



LEARNING DOMAINS

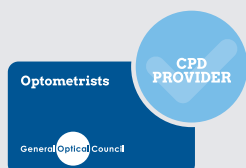


PROFESSIONALISM



COMMUNICATION

PROFESSIONAL GROUPS



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This CPD session is open to all FBDO members and associate member optometrists. Successful completion of this CPD session will provide you with a certificate of completion of one non-interactive CPD point. The multiple-choice questions (MCQs) are available online only from Thursday 1 June 2023. Visit www.abdo.org.uk After member login, scroll down and you will find CPD Online within your personalised dashboard. Six questions will be presented in a random order. Please ensure that your email address and GOC number are up-to-date. The pass mark is 60 per cent.

CPD CODE: C-105474

Dementia Things:

the impact of language used about people with dementia

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Many people have pre-conceived ideas about dementia and, in the author's experience of meeting ABDO members at education events, this also holds true for many dispensing opticians. The aim of this article, therefore, is to question assumptions about dementia, and provide new perspectives by opening up the conversation. In particular, it will explore language and the impact that it has on people living with dementia and their families. If we are uncomfortable or feeling uneasy about the condition, especially if we have no first-hand experience, it is most likely due to outside influences. When we understand this, it is easier to make changes and to help our patients to live well for longer.

Millions of people all around the globe have watched the Netflix series *Stranger Things*. Here, the heroes of the show are pitted against evil entities, which inhabit an upside-down universe threatening their existence. It is possible to use this as an analogy to position dementia, where the dark elements can be thought of as the stigma and negativity attached to dementia, while the heroes/protagonists are the person/s with dementia (PwD) who are striving to demystify the condition.

Language used in describing dementia

has a role to play in conceptualising dementia and influencing a person's sense of self (by bolstering or crushing it)¹. Language, written or spoken, always has an impact. Many of the derogatory terms seen in **Figure 1** have been identified as influencing perceptions of self, and encouraging PwD to hide their diagnosis from others².

The idea of dementia is often built on hearsay, not interaction or discussion about the condition with people with lived experience. It is almost a taboo subject, mainly because it touches on mental capacity – even though people are becoming more open about mental health issues³. Therefore, conversations about topics such as dementia should be made easier.

The way we talk about dementia matters. If we communicate about dementia using appropriate words and inflections, then narratives can be shaped about living well, adding more humanity and less despair to a diagnosis. Negative language can lead to 'social death' and exclusion, with PwD risking alienation from society⁴ (**Figure 2**).

Saying 'living with dementia' rather than 'suffering from dementia' becomes immediately more positive. Despite communication channels opening, dementia has a negative press: 49 per cent



FIGURE 1: Belittling language in dementia



FIGURE 2: Dementia personified as a killer

of people believe they will be mistaken as crazy (tying in with the taboo theory)⁵. Sixty-two per cent feel it means 'life is over' (death, dying and suffering are all emotive subjects)⁵.

SOCIAL PERCEPTIONS AND POPULAR CULTURE

Popular culture is guilty of encouraging stigma around dementia. Whether it be through literature, film or the news media, negative language and images are known to create social distance between PwD and those without the condition. Several stereotypes of dementia in the media use language and images that suggest PwD are inactive due to impairment or age, with no quality of life^{7,8}.

Low and Purwaningrum⁹ studied books and films pertaining to dementia, finding that many told stories with negative narratives, such as decline, death and institutionalisation (Figure 3). The press tends to depict dementia as always bigger than the person, overwhelming PwD who feel that there is no way out¹⁰.

LANGUAGE AND MEDICINE

Healthcare professionals should be mindful to interact with people by using language that supports person-centred care^{11,12}. There are anecdotal reports of conversations littered with inappropriate medical jargon. Dementia is a social issue and not just a medical one, so language should reflect this.

Alzheimer's, which is often mistaken for dementia, is marketed in the media as debilitating, demeaning and desperate¹³. Phrases like "Condition for which there is no cure" or "Nothing can be done" immediately eliminate any sense of hope or notion of maintaining quality of life. Relegating dementia into the ranks of terminal disease fuels fears about its development.

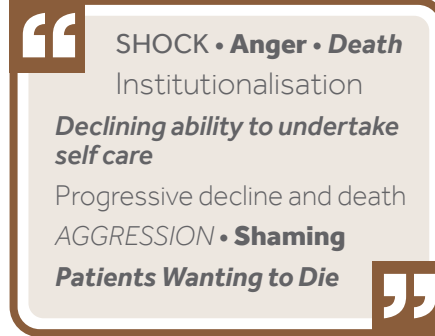


FIGURE 3: Associations made with dementia in films and books

Many people are too scared of a dementia diagnosis to follow up any symptoms, thereby delaying seeking help¹⁴. In 2012, only an estimated 42 per cent of people with dementia in the UK had a formal diagnosis¹⁵. Globally, the non-disclosure rate is estimated to be around 40 per cent. The most common reason medics give is the emotional distress their words may cause¹⁶. The effect of not having these discussions is that the PwD is denied the chance of making key decisions regarding their future¹⁷, putting their affairs in order¹⁸, thinking of how they wish treatment to be administered in the later stages of dementia¹⁹, or even if they wish to take drugs to improve their quality of life¹⁷.



FIGURE 5: Public campaign headlines with militaristic tones

STIGMA AND HORROR

In keeping with the Dementia Things narrative, it may be helpful to look at the work of Susan Behuniak²⁰. The language she studied conjures up graphic images. There is a heavy emphasis on notions of PwD being zombie-like, in a shell-like state and the living dead. Any person stumbling over any of the films, articles or metaphors referenced in her paper, would naturally be scared if they were new to the condition. If they had personal connections to dementia, it should stimulate feelings of anger.

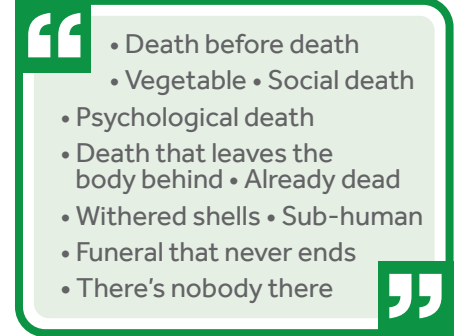


FIGURE 4: Living dead language

Language treating PwD as 'already dead' or 'walking corpses' (despite obvious signs of life) leads to them being pitied and feared (Figure 4)²¹. How are people supposed to live their life with any sort of purpose if they think their fate is a drawn-out slow death?

Scholl and Sabat²² highlight that emotional responses such as disgust and terror position PwD as 'others', outcast from society. Butchard and Kinderman¹ state that dehumanisation, from emotive, terrifying descriptions, make PwD less worthy of compassion than others. One wonders, therefore, how people in positions of caring and responsibility react when influenced only by symptoms or inappropriate language or, indeed, correct language not supported by correct values?

BATTLES TO BE WON, ENEMIES TO OVERCOME

The use of war and battle terminologies are commonplace. For instance, a recommended handbook uses terms like 'know your opponent' (the condition) and 'survival tips' (Figure 5)²³. People diagnosed with cancer endure the same language difficulties such as 'fighting a battle' or 'surviving cancer'. When questioned, many cancer patients see these terms as distressing and negative with implications of not fighting hard enough or being brave enough²⁴. 'Brave' is often used, with mixed feelings. The term 'choosing to be positive' was suggested as more appropriate. Others embrace it, feeling like it is almost a congratulatory term.

For people with cancer, a term unanimously disliked was 'victim'. This word is also shunned by PwD and is listed as one to avoid²⁶. The word 'survivor' also meets with mixed feelings and, despite this, is used by some cancer charities and organisations as they feel that it has resonance with the public and can help to

loosen the purse strings²⁴. This is also the dilemma facing dementia charities and organisations: treading the fine line between using shocking language and being sensitive regarding stereotypes.

Terms that were preferred by people surveyed were 'living with cancer' and 'recovering from cancer treatment', keeping things factual and avoiding labelling by an illness. The Dementia Engagement and Empowerment Project (DEEP)²⁵ concurs – suggesting the term 'person (living) with dementia'. Anecdotally, there seems to be a feeling of 'it's a shame' when someone with cancer dies, whereas when someone with dementia dies it is met with undertones of 'probably for the best' and resignation.

CANCER: LESS SCARY THAN DEMENTIA

Talking about cancer in more positive tones and having endorsements from celebrities via fun baking shows, tribute concerts and interviews has shifted public perception and helped to shine a light on the positives, encouraging financial support along the way. Statistics showing increasing survival rates have given hope to people who get a diagnosis. The doom-and-gloom narrative associated with dementia is not shared. 'Hope for survival' is not a language that can be employed for PwD. The one certainty is they will die with the condition, which is not a great advert for drumming-up positivity.

DEMENTIA AND AGEIST LANGUAGE

There is also another problem that the wordsmiths and spin-doctors must face: dementia is associated with ageing. The stigma from ageist language adds to their disability²⁶. Even though dementia is not classified as an age-related condition, this makes it even more unfair. The double whammy turns into a triple threat, when mental health muscles in by also stigmatising the older person²⁷.

The knock-on effect of ageist language means that assumptions are made about people in the form of negative stereotypes, challenging their limited social lives and dependence upon others. This is made worse with a dementia diagnosis. The direct impact of ageist propaganda leads to poor quality care, being excluded by society, and neglect²⁸. If you are old and discriminated against, feelings of

desperation, loneliness and worthlessness will all play a role in affecting the older person's well-being. Quality of life in terms of access to services and inclusion can also be affected²⁹.

CATASTROPHIC LANGUAGE

Dementia is often written about in terms of natural catastrophes and disease. Zeilig noted an increase in the prevalence of such words indicating dementia was a force of nature threatening to overpower everyone (**Figure 6**)³⁰. Epidemic language suggests that PwD can pass on the condition like a plague, inferring they be avoided. This is worth noting, since many PwD talk of being lonely and feeling isolated³¹. Unfortunately, optimistic counter claims are scarce as they do not sell newspapers³².



FIGURE 6: Natural disaster/ epidemic language

CHANGING THE NARRATIVE

Suppose we follow the upside-down theme, flip the narrative and hear from people actually living with dementia? Many generous advocates have come forward to document, in writing or via video, their personal experiences and viewpoints. Some advocates make up the Dementia Advisory Board at the University of Hull. It helps people who do not have the condition to 'walk in their shoes', and to better understand the consequences of negative words and actions.

Some PwD choose to get involved with more structured research. One such recent study looked at PwDs' reactions to language used to describe behaviour changes. PwD found some language used to be offensive and disrespectful of human rights³³. Language, especially that which implies that the PwD is difficult or wilfully obstructive, was deemed unacceptable. Some terms were referred to as having terrible long-term outcomes, and thought to be dangerous, possibly leading to

restraint or unnecessary medicating such as sedation.

The authors recommended knowing the realities and experiences of PwD as the only people able to destigmatise the condition and communicate what language is appropriate³⁴.

SPEAKING TRUTH ABOUT DEMENTIA

There are many uplifting stories from people who live with dementia and their family members. Authors such as Dr Jennifer Bute (Dementia From the Inside) and Wendy Mitchell (What I Wish People Knew About Dementia and Somebody I Used To Know) have encouraged people who have a diagnosis with their frank and positive reflections on their condition. Apart from writing books, they have been involved with speaking at conferences and writing blogs. Wendy's blog is titled, 'Which me am I today?' and is very inspiring. It can be found at <https://whichmeamitoday.wordpress.com>

Another source for hearing from PwD is through a website called Innovations in Dementia. This is a not-for-profit community interest company (CIC) whose raison d'être is to promote a positive but realistic view of dementia and to give hope to people living with the condition to keep control of their lives. The website can be found at www.innovationsindementia.org.uk. Linked to this is Dementia Voices at <https://dementiavoices-id.org.uk>, which provides mini-sites for five of their key projects: DEEP25 (the UK network of Dementia Voices), Dementia Diaries, Dementia Tip-share, Dementia Creatives, and Dementia Enquirers.

There are a number of people writing about their experiences of living with dementia. Peter Berry enjoys life riding his bike, sharing his words and transferring his voice to paper in the form of poetry. Via interviews, he urges people to not talk about PwD but to PwD³⁵. He uses positive language about living with dementia, such as 'inspiring', 'adapting' and 'different'.

Eloquence and advocacy come from ex-primary headmaster, Keith Oliver, who was diagnosed aged 55 whilst at the top of a career he loved. He carried on in his leadership role until he felt his standards starting to slip. This is when he decided to use his communication skills and real-life experiences to help others, including

REFLECTION ONE

Samantha has dementia. She has seen the dispensing optician, Marcus, today to collect her new spectacles and some dry eye treatments. There are three people in the waiting area queuing to see Marcus.

MARCUS: "Do you need a bag?"

SAMANTHA: "A bag?"

MARCUS: "They're 10p each"

SAMANTHA: "I'd better take one"

MARCUS: "Would you like help packing the bag?"

SAMANTHA: "Help? Packing?"

MARCUS: "Putting things in the bag?"

Meanwhile the people in the waiting area are getting restless.

MARCUS: "Would you like some help?"

SAMANTHA: "I'll just leave it!" *walking away not making eye contact.*

REFLECTION TWO

David has dementia. He feels his vision is not as good as it was and has decided he needs to have an eye test.

RECEPTIONIST: "Bright Eye Opticians"

DAVID: "I need to make an appointment"

RECEPTIONIST: "What type of appointment?"

DAVID: "An appointment!"

RECEPTIONIST: "Yes, what type of appointment do you need?"

DAVID: "I can't see as well"

RECEPTIONIST: "How long has this been going on?"

DAVID: "How long has what been going on?"

RECEPTIONIST: "Your vision problems?"

DAVID: "I need to see someone about my eyes"

RECEPTIONIST: "Yes, I am trying to ascertain how quickly we need to see you"

David has hung up.

FIGURE 7: Conversation examples for reflection

authoring the book, *Dear Alzheimer's: A Diary of Living with Dementia*^{36,37}.

Kate Swaffer talks passionately about her diagnosis in her work, how she is outraged at some of the language used and misconceptions generated, and how she plans to further awareness and research³⁸. We should all learn from listening to and engaging with the writings of many PwD, discovering personal journeys and understanding their evolving views about dementia, and themselves, over time³⁹.

The author has noted from discussions with other healthcare professionals that many PwD become almost secondary – with professionals preferring to engage in conversations with a carer or family member. It may be helpful to reflect on some everyday scenarios that could occur in practice, to consider how the situation could be managed better and how careful consideration of language may support a better outcome for the patient. **Figure 7** provides two brief conversations to reflect on.

IN SUMMARY

Every person living with dementia is different. Dementia affects people in a multitude of different ways and our patients will be at different points on their dementia journey. Key is sitting down with them, getting to know about them as people rather than a condition, discovering their needs and how their quality of life can be improved. Understanding how individuals may have been pre-conditioned to think in a certain way about dementia will help eyecare professionals better serve this growing population in the future.

FURTHER RESOURCES

- PETER BERRY:
<https://www.youtube.com/watch?v=0e-u0XU3g28>
- KEITH OLIVER:
<https://www.kmpt.nhs.uk/get-involved/participation-and-involvement/living-with-dementia/dementia-envoys/keith-oliver/>
- KATE SWAFFER:
<https://www.youtube.com/watch?v=ycTNVf2toG0>

REFERENCES

References can be found when completing this CPD module. For a PDF of this article with references, email the ABDO CPD team at abdocpd@abdo.org.uk

ELAINE GRIDALE qualified as a dispensing optician in 1985. Between 1989 and 2001, she worked as international professional relations manager for opticianry and optometry at Essilor, France, liaising with professional bodies, vision scientists and academic institutions internationally. In 1998, she was instrumental in creating the Varilux University, the first international training centre dedicated to presbyopia and the ageing eye. Elaine currently holds the roles of head of professional services and international development for ABDO, and director of development for the International Opticians Association. She has many years of experience of lecturing internationally including writing and delivering CPD in the UK.

LEARNING OUTCOMES FOR THIS CPD ARTICLE

DOMAIN: Professionalism

4.1: Consider the language you use when supporting patients with dementia to ensure you treat them with dignity and respect.

13.2: Do not discriminate against patients with dementia and ensure your dealings, including the language you use is inclusive.

DOMAIN: Communication

1.3: Assist patients with dementia in exercising their rights and making informed decisions about their care. Respect the choices they make.



PROFESSIONALISM



COMMUNICATION

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