful, but they can also be damaging if they create or reinforce a generalisation of what someone living with dementia looks or behaves like. Generic stock images of older white women, isolated, holding their head in their hands are often used in stories about dementia.

Strong stories and great content can be diluted by the use of an inappropriate or misleading image. Keep the following process in mind:

- Find an image that is truly relevant to the piece, not just the first image you find.
- As with mental health stories, avoid the ‘head clutcher’ image.
- With most people with dementia living in the community, images of care homes, hospitals, wards or in-patients facilities can be misleading – make the image relevant to the story.
- Check with people featured in the articles that they understand how the image will be used and they are prepared to be identified in the story as having dementia.
- Be sensitive when illustrating stories about celebrities or high profile individuals if they say they have dementia.
- Picture agencies can remove or reduce stigmatising pictures from image libraries and amend categories and keywords to help picture editors find appropriate images.

What people with dementia have told us:

“

‘The stigmatised images – makes you think that that’s all there is – that there’s nothing left to look forward to, but they’re wrong.’



Get in touch with Alzheimer’s Society for advice on which images will be relevant to your piece.



Guidance on storytelling when portraying dementia in soaps, theatre and drama

Authentic storylines can help start crucial conversations about dementia. Soaps, dramas and theatre have the power to entertain and inform, but also to help people to better understand difficult issues.



Developing and featuring well-known characters, either living with dementia or affected through their role as loved one or carer, in soaps and dramas can have a positive impact on raising awareness, recognising dementia and seeking support.

However, getting it wrong can reinforce stereotypes and lead to negative outcomes. Simplistic portrayals and misinformation for viewers can lead to misunderstandings of dementia and negatively impact those affected by it. Dementia will impact many of your audience, getting it wrong or sensationalising could risk alienating a large part of your audience.

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

Dementia in the soaps

The Archers, Coronation Street, EastEnders and Emmerdale have all covered dementia in a storyline over the past decade. All have been commended for tackling this challenging topic in a sensitive light responsibly. Covering dementia can help improve understanding and attitudes by:

- providing accurate information about dementia.
- encouraging people to seek help, for instance by providing helpline numbers.
- breaking down myths about dementia, encouraging openness and including the voices of people affected.
- remembering that anyone can get dementia – it could be you, a friend, a relative or a colleague.

What people with dementia have told us:

“

‘We are all very different, whether an illness we might have, or our age.’

‘It doesn’t feel like me.’

‘I have never seen a storyline of 3 or 4 people with dementia interacting with each other.’

‘No depiction of the day to day – it’s always the same.’



Alzheimer’s Society Stories team can put you in touch with people living with dementia or their family and carers, across the country who can share their own experiences of dementia.

Creating realistic characters

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 symptoms, 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.
- ✓ **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.
- ✓ **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 dementia often manifest over a period of time and the process for getting a diagnosis can take months or years. Think about how other characters might react or cope with this uncertainty.
- ✓ **Medication is not a miracle cure:** Medication is not suitable for all types of dementia.
- ✓ **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.
- ✓ **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 sleeping problems can provide the audience with clues.
- ✓ **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.
- ✓ **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.

Appropriate and inappropriate use of dementia

Dementia or demented may be used as an insult, an offhand remark or comment on a person's ability. People may use dementia inappropriately in a 'humourous' way. It's important to challenge this and not reinforce stereotypes.

We spoke to people living with and affected by dementia about their view of dementia being used in comedy. People commented that there is a casualness about dementia differently to other conditions like cancer. Everyone agreed there can be funniness in anything and there is room for humour with dementia, especially as it can help people come to terms with their situation. But it must not be cheap or directed at the person. Comedians shouldn't shy away from dementia but need to be aware of the impact what they are saying or doing can have on perceptions of dementia.



Using dementia as an insult or simile

As with other conditions dementia is sometimes used as an insult, an offhand remark or comment on a person's ability. Sometimes dementia is used as an adjective or as a suffix to create a trivial association, this is often unchallenged in supposedly humorous way. Referring to someone as demented or making comparisons that you might have dementia as you have lost your keys is unhelpful as it can trivialise the condition and is insensitive to those affected.

What people with dementia have told us:



'There is a funny side to dementia, but dementia isn't funny.'

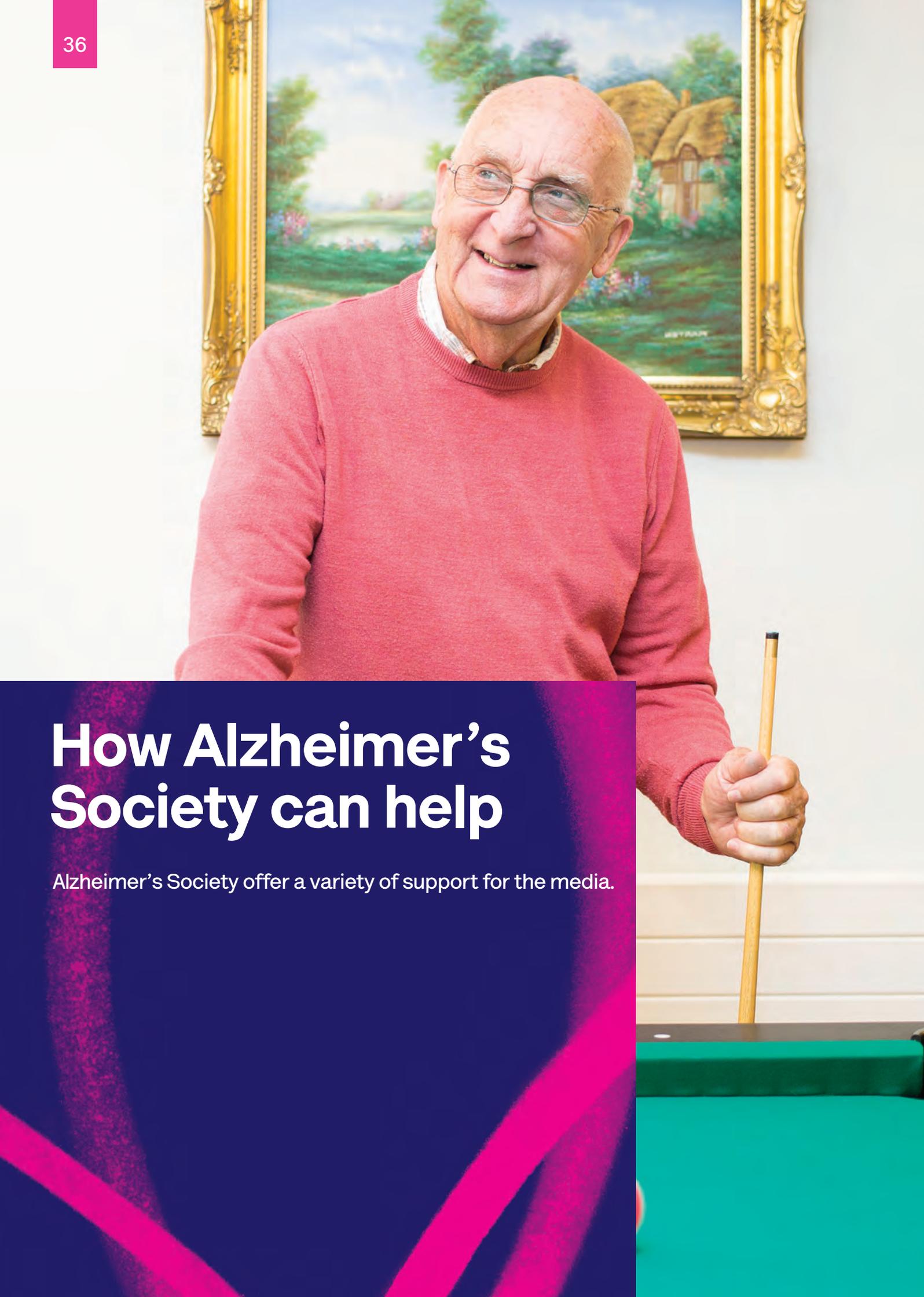
'Making fun of something often comes from fear.'

'Huge funny side to dementia. We use it a lot, but aware that some people don't like it.'

'I don't like when used derogatory term like demented – especially when it's used as an insult.'

'We need humour and comedy, it shouldn't be shied away from – people are frightened and frightened to say the wrong thing.'



An elderly man with glasses, wearing a red sweater, is smiling and holding a pool cue. He is standing in front of a painting of a thatched cottage. The background is a white wall with a gold-framed painting. The bottom of the image features a dark blue and purple abstract graphic overlay.

How Alzheimer's Society can help

Alzheimer's Society offer a variety of support for the media.

Some of the things we can help with include:

- Background information about are symptoms of dementia, progression, treatment, therapies and ways to live well with dementia.
- Key statistics, facts and figures on dementia in the UK, as well as regionally and globally and impact to particular sectors and industries.
- Consultation and advice for news stories and documentaries including fact-checking and research.
- Help with script formulation to support realistic, accurate and sensitive portrayals of dementia.
- Our Stories team can put you in touch with case studies of similar age, location or background who have direct experience of dementia who can provide a unique insight into your character and storylines.
- Provision of expert opinion through our spokespeople or ambassadors.
- Signposting you towards information or other relevant organisations.
- Hosting a series of events aimed at inspiring and informing different sections of the media.
- Providing online information and guidance on best practice for anyone working in the media.
- Our Training and Consultancy team can support individuals and groups to learn more about dementia.



Our website and dedicated Media Team can provide support for anyone working on coverage of dementia.



Appendix 1: Core information on dementia

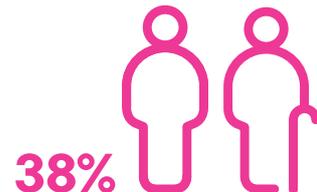
Key statistics

Statistical information can be a key factor in reporting dementia – therefore it is important that you are aware of how these are calculated. Use statistics with caution check with Alzheimer’s Society or the relevant national statistical agency to make sure you have the most recent data and are comparing like with like.

Prevalence of dementia in the UK



There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051.



24.6 million people in the UK – 38% of the population – know a family member or close friend living with dementia.



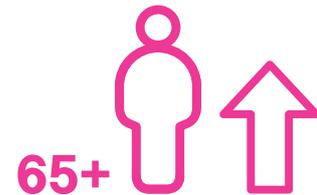
1 in 3 people born in the UK this year will develop dementia in their lifetime.



225,000 will develop dementia in the UK this year, that’s one every three minutes.



1 in 6 people over the age of 80 have dementia.



1 in 14 people over the age of 65 have dementia.



70 per cent of people in care homes have dementia or severe memory problems.



There are over 40,000 people under 65 with dementia in the UK.



More than 25,000 people from black, Asian and minority ethnic groups in the UK are affected.



There are 700,000 informal carers for the 850,000 people living with dementia in the UK.

Types of dementia

Dementia is often misrepresented in the media, it is a term referring to over 100 different types of conditions. Use the word dementia if talking about more than one condition or you do not know which type of dementia, and use the name of the particular condition if it is known.

Alzheimer's disease is the most common type of dementia. The prevalence for different types of dementia can be broken down as follows:

62%

Alzheimer's disease

2%

Frontotemporal dementia

17%

Vascular dementia

2%

Parkinson's disease dementia

10%

Mixed dementia

3%

Other types of dementia

4%

Dementia with Lewy bodies

Risk factors

There are many diseases that result in dementia. If you, or someone you know, has developed dementia, it is natural to ask why. It is not usually possible to say for certain, although a doctor may be able to say which factor(s) might have contributed. In most cases a mixture of risk factors – potentially avoidable and not – will be responsible.

Risk factors include age, genetics, lifestyle choices and health conditions. There is still a lot we don't know about the causes of dementia. We can't tell an individual what their overall risk of developing dementia is. We can only identify things that might put them at a higher or lower risk than other people of the same age. No single cause or risk factor is sufficient to lead directly to the illness, but each combines to raise the risk to the individual. Research is being conducted into all these aspects, with genetics and neuroscience being the most recent lines of enquiry. Although we can't change our genes or stop ageing, there are lifestyle changes that we can make to reduce our risk of dementia.





Age: The chance of developing dementia varies from person to person. Everyone has some risk because age is the strongest risk factor and we're all growing older.



Genes: Everyone else will inherit a combination of genes that increases or decreases their risk of developing dementia in much less direct ways. Apart from some rare cases, most instances of dementia are not inherited. But we can inherit certain genes from our parents that make us more vulnerable to developing dementia. In a very small number of people, certain types of dementia are inherited as a single gene that directly causes the disease. People with one of these genes will usually get dementia before the age of 65.



Gender: Women are more likely to develop Alzheimer's disease than men. This is the case even if we allow for the fact that women on average live longer. The reasons for this are still unclear. It has been suggested that Alzheimer's disease in women is linked to a lack of the hormone oestrogen after the menopause. However, controlled trials of hormone replacement therapy (HRT, which replaces female hormones) have not been shown to reduce the risk of developing Alzheimer's. For most dementias other than Alzheimer's disease, men and women have much the same risk. For vascular dementia, men are actually at slightly higher risk than women. This is because men are more prone to stroke and heart disease, which can cause vascular and mixed dementia.



Ethnicity: There is some evidence that people from certain ethnic communities are at higher risk of dementia than others. For example, South Asian people (from countries such as India and Pakistan) seem to develop dementia – particularly vascular dementia – more often than white Europeans. South Asians are well known to be at a higher risk of stroke, heart disease and diabetes, and this is thought to explain the higher dementia risk. Similarly, people of African or African-Caribbean origin seem to develop dementia more often. They are known to be more prone to diabetes and stroke.



Lifestyle choices: Making certain lifestyle choices can increase or decrease our chances of developing dementia. Exercise, mental stimulation, maintaining a healthy weight and socialising might help to protect us from dementia. On the other hand, smoking and drinking too much alcohol can increase our chances.



Other health conditions: Your chance of developing dementia can be greater if you have other health conditions like type 2 diabetes, obesity or high blood pressure in middle age.



Cost of dementia

- Two thirds of the cost of dementia is paid by people with dementia and their families.
- Unpaid carers supporting someone with dementia save the economy £11 bn a year.
- Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke. As a country we spend much less on dementia than on these other conditions.
- The economic annual cost to the National Health Service, local authorities and families is £26 billion a year; more than cancer and heart disease combined (Alzheimer's Society 2013a, Luengo-Fernandez et al. 2010).
- The economic cost of dementia in the UK is expected to double in the next 25 years, from £26bn to £55bn in 2040.

Comorbidities

A comorbidity is a secondary or additional disease or disorder that a person may have. People with dementia are often living with a number of comorbidities which are often undiagnosed, for example these might include conditions such as hypertension and diabetes.

Diagnosis

Not everyone with dementia has a diagnosis. This can be due to a number of factors including difficulty diagnosing in the early stages, the slow progression and limited public awareness of the diseases that cause dementia. 62% of people feel that a diagnosis of dementia means that their life is over and 56% of people put off seeking a diagnosis for up to a year or more.

Treatment

There's no drug to cure, prevent or slow down dementia yet, but it's often possible to relieve some symptoms. However, medicines have been developed for Alzheimer's disease that can temporarily alleviate symptoms, or slow down the progression of symptoms in some people. Drug treatment for Alzheimer's disease is important, but the benefits are small, and drugs should only be one part of a person's overall care. There are two types of medication used to treat Alzheimer's disease, which work in different ways.

For more information please visit

alzheimers.org.uk/about-dementia/treatments/drugs

25% 

It has been estimated that 1/4 of beds in hospital are occupied by people living with dementia.

Acetylcholinesterase inhibitors (or 'cholinesterase' inhibitors)

The generic names for the cholinesterase inhibitors are donepezil, rivastigmine and galantamine:

- Donepezil was originally patented as the brand name Aricept, but is more widely available now as just generic donepezil.
- Rivastigmine was patented as Exelon and is now also available as other brands, as well as generic rivastigmine.
- Galantamine was patented as Reminyl and is now also available as generic galantamine and the brands Reminyl XL, Acumor XL, Galsya XL and Gatalin XL.

NMDA receptor antagonists

The NMDA receptor antagonist is memantine. It was originally patented as Ebixa and is now also available as generic memantine.

Other UK brand names for memantine include Maruxa and Nemdatine.

Research

- There is no cure for Alzheimer's disease or any other type of dementia. Delaying the onset of dementia by five years would halve the number of deaths from the condition, saving 30,000 lives a year.
- Dementia research is desperately underfunded. For every person living with dementia, the annual cost to the UK economy is over £30,000 and yet only £90 is spent on dementia research each year.
- There are not enough researchers and clinicians joining the fight against dementia. Five times fewer researchers choose to work on dementia than on cancer.
- Alzheimer's Society is committed to spending at least £150 million over the next decade on dementia research to improve care for people today and find a cure for tomorrow. This includes £50 million to develop the UK's first dedicated Dementia Research Institute.
- Developing a new drug is expensive and takes a number of years, the complexity of the disease and the size of clinical trials will have an impact on both.
- If the onset of dementia could be delayed by 2 years, the savings would be £12.9bn a year by 2050.



For information on diagnosis and prevalence please visit **Public Health England Fingertips tool**.

For more information see [alzheimers.org.uk/about-us/news-and-media/facts-media](https://www.alzheimers.org.uk/about-us/news-and-media/facts-media).

Negative public perceptions

In May 2018 we asked over 2000 members of the general public about their perceptions of dementia. We found that:

68%

thought that people with dementia can be unpredictable

60%

thought that people with dementia should not be allowed to drive

56%

thought that people with dementia experience discrimination

50%

did not think people with dementia can go on holiday on their own

47%

thought that people with dementia should not be left alone

39%

thought that people with dementia need constant supervision

29%

did not think that people with dementia could live on their own

25%

thought that people with dementia are likely to be violent

19%

did not think people with dementia can continue working

In Alzheimer's Society's largest ever consultation with people with dementia (published May 2017), many of the conversations we had underscored the belief that stigma prevails and that other people do not understand dementia – or even know how to talk to someone living with it. After speaking to carers, the public and people living with dementia in our Turning up the Volume report, we found that:

79%

of the public thought that curing dementia will benefit society as a whole, not just those affected

65%

of carers did not think that there is enough support available for those who care for people with dementia

63%

of the public agree they worry that they or a loved one will develop dementia

56%

of the public thought that if they had dementia, they would feel my life is over

27%

of carers of someone living with dementia feel cut off from society

48%

of the public worry about becoming a burden



49%

of the public thought that people with dementia inevitably experience worse care and support than people with other long term conditions (such as cancer or heart disease)



Appendix 2: Code of practices, standards and rules for the industry

There are a series of code of practices, standards and rules that regulate different parts of the sector. These are the following which either cover people living with or supporting someone with dementia, or are the closest to best practice that we feel useful to highlight. Dementia is defined as a disability under the Equality Act 2010 and so any reference to disability in the below automatically covers dementia.



Press Complaints Commission code of practice

When dealing with a topic already entrenched with stigma and misunderstanding, fair and accurate journalism is essential.

The Press Complaints Commission code of practice states that:

1. The press must avoid prejudicial or pejorative reference to an individual's race, colour, religion, gender, sexual orientation or to any physical or mental illness or disability.
2. Details of an individual's race, colour, religion, sexual orientation, physical or mental illness or disability must be avoided unless genuinely relevant to the story.

National Union of Journalists Code of Ethics

A journalist:

1. At all times upholds and defends the principle of media freedom, the right of freedom of expression and the right of the public to be informed.
2. Strives to ensure that information disseminated is honestly conveyed, accurate and fair.
3. Does her/his utmost to correct harmful inaccuracies.
4. Differentiates between fact and opinion.
5. Obtains material by honest, straightforward and open means, with the exception of investigations that are both overwhelmingly in the public interest and which involve evidence that cannot be obtained by straightforward means.
6. Does nothing to intrude into anybody's private life, grief or distress unless justified by overriding consideration of the public interest.
7. Protects the identity of sources who supply information in confidence and material gathered in the course of her/his work.
9. Produces no material likely to lead to hatred or discrimination on the grounds of a person's age, gender, race, colour, creed, legal status, disability, marital status, or sexual orientation.

IMPRESS Standards Code

1. Accuracy

- 1.1. Publishers must take all reasonable steps to ensure accuracy.
- 1.2. Publishers must correct any significant inaccuracy with due prominence, which should normally be equal prominence, at the earliest opportunity.
- 1.3. Publishers must always distinguish clearly between statements of fact, conjecture and opinion.
- 1.4. Whilst free to be partisan, publishers must not misrepresent or distort the facts.

4. Discrimination

- 4.1. Publishers must not make prejudicial or pejorative reference to a person on the basis of that person's age, disability, mental health, gender reassignment or identity, marital or civil partnership status, pregnancy, race, religion, sex or sexual orientation or another characteristic that makes that person vulnerable to discrimination.
- 4.2. Publishers must not refer to a person's disability, mental health, gender reassignment or identity, pregnancy, race, religion or sexual orientation unless this characteristic is relevant to the story.

7. Privacy

- 7.1 Except where justified by the public interest, publishers must respect people's reasonable expectation of privacy. Such an expectation may be determined by factors that include, but are not limited to, the following:
 - a) The nature of the information concerned, such as whether it relates to intimate, family, health or medical matters or personal finances;
 - b) The nature of the publication, such as whether it is a newspaper, magazine, website or other publication;
 - c) The nature of the information, such as whether it is of a confidential or sensitive nature;
 - d) The relevant attributes of the person, such as their age, occupation or public profile; and
 - e) Whether the person had voluntarily courted publicity on a relevant aspect of their private life.
- 7.2 Except where justified by the public interest, publishers must:
 - a) Take all reasonable steps to ensure that the information is accurate and that it is not misleading;
 - b) Take all reasonable steps to ensure that the information is not defamatory;
 - c) Take all reasonable steps not to exacerbate grief or distress through intrusive newsgathering or reporting.

Independent Press Standards Organisation's Editors' Code – Clause 5: Intrusion into grief or shock

- i) In cases involving personal grief or shock, enquiries and approaches must be made with sympathy and discretion and publication handled sensitively. This should not restrict the right to report legal proceedings, such as inquests.

Ofcom Rule 1.28 to 1.29 The involvement of people under eighteen in programmes

If a person aged under-eighteen appears in, or participates in any respect in a programme, the broadcaster must ensure that it complies with Rules 1.28 and 1.29. Broadcasters should take due care to protect any participants aged under-eighteen. The level of care required will depend on all of the relevant circumstances, including the nature of the appearance and level of participation of each under-eighteen. This applies whether the material is originally produced or is acquired from another source. Consideration of the child's welfare should be at the heart of the production.

Rule 1.28

“Due care must be taken over the physical and emotional welfare and the dignity of people under eighteen who take part or are otherwise involved in programmes. This is irrespective of any consent given by the participant or by a parent, guardian or other person over the age of eighteen in loco parentis.”

Rule 1.29

“People under eighteen must not be caused unnecessary distress or anxiety by their involvement in programmes or by the broadcast of those programmes.”

Advertising Standards Authority, UK Code of Non-broadcast Advertising and Direct & Promotional Marketing

- 4.1 Marketing communications must not contain anything that is likely to cause serious or widespread offence. Particular care must be taken to avoid causing offence on the grounds of race, religion, gender, sexual orientation, disability or age. Compliance will be judged on the context, medium, audience, product and prevailing standards.

Marketing communications may be distasteful without necessarily breaching this rule. Marketers are urged to consider public sensitivities before using potentially offensive material.



Appendix 3: Evidence review: Why does the portrayal of dementia in popular discourse matter?

We conducted a review of how dementia is covered in print, broadcast, comedy and the arts.

We conducted a review of how dementia is covered in the media, arts and popular culture. We know that what is portrayed in media and entertainment usually mirrors what people currently think, which is then reflected back and further perpetuated. We have found previously common medical language like ‘senile decay’ with its negative connotations has declined, but other key stereotypes persist. Through talking to people with dementia, the industry and reviewing coverage we made the following observations and themes that frame how dementia is portrayed.

Focusing on the dementia not the person

Dementia doesn't define a person – the dialogue around the condition needs to change to reflect that.

- After discovery of someone's dementia, they are sometimes reported about in the past tense, for example, recent coverage of Barbara Windsor.
- Obituaries devaluing accomplishments through comments such as ‘brilliance dimmed by disease’ and ‘philosopher and novelist who fell from flights of genius to watching *The Teletubbies*’ (Iris Murdoch).
- The voice of the affected is usually heard through others, partners or family members.

Reinforcing negative stereotypes and stigma

- Dementia retains a certain stigma – particularly among certain ethnic groups and demographics. It is still the case that when people think of dementia they picture a frail, elderly person sitting in a care home who can't remember their children and can no longer really function. Many don't see, or realise, that people can live with dementia for a number of years and, with the right support, can retain their independence and continue to engage with society.
- These narrow views of dementia are captured in a recent article in a mainstream magazine, where the journalist argued in favour of euthanizing those with dementia ‘whose advanced senility means they can bring neither happiness nor usefulness, even to themselves.’

- Meanwhile, a progressive motion by the Royal College of Nursing to support practising nurses that have been diagnosed with dementia to continue working in the early stages of the condition was widely met with horror, with one patient body labelling it ‘frightening and extraordinary.’
- Media can transmit stereotypes regarding dementia with individuals always being portrayed ‘victims’ of the condition. Challenging outlets, industries and businesses is important, but often these can be scaremongering. Negative stories make news and it is right that the media highlight problems, but an impression can be left that there are no services or support for people with dementia, or that all services are failing, which demonises caring, committed staff and can create fear for people living with and families affected by dementia.
- Often language used is sensationalist reinforces the view that you cannot live well with dementia and there is little hope. In the media and public discourse people living with the condition are routinely labelled in passive terms, being victims, sufferers, recipients of care or succumbing to dementia. Offensive terms such as ‘senile’ and ‘demented’ are yet to have completely faded from common use. Dementia is often reported in catastrophic terms such as ‘misery’, ‘tsunami’, ‘worse than death’, ‘ticking time bomb’, ‘a slow death’, ‘mind-robbing’. This creates fear and anxiety.

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‘Include me in the conversation. Talk to me, not my partner. I'm still here and I have a voice that needs to be heard.’

Dementia victims to have drugs rationed



Stigmatising images

Images used are often not reflective of the people living with dementia. Primarily these are despondent white older women in a care home or people with their head in their hands.

Inaccurate or sensationalist accounts

- Dementia is often portrayed as just memory loss or as a joke to infer when someone is getting older. This is shown in characters including Pete's mother in Gavin and Stacey, Abe from The Simpsons and in American sitcom Raising Hope. The latter came under fire for being 'not funny, but insensitive and cruel', with the character affected often the butt of the show's jokes; she rarely has any lucid moments, mistakes her grandson for her late husband, and forgets to put a shirt on.
- Caring for people affected by dementia being portrayed as simple and fun which doesn't reflect experiences of carers. American sitcom Raising Hope doesn't reflect the huge effort required when caring of patience, understanding and strength.
- Comparatively a narrow focus on hopeless narratives, lack of support and scaremongering with the media feeding off public anxiety about dementia. From the condition being talked about as 'a misery' or 'hopeless'; to people with dementia being used, taken advantage or controlled for example in Mad Men Pete Campbell exploiting his mother's dementia to control her and then her being scammed and murdered by her carer.
- Dementia predominantly portrayed as affecting only white middle class women which can make it difficult for men or BAME groups affected to identify. Reinforced through well-known and high profile TV and film coverage including: Still Alice, The Notebook, Grey's Anatomy, The Iron Lady and Iris.
- Accounts of dementia being romanticised, inaccurate or unrealistic including 'happy endings' where dementia is not progressive, can be reversed through reminiscence like in the Notebook which can create frustration by people affected by dementia due to their very different experiences of the condition.
- Reporting of avoidance tactics or cures which are not scientifically based, such as telling people to complete a crossword a day to stave off dementia. This can create a feeling of self-blame.

It is still considered fair game for dementia to be the butt of jokes in a way that would be unacceptable for other diseases such as cancer.

From the discourse of 'oh I've lost my keys I must have dementia', to it being used to explain unusual behaviour.

- Using dementia as a humorous headline, for example, 'Older man with dementia spends 13 hours walking the dog.'
- Keeping Mum was seen as trivialising dementia for comedic purposes focusing somewhat indolently upon dementia as a vehicle for the humour of discomfort.
- Have I Got News For You? joke comparing Theresa May's repetition is due to her having dementia.
- Media reporting Trump as having dementia, being childlike, comparisons to Ronald Regan.

“

“The portrayal of dementia in the media is totally wrong – we're not lunatics and we still have a life to lead’.

“

‘It can panic people and making them less inclined to get a diagnosis because they think it's all doom and gloom.’

Useful resources and organisations

The following organisations can offer guidance or resources for someone living with dementia, or who cares for someone with dementia, towards sources of specialist support and advice

General resources

Alzheimer's Society Media team

press@alzheimers.org.uk

dementiainthedia@alzheimers.org.uk

National media

To contact the national media team please call **08450 744 395** or email press@alzheimers.org.uk

If you are a journalist with an urgent, national media, out of hours inquiry please call **07802 688 774**

Regional media

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

If you are a journalist with an urgent, regional media, out of hours inquiry please call **0117 965 8093** or email regionalpress@alzheimers.org.uk

Alzheimer's Society publications

alzheimers.org.uk/publications

Publications order line: 0300 303 5933

Alzheimer's Society publications provide information about all aspects of dementia.

Dementia Connect Online Directory

alzheimers.org.uk/dementiaconnect

Alzheimer's Society online dementia services directory for anyone affected by dementia in England, Wales or Northern Ireland. Find support in your local area.

National Dementia Helpline

alzheimers.org.uk/helpline

0300 222 1122

For information, support or advice about dementia call our helpline. Please see the website for up to date opening hours.

Talking Point Online Community

alzheimers.org.uk/talkingpoint

Talking Point is a support and discussion forum for anyone affected by dementia.

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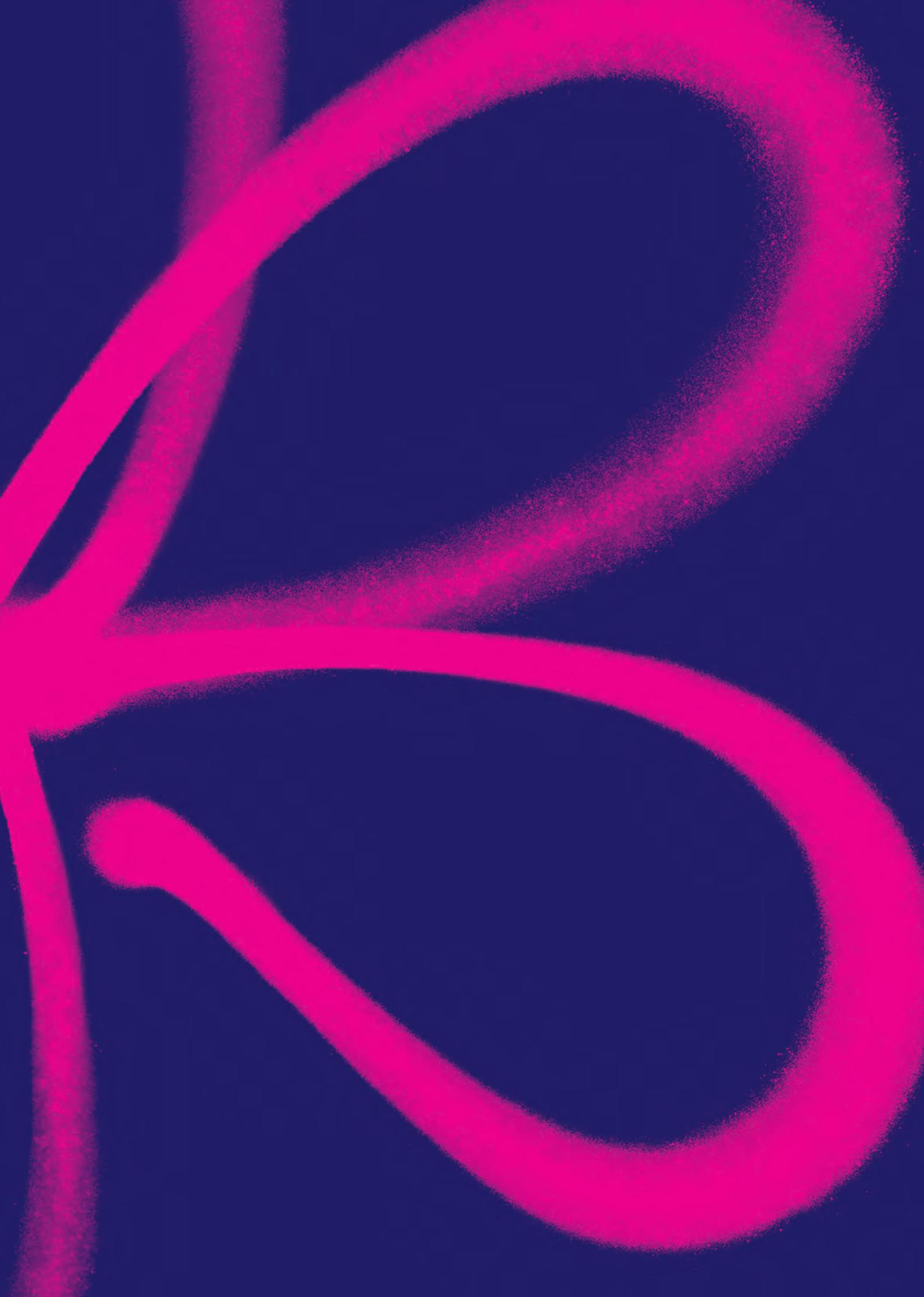
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**Alzheimer's Society is the UK's leading dementia charity.
We provide information and support, improve care, fund research,
and create lasting change for people affected by dementia.**

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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