Representing dementia:

Insights from people affected by dementia.

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Illustrations by Josh Mallalieu

Acknowledgements

This summary document of my doctoral research is dedicated to my participants. Thank you for making this project possible through generously sharing your time and insights - I hope that my work can go some way to doing your perspectives justice.

Josh Mallalieu is the talented artist responsible for all of the illustrations you see in this document. You can see more of Josh’s wonderful work on his website, https://www.joshmallalieuartdesign.com/.

Contents

Introduction

Dementia is increasingly recognised as a public health priority since it is a major cause of disability, lacks an effective cure and requires much greater overall awareness and support.[1] Dementia is often reported to be the most feared condition in the UK, and the stigma that surrounds it has many harmful consequences, especially for people affected by dementia, who often report being socially excluded, ignored and devalued, which in turn affects people's confidence, health and wellbeing, Indeed, Kate Swaffer, who has young onset dementia, argues that '**the ugliest part of having dementia is probably the reaction of others**'.[2]

What is dementia?

Dementia is an umbrella term for a range of conditions that affect the brain, including Alzheimer's disease, vascular dementia, frontotemporal dementia and mixed dementia.

A person may experience changes to their memory, thinking, orientation, calculation, language, judgement, social behaviour and/or motivation. While age is the biggest risk factor, dementia is not an inevitable part of ageing and people of any age can develop dementia.

How society represents dementia is therefore very important. Combined, the types of images, stories and language that are popularly used (for example, in the news) offer us a kind of 'cognitive window' through which we can see people and events.[3] The window will inevitably emphasise some aspects of an issue and ignore others, just as any window focuses our attention on what we can see of a wider view.

Research suggests that depictions of dementia can be broadly divided into two camps: showing dementia as a *tragedy* versus focusing on the positives of *living well* with dementia. These both foreground extremes, which can cause problems for people affected by dementia by failing to accurately depict life with the condition.

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[1] World Health Organization (2017). *Global action plan on the public health response to dementia 2017-2025*. Geneva: World Health Organization. Available at: https://www.who.int/publications/i/item/9789241513487

[2] K. Swaffer (2016) *What the hell happened to my brain?: Living Beyond Dementia*. London: Jessica Kingsley Publishers, p.66.

[3] Z. Pan and G. Kosicki (1993) 'Framing analysis: An approach to news discourse', *Political Communication*, 10(1): pp.55–75, p.58.

Currently, the voices of people with dementia are largely absent from mainstream media. Yet, research is increasingly recognising the need to listen to the insights of people who are **experts through experience** – here, I mean people with dementia, carers and close family/friends. Such individuals can give more nuanced accounts and reflect on, challenge and develop existing portrayals to better convey the complexity and diversity of life with dementia.

> "Everybody's got a different story to tell"
>
> - *Family carer of someone with dementia*

The project

This study conducts interviews and focus groups to explore the perspectives of **51 people** who are affected by dementia, either by having a diagnosis or being a carer or loved one of someone who does. I ran 8 focus groups and 7 interviews in and around Nottinghamshire between October 2019 and March 2020, with:

- **17** people with a dementia diagnosis
- **1** person with a mild cognitive impairment that she regarded as pre-dementia
- **33** participants without dementia, who identified as carers and/or family/friends

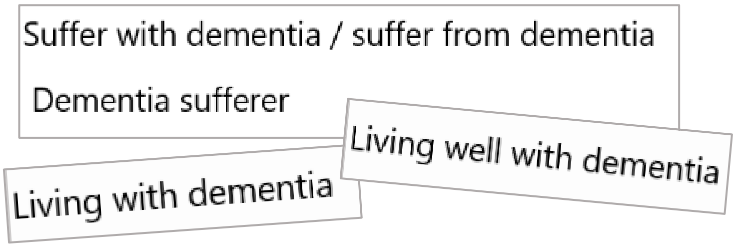
Participants were aged 21 to 87 (mean age: 64.3). People were predominately White British, with 22 men and 29 women taking part. Conversations most often featured Alzheimer's disease, vascular dementia and young onset (working age) dementia. Time since diagnosis ranged from less than a year to over 8 years.

In our sessions, participants discussed their experiences and understandings of dementia. They also directly responded to images, phrases and headlines that were drawn from newspapers, charities, stock image banks and research. Below are some examples of items that were used, which will be discussed further under the section 'Representing dementia':

Image: Shutterstock

Will you advance research to beat the UK's biggest killer?

Image: Photo taken by the author of an Alzheimer's Society envelope received in the post



Suffer with dementia / suffer from dementia

Dementia sufferer

Living well with dementia

Living with dementia

Key questions

This project is interested in how people affected by dementia represent dementia and relate to popular representations. I ask, **how do participants with experience of dementia:**

- **represent** the condition and people affected?
- **respond** to language and imagery used to portray dementia?
- **reflect and/or challenge** popular representations of dementia?

Analysis

My approach to analysis is called thematic multimodal critical discourse analysis. I carefully read (and re-read, then re-read again) approximately 143,500 words from the interviews and focus groups, looking for **patterns across the data** (*thematic*) and for **how participants talk about certain topics and people** (*discourse analysis*). I am interested in multiple modes of communication, namely images and words (*multimodal*), and in challenging, rather than accepting, the status quo (*critical*).

With such a rich range of stories, perspectives and representations, I can only present some of these for you across the next few pages. Findings are divided into four sections: 1) Diversity and nuance, 2) Dementia in society, 3) Representing dementia, and 4) Recommendations.

We are finding "ideas and questions [..] and answers to questions that Emma would never have thought of"

- *Friend of someone with dementia*

Diversity and nuance

Consistently, participants emphasise the **diversity** of dementia and the people who experience the condition. People call for **more nuanced accounts** of what it means to have dementia, including regarding types, effects and experiences.

Types of dementia

Dementia is far more diverse than its most common type, Alzheimer's disease. Indeed, dementia is an **umbrella term** for a range of different conditions, leading a professional carer to argue that it's plural, '**dementias**', may be more apt.

Effects of dementia

Although dementia affects aspects of a person's memory, it is much more complex than that.

- **Only some of a person's memory is affected, and this can be fluid.** One group explain this by comparing memory to bookshelves. Sometimes the right books (memories) are on the shelf and at other times they have been taken off or misplaced.
- **Dementia is far more than memory loss.** Having dementia can impact a range of abilities, including driving, walking, eating, communicating and doing DIY.

People with dementia

One person with dementia calls it a '**lottery**', as anyone can develop the condition, regardless of age, lifestyle and social status.

Participants with dementia tend to acknowledge the dementia as part of their identity but **resist being defined by it**. People talk about being physicists, authors and activists, and the group showcases a rich array of personalities, lives and approaches to dementia, which needs to be recognised more broadly.

A person's experience of dementia

Dementia (and how society treats people with dementia) poses a significant threat to individuals' lives and identities. **People must navigate changes** in not only their abilities but their relationships, social identity and sense of past, present and future self.

One participant with mild Alzheimer's disease, who previously cared for her husband when he had vascular dementia, is particularly self-reflective about some of her future fears: "I worry about myself, at times, I try to put it in the back of my mind. What is to become of me? What will I be like? *[Pause.]* Would I become violent, and have to be taken away?" For this individual, her relationships with her family and God bring especial comfort and confidence moving forward: "I just have to trust".

Of course, experiencing dementia may not always be negative, with one person declaring that 'I've cheered up [laughing] since having the dementia'. Throughout, participants demonstrate that having dementia entails more than loss; people experiencing dementia **learn and grow** as individuals, including through taking up advocacy work, starting new hobbies and forming or adapting (and sometimes strengthening) relationships.

Life with dementia is thus, as with any life, exceptionally **nuanced**. A professional carer compares dementia to a tree to emphasise its plurality, with many subtypes and ways of experiencing the condition. **Like a tree**, life with dementia branches off into many aspects and experiences; for instance, as well as "the sad side", "there can be moments of, great humour".

Dementia in society

Cure versus care?

> "I know there's this conflict, isn't there, that's going off. About whether the money should be going into **support** or whether it should be going into, **research**. […] I mean it's got to be a bit of both really, hasn't it. It's just **where do you put the balancing line on it all?**"
> *- Family carer of someone with dementia*

The hope of a **cure** is important to many people affected by dementia, but, as one family carer puts it, "we just cope everyday with what we're faced with", rather than overly relying on an imminent cure. This makes issues regarding how to **improve support** more relevant for most participants…

Accessing support

Participants have **mixed reports** of official sources of support. For example, doctors and hospitals can provide valuable information, medication and care, but this is **inconsistent** depending on who and where you are, and what type of dementia you have. One participant with dementia reports that when she had hip surgery, the staff "**didn't know enough about dementia**" and therefore just assumed that she would be like another recent patient with dementia, despite them being entirely different people, with their own individual needs.

Peer support

For the majority of participants, being with peers who are also affected by dementia is exceptionally important. In spaces such as Memory Cafés, choirs and support groups, people can share their experiences, and learn from and support each other.

A lot of people talk about becoming **brighter** in groups where carers and people with dementia can enjoy the company of others, take part in different activities and feel **accepted**.

Participants consistently talk about the mutual **understanding** that is gained through shared **experience** with dementia. This is set against the lack of understanding of other people that participants interact with, including friends, family, neighbours and medical professionals who have not themselves had much personal contact with dementia. Helping to **bridge this gap** through recognising the expertise of people affected with dementia should improve support in society more broadly. Some of these issues are explored next…

> "**We understand each other** which, most of the time is a bigger help than the specialists"
> *- Carer of someone with dementia*

> "Unless you've had it, you can't talk the language. It's like any disease, experience gives you an insight."
>
> *- Person with dementia*

Wider society: what needs to change?

1. Tackle discrimination

Participants consistently show that people with dementia are **side-lined** and written off by people in society, while carers are also **undervalued** and **under-supported**.

Having dementia doesn't exist in a vacuum. Amongst other things, people may experience sexism, racism and/or ageism. **Ageism** is a particularly normalised form of discrimination in the UK (e.g., think of all the times that older people are referred to as a burden). Ageism has serious **consequences**. These include:

- experiencing discrimination (at work or elsewhere),
- internalising a fear and disgust of the ageing process, which can damage wellbeing and health.

Such consequences relate to a tendency to see ageing in terms of **decline only**, with older people being

> "very often, people who are, older in age have got a lot to talk about, a lot of memories, **a lot of expertise that gets lost** because we've become [pause] not part of society so easily, it's, that we're sort of **side-lined**"
> *- Person with dementia*

Question:

What words and images do you associate with older age?

How do you feel about this?

characterised as frail, vulnerable and dependent.[4] Older people who have dementia therefore face double the **social stigma** of being older *and* having dementia, both of which can result in being "side-lined" by society.

2. Challenge stereotypes

The stereotypes of older people are also applied to people with dementia (i.e., being frail, vulnerable and dependent). Indeed, the **stereotypical person with dementia** is an older person. This causes problems for everyone who does not fit this stereotype. As one carer puts it, your **personal "reality"** does not fit in with other people's **"preconception"** of what dementia means. This discrepancy creates many moments of tension in the everyday lives of people affected by dementia.

> "There was I in the lane that was especially for the Alzheimer's and [...]
>
> She said erm, 'well, I'm sorry, but you can't go there. That's for the dementia group.'
>
> And I said, 'how do you tell?'"
>
> *- Person with young-onset dementia*

A similar tension is true for all stereotypes, for example, that having dementia means experiencing the most common subtype, **Alzheimer's disease**. One carer describes her steep learning curve when her mother had vascular dementia. Initially, they expected a fairly linear progression like Alzheimer's disease, before they came to realise how different these two types are.

These are two of many examples amongst participants of how stereotypes can be harmful. Stereotypes misinform, restrict and exclude – and must therefore be challenged to facilitate better support for people experiencing dementia.

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[4] Centre for Ageing Better (2020). *An old age problem? How society shapes and reinforces negative attitudes to ageing.* Available at: https://ageing-better.org.uk/publications/old-age-problem-how-society-shapes-and-reinforces-negative-attitudes-ageing.

3. See the whole person

As well as challenging narrow stereotypes and tackling other forms of discrimination, to better support people with dementia as a society, **we need to expand our ideas of what it means to be a person**.

Question:

How would you explain what it means to be a person?

What characteristics are the most valued in our society?

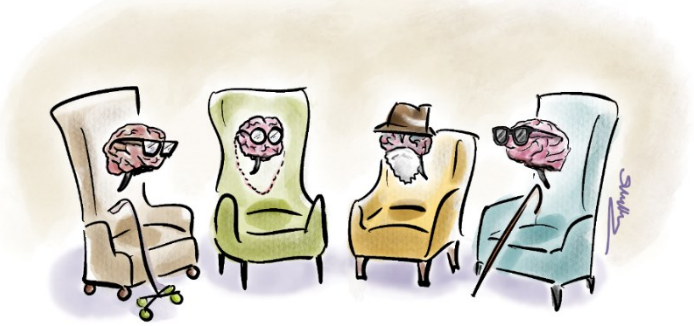
I don't need to tell you that people are complex. We have our own free will and moral code. We navigate an incredible range of emotions and experiences. We all have diverse personalities, relationships, talents and ways of expressing ourselves. The list goes on...

But we live in a society where certain qualities are deemed to be more important than others. Our society has been called **'hypercognitive'** because it is hyper-focused on cognitive qualities like **rational thinking, independence, self-control and economic productivity**.[5] Think, for instance, of how much more you might earn working in finance than in a caring profession.

This hypercognitive focus is dangerously narrow, as it ignores other important aspects of being a person, including **emotions, desire, relationships and creativity**. This makes it a very exclusionary value system, which further discriminates against people with dementia. Notably, when a participant with dementia mourns the "loss to what I was", it's as a "competent, efficient" and "fairly high powered" nurse. This ignores the same person's continuing kindness, gardening talents, desire to write stories and close relationships with family and friends at the time of talking with me.

> "You don't go into a care home and just see brains, sort of, floating there [laughter]. You see people."
>
> - *Professional carer*

We need to see the **bigger picture** of what it means to be a person. We need to value our interconnectedness, emotional experiences and non-verbal expressions of who we are and how we feel. This will help all of us better embrace our full humanity.



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[5] Stephen Post (2000). 'The Concept of Alzheimer Disease in a Hypercognitive Society', in P.J. Whitehouse, K. Maurer, and J.F. Ballenger (eds). *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*. Baltimore: Johns Hopkins University Press.

Representing dementia

How do we represent such a diverse condition? There are many useful **communication guidelines** that have been produced by non-profit and advocacy organisations, such as the Alzheimer's Society and the Dementia Engagement and Empowerment Project (DEEP):

DEEP Guide

deep
The Dementia Engagement and Empowerment Project

Dementia words matter: Guidelines on language about dementia

Key messages
- This guidance is for journalists, organisations and communications departments.
- The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.
- People with dementia prefer words and descriptions that are accurate, balanced and respectful.

Dementia is discussed more regularly now in the media - both on television and in newspapers and magazines. The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. People with dementia prefer words and descriptions that are accurate, balanced and respectful.

These recommendations are written by 20 people with dementia who came together for a day in Liverpool to discuss the words that are used about dementia.

Positive language
An Alzheimer's Society guide to talking about dementia

April 2018
alzheimers.org.uk

Alzheimer's Society
United Against Dementia

Dementia-friendly media and broadcast guide

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

Alzheimer's Society
United Against Dementia

This project builds on existing guidelines in two key ways:

1. **It focuses more on individual voices and differences**. Guidelines emphasise that you should "find out how the person identifies themselves"[6] but generally don't have the space for exploring some of these differences.
2. **This project examines images in much more detail.** Guidelines usually focus on words, yet images carry a lot of ideological weight, as reflected by the phrase, 'a picture says a thousand words'.

I will explore some of these individual uses of language and images in this section, in the hope of adding something new to the collection of communication guidance.

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[6] DEEP (2014) *Dementia words matter: Guidelines on language about dementia*. The Dementia Engagement and Empowerment Project, p.3. Available at: https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf. (First front cover)

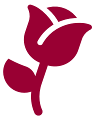
Also see:
Alzheimer's Society (2018) *Positive language: An Alzheimer's Society guide to talking about dementia*. London: Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf (Second front cover)

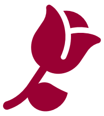
Emma Bould (2018) *Dementia-friendly media and broadcast guide: A guide to representing dementia in the arts, culture and popular discourse*. London: Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/2018-09/Dementia%20Friendly%20Media%20and%20Broadcast%20Guide.pdf (Third front cover)

Language choices are personal

Questions:
How would you describe your life?
Is your life a journey, and if so, what does this mean to you?
Would you consider yourself to battle your obstacles?
What role has suffering played in your life and identity?
Finally, what does it mean to live life 'well', and is it useful or detrimental to measure life in such a way?

Some people suggest that the words we use don't matter. One person with dementia quotes Shakespeare's famous line from *Romeo and Juliet*: "A rose by any other name would smell as sweet" to argue this. Yet the same individual tells me that it hurts to hear people with dementia called "loony". This supports that it actually *is* important to consider the language we use. To adapt the common phrase, sticks and stone may break your bones, but words can hurt you too.





Suffering and living well

Overall, participants seem to agree that:

- It's important to be able to discuss the **suffering** **(verb)** that people experience *without* reducing people with dementia themselves to only being '**sufferers**' **(noun)**. As one carer tells me, "People with dementia are not sufferers, they have dementia, they are a person."
- Many participants, especially those with dementia, appreciate language around '**living well with dementia**', as it "gives you help, and hope" as it "conveys to you [that] you can still do things, you can keep your life going".
- Against this, other participants (notably carers and other people without dementia) criticise 'living well' for providing unrealistic expectations and suggesting that you are "failing" if you are "at screaming point"...
- Overall, '**living with dementia**' appears more neutral, as it can encompass both 'suffering' and 'living well'.

'With' versus 'have'

In one focus group, participants additionally point out that for them, saying that someone is 'living **with** dementia' suggests that dementia is a **companion** that you must cope with, much like being in a couple ("oh here comes Bridget and her dementia") or having "a little gremlin on [your] shoulder".

In contrast, saying that you '**have** dementia' makes dementia something that you **possess**. Here, it is a part of you, rather than a "burden" you must bear.

Question:
'With' or 'have', what do you think?

Using metaphors

Both life and dementia are complex and therefore are very difficult to put into words. To help, many participants use metaphors, which are very powerful resources when it comes to representing dementia. We'll explore some of the metaphors used in the next few pages…

What is metaphor?
It's hard to go a day without using metaphor, which means explaining something (like life) by discussing it in terms of something else (like a book or journey). We use metaphors all the time. "Take a leaf out of her book!" "This year, I'm starting a new chapter!"

Battling dementia

First up are **battle metaphors**, which are popularly used for dementia in wider society (consider the many newspaper headlines that say something like: 'NEW BREAKTHROUGH IN BATTLE AGAINST DEMENTIA'). In a nutshell, battle metaphors tend to pitch humans against dementia, as if it is an enemy to fight and beat.

Some participants use this kind of metaphor to **express frustration at the harm that dementia does**, much like an enemy. One carer calls dementia "evil" for entrapping his wife. Elsewhere, a participant with dementia talks of his adversary "Mr Alzheimer's", who "has a lot to answer for", since his dementia stops him from doing so many things he wants to do, such as driving and DIY.

Another person with dementia has a running joke with his vicar about calling his dementia **"the alien"**. This is inspired by a *Star Trek* episode where an alien takes over a crew member. The participant tells me that this is similar to dementia as sometimes "you want to do something […] but you can't". His dementia is therefore described as an alien invader that he's now just "got to work with". Every Sunday, his vicar jokingly asks "how's the alien?", similarly to how you'd ask "how's the missus?"

(Mr Alzheimer's, the alien and the gremlin cause trouble when dementia makes finding your keys harder)

Generally, participants suggest that “you’re not gonna beat it but yeah you can fight it”. Even if a complete victory is currently out of reach, it can be empowering to focus on individual battles, such as day-to-day struggles and small victories, alongside a more collective fight “for the cure” and “to help the people until they get the cure”. Relatedly, something that people *can* successfully work to change is society’s treatment of people affected by dementia. For instance, people discuss their role in fighting stigma or the misbelief that dementia only affects older people, in order to improve people’s experiences.

Sometimes, participants resist battle-oriented language and suggest that other word choices might be better, such as working to “overcome” obstacles or “learn how to survive” or “cope” with dementia. **Coping, overcoming and surviving** are united by the act of prevailing in the face of adversity and can be said to focus more on the person’s experience than on violence or enemies.

Life with dementia is a journey

Some people instead find the metaphor of a journey useful. As your dementia progresses, you are seen as moving “further along” and “deeper into the journey”.

A few people with dementia commend the journey metaphor for being more nuanced, since “a journey means it can be good or bad”. A journey has many routes and destinations, contrasting the win, lose or draw outcomes of a fight. Of course, since all life must ultimately end with death, “You’re only going to go in one way. But you’re not going to go in one way, in a straight line”. In other words, although every life eventually ends with death, we each get to choose the journey we embark on to get there, and the experiences that we have, which is what we should focus on.

Showing dementia in images

It’s also important to consider how we visually represent people with dementia, and dementia as a condition. This project shows that how we interpret images depends on our personal histories and worldviews, as well as what the image itself is showing. There are, however, some things to look out for, and this project is inspired by the work of Gunther Kress and Theo van Leeuwen - many of the features I’ll be pointing out are in their (2006) book, *Reading Images: The Grammar of Visual Design.*[7]

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[7] Gunther Kress and Theo van Leeuwen (2006) *Reading Images: The Grammar of Visual Design*. Second edition. Oxon: Routledge.

Losing pieces of the puzzle

Often, people with dementia are shown as **disengaged, isolated and incomplete**. The below picture uses a visual form of metaphor, where a person is a jigsaw and a person with dementia has a missing piece.

Building on the analysis of Kevin Harvey and Gavin Brookes,[8] using lots of images like the one below could be interpreted as suggesting that people with dementia are incomplete, lifeless and not worth engaging with:

Dull colour palette suggests lifelessness…

Image 1: Getty Images

No eye contact: as in real life, this creates a sense of distance between you as the viewer and the woman shown here.

In contrast, eye contact invites you to engage…

Black space in the brain area where the puzzle piece has come out suggests darkness and emptiness within. This reflects fears in our hypercognitive society, where cognitive abilities are most valued.

Indeed, some participants interpret the image as **metaphorically** showing that "**part of me is missing**" as people are "losing functions of the brain". Here, the woman is incomplete, rather than remaining a whole, if changed, person.

Other participants focus on the **woman's face**. One person with dementia focuses on her mood, saying that "she looks how I feel". Meanwhile, another person with dementia highlights the need for "stimulation", telling us of someone who initially looked like this in a care home but whose "face lit up" when they started singing together.

While some participants like this image, other people criticise it as being too "stark", with one person with dementia saying that the woman's "blank" expression "affects me". There are evidently many ways to read this image. What do you think?

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[8] Kevin Harvey and Gavin Brookes (2019) 'Looking Through Dementia: What Do Commercial Stock Images Tell Us About Aging and Cognitive Decline?', *Qualitative Health Research*, 29(7): 987–1003.

Different types of hands

People with dementia are commonly shown using images of hands. This can be problematic as it **depersonalises** the individual represented by reducing them to a body part. As one carer puts it: “just seeing the hands and so close up, in a way it kind of separates it from the whole person for me”.

Questions:
How do you feel about the people shown in the images below? For you, is there any kind of distinction between images 2 and 3?

The hands cause quite a lot of **confusion**, as people aren’t sure what they show. This is likely because so little context is given, something that one person with dementia argues leaves them too “open” to “misinterpretation”.

Overall, participants tend to prefer image 3. Potential reasons for this include:

Image 2: Getty Images

Image 3: Getty Images

- **Camera angle looks down** at the person’s hands as if the viewer is standing above them. This makes it more “victimy”, as generally, someone who is looked down on has less power.
- **Bright lighting** emphasises signs of ageing, which tend to be negatively evaluated (a reflection of ageism).
- **Only shows one person, alone and not doing anything.** This reflects a common trend that passivises people with dementia and associates dementia with “old age and loneliness”.

- **Closer camera angle.** This makes it feel more intimate as it mimics our real-life use of space: generally, we are happy to be physically closer to people we feel close to.
- **Shows two people holding hands**. This is evaluated as “comfy and friendly” as it reminds people of their own relationships and interactions. People highlight the importance of touch for communicating without words, and many see this as a “very human” moment of care.

Brain scans versus trees

Brain scans

Frequently, people with dementia are represented in terms of their brain. The jigsaw image on page 15 is a more subtle example of this, as the puzzle piece is missing from the area where the woman's brain would be.

Image 4: Alamy

Brain scans are a popular means of visualising dementia. However, discussions with participants echo existing criticisms that although brain scans are widely **trusted** icons of scientific knowledge, they remain **inaccessible** to those of us without relevant training. As a result, as members of the public, we are prone to interpreting brain scans as showing 'normal' versus 'diseased' brains. This can reinforce a sense of an **'us' versus 'them'**, which distances people with dementia from the 'us' group.

Trees

As explored with language, metaphor offers us a way to explain complex, intangible concepts using more familiar, everyday ones. For image 5, this involves representing the brain with dementia in the form of deciduous trees losing their leaves as the seasons shift from summer to autumn (and eventually winter). This plays on a common metaphor that the brain and/or its neurons are a tree, for instance, we often talk of a brain or neuron 'forest'.

Image 5: Shutterstock

What do you think of this image?

Many participants praise this image as being the best explanation of dementia. One person with dementia tells me that "I'm going through it myself" and that "looking at this, **it explains what happens to your brain**". The loss of leaves over autumn is said to be very relevant to the loss of brain cells with dementia.

However, other participants criticise this image for only showing dementia as a linear loss. Someone with dementia emphasises that this image **oversimplifies** the experience of dementia, as its progression is "not a straight line" and has many stages. Indeed, he argues that "you could have a forest of those trees". Similarly, other participants ask for leaves to float around the trees to represent the flux of life with dementia, where abilities, memories and moods come and go. Sometimes they "blow away" but at other times they return and "settle down".

Some family members highlight that **a person with dementia "isn't disappearing"** the way that the image suggests. They emphasise that instead, all of our identities are complex and fluid. If in a different mood, or with a different person, we usually behave differently. People with dementia are therefore "still them" and relationships need to be recognised as an important part of a continuing self throughout dementia. Again, people are far more than their brains.

Building on this, one person with dementia interprets image 5 as showing how people "get **eroded**" by their environment. Indeed, there is a lot of evidence that although the abilities and behaviours of people with dementia are often attributed to brain changes, the surrounding social and physical environment has a huge impact. This is important because environments that initially disable people *can* be improved to provide better support.[9]

> "Everybody's dementia's different like everybody's fingerprint is different."
>
> - *Person with dementia*

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[9] Steven R. Sabat (2018) *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. New York: Oxford University Press.

Recommendations

How can we improve representations of dementia moving forward? Here are three key recommendations that have emerged from our discussions:

1. Normalise dementia

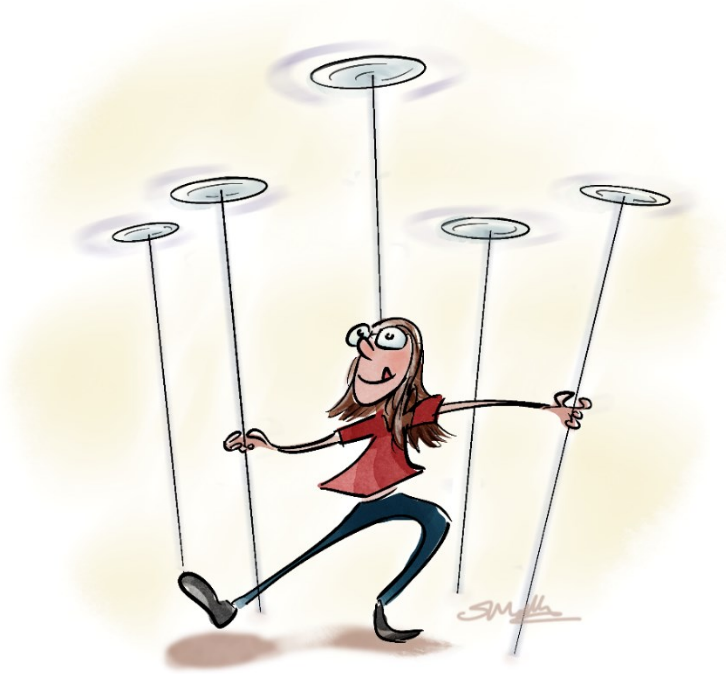
Participants point to the media as having a "powerful role" to play in normalising dementia as part of life. This should help to reduce the fear and stigma currently surrounding it.

People suggest swapping out sensationalist depictions for "more facts" and an overall "truer story" about the day-to-day challenges that people face. The hope is to ground representations in more "familiar" and "personal" spheres. This should help to de-stigmatise having dementia and show that "there is life after the diagnosis".

2. Provide more nuanced representations

a) Show the "diverse face" of people with dementia

In order to normalise dementia, representations of people with dementia also need to become less reductive. Participants ask that representations reflect "the diverse face of dementia", which is too often conflated with one type (Alzheimer's disease), one symptom (memory loss) and one demographic (people over the age of sixty-five).



b) Multi-faceted representations of experiencing dementia

Participants call to balance both the "positives and negatives" of life with dementia, including the "sad side" and "moments of great humour". The experience of dementia must be allowed to be a "multi-headed thing" with many aspects.

> "It is hard to get a balance" between being "all doom and gloom" and "painting it as all roses"
> - *Family member*

c) Move beyond biomedical understandings

Increasing nuance includes expanding how we frame dementia itself, so that it is not simply a biomedical disease, but also a social, relational and structural concern (e.g. "I would really like to see a move away from the clinical, medical, stuff [to the] more personal").

As such, one carer notes the need to highlight that people can have "fun" because of "what is available to them". The importance of opportunities, such as joining exercise groups and choirs, or accessing the local park for a walk, needs to be better considered when discussing dementia, since these can either empower or disempower people with dementia and carers.

3. Better advocacy for people affected by dementia

Above, a person with dementia talks about how being "side-lined" means that "a lot of memories, a lot of expertise [...] gets lost". The recommendation here, then, is to **recognise the expertise of people with dementia and carers/supporters**, who provide an alternative form of "understanding" to more traditional experts, such as doctors or researchers, and can give "insight into how we are actually working, and reacting and talking".

As one person with dementia tells me, "the more we can use the media, the more people realise that we, we are ok and and that we aren't to be feared". It is vital that people with dementia, and carers/supporters are better listened to and recognised as experts through experience, something that is increasingly established in health and research fields but that is yet to reach society more broadly.

The more perspectives that are considered, the more nuanced and comprehensive social understandings of dementia can become. This can better reflect that "everybody's dementia's different like everybody's fingerprint is different", and better support people affected by dementia.

Summary of recommendations:

- First, make dementia more familiar and relatable for people through providing a more **balanced** and **person-oriented** account of life with the condition.
- Second, provide more **nuanced representations** that acknowledge the diversity of subtypes, people and experiences in relation to dementia.
- Third, **value** people with dementia and carers/supporters as being **experts through experience**. As a society, better listen to and share the perspectives, needs and advice of such individuals.

Where next?

If you're interested in finding out more about the topic, below are some alternative sources of images that you may be interested in:

The Centre for Ageing Better is dedicated to challenging ageism and improving national discussions surrounding ageing and disability. They have recently launched a free image library to counterbalance negative stereotypes and encourage more realistic depictions of ageing and living with a disability.

See: [Age-positive image library launched to tackle negative stereotypes of later life | Centre for Ageing Better (ageing-better.org.uk)]()

Cathy Greenblat is a photographer who has worked with people with dementia and their supporters across the world. She specialises in showing and promoting the lives, relationships and experiences of people with dementia, in a bid to challenge tragic, loss-oriented representations and showcase good caring practices. Cathy has done numerous projects, and her website offers a good overview of her work: [https://www.cathygreenblatphotography.com/]()

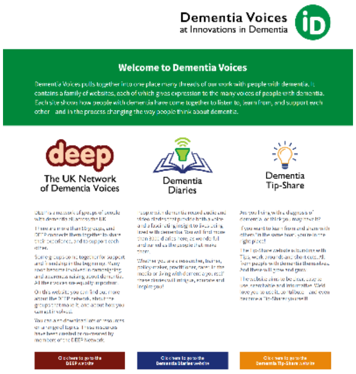
You can also find some other interesting resources and projects, including:

Dementia Voices

Dementia Voices is a family of websites, each of which gives expression to the many voices and activities of people with dementia.

Websites include diaries, tip sharing, creative projects, research and activism.

See: https://dementiavoices-id.org.uk/



Dementia Voices
at Innovations in Dementia

Welcome to Dementia Voices

Dementia Voices pulls together into one place many threads of our work with people with dementia. It contains a family of websites, each of which gives expression to the many voices of people with dementia. Each site shows how people with dementia have come together to listen to, learn from, and support each other – and in the process changing the way people think about dementia.

Talking life podcast

Created Out of Mind present *Talking Life*, a series of podcast conversations led by Susanna Howard with a person, or people, experiencing a dementia. The podcast explores the guests' relationships with everyday topics such as beauty, willpower, self-expression, purpose, connection, and sleep.

See: http://www.createdoutofmind.org/talking-life

CREATED OUT OF MIND

Get in touch:

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